A MULTI-PERSPECTIVE REVIEW OF THE EXPERIENCES, CHALLENGES AND NEEDS OF PRIMARY CAREGIVERS CARING FOR ADOLESCENTS LIVING WITH HIV: GUIDELINES FOR SOCIAL WORK PRACTICE

by

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DECLARATION

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A multi-perspective review of the experiences, challenges and needs of primary caregivers caring for adolescents living with HIV: Guidelines for social work practice.

I declare that the above dissertation is my own work and that all the sources that I have used or quoted from are indicated and acknowledged by means of complete references.

I further declare that I submitted the dissertation to originality checking software and that it falls within the accepted requirements for originality.

I further declare that I have not previously submitted this work, or part of it, for examination at Unisa for another qualification or at any other higher education institution.

SIGNATURE:  DATE: 20 August 2025

DEDICATION

This project is dedicated to the following people:

- My late husband Johannes Matsimbi and my late parents Piet Chindane and Violet Chindane, who will always be in my heart.
- My children Nyeleti and Nkateko Matsimbi for the love and care they showed me throughout this project.

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ABSTRACT

A noticeable gap exists in the South African homegrown social work research and literature about the experiences, challenges and needs of primary caregivers caring for adolescents living with HIV (ALHIV), as well as the means through which social work interventions can be enhanced in supporting this category of social work service beneficiaries. In an attempt to bridge this gap, a study was conducted in South Africa's four municipal areas of Gauteng province: the cities of Johannesburg, Sedibeng, Tshwane and Ekurhuleni. The purpose was to develop guidelines for supporting caregivers based on their experiences, challenges and needs of caregivers in relation to caring for ALHIV, the experiences of ALHIV regarding being cared for by a primary caregiver and the current and suggested support systems for caregivers caring for ALHIV.

Three categories of participants were purposefully sampled through a predetermined inclusion criteria from the populations of (1) primary caregivers caring for ALHIV; (2) ALHIV who were in the care of primary caregivers and (3) social workers working for the Department of Social Development (DSD) funded Non-Profit Organisations (NPOs) rendering social work services to ALHIV and their primary caregivers. From this sample, a total of 24 participants participated in individual semi-structured face-to-face interviews, facilitated through the interview guide comprising of open-ended questions. For data analysis and study trustworthiness, the study respectively followed Tesch's (in Creswell, 2024) thematic analysis and Guba and Lincoln's strategies of credibility, confirmability, dependability and transferability. The main contribution made by this study was to highlight the experiences, challenges and needs of primary caregivers caring for adolescents living with HIV (ALHIV) from a social work disciplinary perspective and to produce guidelines for supporting the primary caregivers of ALHIV. The study findings revealed that primary caregivers experience challenges such as financial burden, lack of means to meet basic needs, stigma and discrimination. In addition, the three categories of participants of this study pointed to various needs including financial support and employment. It is crucial to note that if these needs are met it would enable primary caregiver to be able to meet other basic needs such as nutritious food and transport money to go to the clinic, of which are vital for ALHIV to adhere to their HIV treatment and to remain in care. In addition, need for psychosocial support was emphasised, which included psychosocial support

programmes such as counselling, treatment adherence support, disclosure counselling to primary caregivers and their ALHIV.

Key words/ Concepts: Adolescents living with HIV (ALHIV); Challenge; Experience; HIV; Needs; Multi-perspective review; Primary caregivers; Social work.

ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ALHIV	Adolescent living with HIV
ART	Antiretroviral Therapy
ARVs	Antiretroviral
CBOs	Community-Based Organisations
CDC	Centers for Disease Control and Prevention
CHBC	Community Home-Based Care
COVID-19	Coronavirus disease
CPD	Continuing Professional Development
D&D	Design and Development model
DOH	South African Department of Health
DSD	Department of Social Development
GTAC	Government Technical Advisory Centre
HIV	Human immunodeficiency virus
HIVSA	HIV South Africa
HSRC	Human Sciences Research Council
KZN	KwaZulu-Natal
NGOs	Non-Governmental Organisations
NPO	Non-Profit Organisation
NSP	Non-Profit Organisation
OVC	Orphans and Vulnerable Children
OVCA&Y	Orphans and Vulnerable Children, Adolescents and Youth
PACTSA	Private Agency Collaborating Together South Africa
PEPFAR	President's Emergency Plan for AIDS Relief
PLHIV	People living with HIV
PMTCT	Prevention of Mother-to-Child Transmission
POPIA	Protection of Personal Information Act
RDP	Reconstruction and Development Programme
SACAP	South African college of applied psychology
SACSSP	South African Council for Social Service Professions
SANAC	South African National AIDS Council
SSA	sub-Saharan Africa

SASSA	South African Social Security Agency
SDG	Sustainable Development Goal
SSA	Sub-Saharan Africa
STIs	Sexually Transmitted Infections
TB	Tuberculosis
UNAIDS	Joint United Nations programme on AIDS
UNICEF	United Nations Children's Fund
UNISA	University of South Africa
USAID	United States Agency for International Development
VMMC	Voluntary Male Medical Circumcision
WHO	World Health Organisation

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CHAPTER ONE
INTRODUCTION AND GENERAL ORIENTATION TO THE STUDY

1.1. INTRODUCTION

This chapter introduces the topic of the investigation, which is a multi-perspective review of the experiences, challenges and needs of primary caregivers who are caring for adolescents living with HIV in South Africa. A background to the phenomenon of adolescents living with HIV (ALHIV) is presented from a global perspective down to the African and South African contexts in particular. The chapter outlines the research problem on which the study was based and the significance of understanding the experiences, challenges and needs of caregivers from both the perspective of the caregivers, social workers and the adolescents themselves. The research questions, aims, and objectives of the study are presented, followed by a discussion of the central concepts and an outline of the chapters that follow.

1.2. CONTEXTUAL BACKGROUND

Globally, the increasing number of ALHIV is alarming. According to the Joint United Nations Program on HIV/AIDS (UNAIDS, 2021), it is estimated that during 2019, 1,7 million adolescents worldwide were living with HIV. Additional data from the United Nations Children's Fund (UNICEF, 2023) indicates that in 2022, an estimate of 480 000 adolescent were newly infected with HIV, making HIV infections a growing concern among this cohort. For 2023, from a total of 360 000 young people between the ages of 15 to 24, 140 000 were adolescents aged between 15 and 19. Should these figures continue unabated, an estimated 183 000 annual infections can be expected among adolescents by 2030 (UNICEF, 2023). In addition, the South African National AIDS Council (SANAC) emphasises that adolescents continue to lag in AIDS responses compared to adults; a challenge which is putting too many young lives at risk of sickness and death (SANAC, 2023). The disease burden among adolescents has negatively affected the financial, health, physical and psychological wellbeing of their primary caregivers (Kasande, Natwijuka, Katushabe & Tweheyo, 2022).

On the African continent, the phenomenon of ALHIV is equally alarming (UNICEF, 2016). A report by the Human Science Research Council (HSRC), reveals that in 2019, 1,5 million or 88% of the total global number of ALHIV were living in Sub-Saharan Africa (SSA) (Zungu, Naidoo, Hodes & Mabaso, 2021). Furthermore, a 2017 SSA

study by Cane, Melesse, Kayeyi, Manu, Wado, Barros and Boerma (2021) on HIV trends and disparities by gender and urban-rural residence among adolescents, found that there were more ALHIV in west and central Africa than in eastern and southern Africa. ALHIV in Africa represents a vulnerable population facing developmental, psychosocial and comorbidity issues while coping with a chronic, potentially stigmatising disease in the form of HIV (Dahourou, Gautier-Lafaye, Teasdale, Renner, Yotebieng, Desmonde, Ayaya, Davies & Leroy, 2017). More recently the UNICEF reported that of the 140 000 adolescents reported to have acquired HIV during 2023, 19% were African boys from eastern and southern Africa (UNICEF, 2023). An observation by Winskell, Miller, Allen and Obong'o (2016) is that ALHIV navigates through physiological, social, and behavioural challenges at a time when risk-taking and vulnerability to mental health problems are common, whilst dealing with their HIV-positive statuses.

As part of the international community, South Africa is not immune to the above-mentioned global phenomenon of ALHIV. The current HIV figures for South African adolescents aged between 10 and 19 recorded by the UNICEF (2024) is that the country has a total of 220, 000 ALHIV, of which 28, 000 are new infections. From the total number of ALHIV, boys represented 82, 000 in number and girls 140, 000. In the 28, 000 new infections, boys accounted for 4, 200 and girls 24, 000. A total of 1, 800 ALHIV are reported to have died due to AIDS-related conditions, with boys accounting for 950 and girls 850 (UNICEF, 2024). Although these figures are shocking, there have been signs from as far back as 2019 where the prevalence among ALHIV in South Africa was projected to be 360 000 (Naidoo et al., 2020). These figures are a concern because surveys conducted in all nine South African provinces between 2012 and 2017, revealed a significant increase in HIV prevalence among adolescents (Mabaso, Maseko, Sewpaul, Naidoo, Jooste, Takatshana, Reddy, Zuma & Zungu, 2021). In 2017 a South African study of the lived experiences of adolescents aged between 10–19 years, living with HIV by Naidoo et al. (2020) found that out of the country’s nine provinces, KwaZulu-Natal (KZN) had the highest prevalence, with figures estimated to be around 97,182. Gauteng was the second most affected province with a total of 66, 754 adolescents reported to be living with HIV. Worth noting is that routine data on ALHIV is not readily available in South Africa, which makes it difficult to keep abreast with new trends and to implement the necessary interventions (Naidoo et al., 2020:1).

A Brazilian study seeking to explore the experiences of adolescents who tested seropositive for HIV in São Paulo, found that ALHIV had difficulties to disclose their HIV diagnoses to third parties, navigate interpersonal relationships, and adhere to the HIV treatment regimes. They were also found to be psychologically burdened by living with a chronic illness which is associated with death, stigmatisation and social exclusion (Galano, Turato, Delmas, Côté, Gouvea Ade, Succi, & Machado, 2016). A study in which data from different clinics of Africa were compared by assessing the challenges for ALHIV during transition from pediatric to adult HIV clinics, found that ALHIVs are faced with various physical and psychosocial challenges. They are frequently ill and have difficulties in disclosing their HIV diagnoses, fail to take the medication regularly, feel stigmatised and have challenges practising safe sex (Mapesi, 2020). The abovementioned realities and challenges experienced by ALHIV were also observed by various other scholars in Africa and South Africa (Woollett, 2016; Abubakar, Van de Vijver, Fischer, Hassan, Gona, Dzombo, Bomu, Katana, & Newton, 2016; Nestadt, Lakhonpon, Pardoc, Saisaengjanb, Gopalanc, Bunupuradahd, McKayc, Ananworanich & Mellinsa, 2018). This suggests an urgent need for specialised psychosocial assistance for ALHIV to adjust to their diagnoses in order to navigate the challenges associated with living with HIV (Zungu et al.,2021; Kimera, Vindevogel, De Maeyer, Reynaert, Engelen, Nuwaha, Rubaihayo & Bilsen, 2019).

The challenges experienced by ALHIV should not be considered in isolation, since they also have an impact on their primary caregivers. Generally, the decisions by primary caregivers affect the health statuses of ALHIV (Atanuriba, Apiribu, Mensah, Dzomeku, Afaya, Gazari, Kuunibe, Amooba, 2021). The challenges that ALHIV encounter daily, also play out in the context of families where primary caregivers assume responsibility for the adolescents' wellbeing (Atanuriba et.al., 2021). Primary caregivers in the context of this study, refer to biological parents, foster parents, adoptive parents, grandparents, legal guardians or any other person who is responsible for the needs of the adolescent including the provision of shelter.

The abovementioned challenges experienced by the ALHIV have both direct and indirect negative effects on their primary caregivers (Osafo, Knizek, Mugisha & Kinyanda, 2017). The direct effects as noted by various scholars (Nsibandze,

Downing, Poggenpoel & Myburgh, 2020; Mafune, Lebese & Nemathage, 2017; Casale, Wild, Cluver & Kuo, 2014), translate to primary caregivers feeling physically and emotionally stressed, anxious and depressed, especially when caring for ALHIV takes place under difficult financial and social circumstances. Indirectly, the primary caregivers are affected by a lack of support from other family members, the community, society, and the government. Caregivers also experience stigma by virtue of their association with ALHIV, and they have difficulties in getting the ALHIV to adhere to their treatment regimes. In addition, they must protect themselves from being infected, be contend with poverty and manage financial difficulties associated with meeting their own needs as well as those of the ALHIV (Atanuriba et.al., 2021; Nasuuna, Kigozi, Muwanguzi, Babirye, Kiwala, Muganzi, Sewankambo, Nakanjako & Damalie, 2019). Kasande et al. (2022) expand on these challenges by adding lack of knowledge about HIV, sleep deprivation and feelings of rejection and hopelessness while simultaneously having to provide for the needs and supporting ALHIV.

A Kenyan study focusing on the economic and mental health of primary caregivers of ALHIV, painted a bleak picture of high economic burdens experienced by these caregivers, contributing to poor mental health and igniting a vicious cycle of poverty, which eventually leads to reduced educational opportunities for adolescents (Katana et al., 2020). Osafo et al. (2017) found in their study of the economic burdens and mental health of primary caregivers of perinatally HIV infected adolescents in Kenya, that primary caregivers carry a heavy burden associated with physical health deterioration, burnout, emotional distress, family breakdown and the destruction of household economies while caring for ALHIV. Corresponding with and adding to the list of the challenges mentioned above, a South African study focusing on the challenges of primary caregivers caring for children living with HIV in a semi-rural area, by Mafune et al. (2017), highlights the following challenges amongst caregivers caring for ALHIV: financial burdens; stigmatisation of ALHIV by family members and poor management of the ALHIV treatment regime. Additionally, the adolescents fear disclosing their HIV diagnoses due to discrimination which creates barriers to their school education.

Given the abovementioned challenges experienced by ALHIV and their primary caregivers, it is essential that psychosocial services directed to ALHIV be equally

extended to their primary caregivers (Osafo et al., 2017). As part of a growing commitment to a more holistic and integrated approach to providing psychosocial services to ALHIV and their primary caregivers, various scholars (Winskell et al., 2016; Abubakar, Van de Vijver, Fischer, Hassan, Gona, Dzombo, Bomu,Katana, & Newton, 2016) recommend a move away from individualistic approaches to interventions for ALHIV towards strengthening and integrating primary caregiver interventions. A more holistic and integrated approach will strengthen efforts to improve primary caregiver-adolescent relationships, which will in turn contribute positively for the compliance of ALHIV with their prescribed medications. In addition, researchers point to the need for social and mental health support group interventions for primary caregivers looking after ALHIV to effectively execute their roles and to jointly address their economic and psychological needs (Yarney, Adjei, Asamoah, Bawole & Ahenkan, 2015; Nsibandze et al., 2020). After all, South Africa is committed, through its fifth generation of the National Strategic Plan (NSP, 2023-2028) to, among other commitments, break down barriers to achieving solutions for HIV, TB and STIs (South African National AIDS Council (SANAC), 2023).

1.2.1. Problem formulation

The concept research problem is defined by Yegidis, Weinbach and Meyers (2018) as a state that falls within the ambit of social work; it is an issue that confronts social service professionals or a gap in the body of knowledge concerned, leaving them unsure about how to intervene in solving a client's problems. Creswell (2016) adds that research problems can stem from gaps in literature and previous research and that real life issues can also inform research. These definitions resonate with the researcher's understanding of this concept, which for the purpose of this study constituted the existence of psychosocial issues that negatively affect the lives of ALHIV and their primary caregivers and to which little or no scientific knowledge to guide intervention measures, seem to exist.

The alarming prevalence rate of ALHIV and the challenges that they and their caregivers contend with on a daily basis, as already mentioned, calls for governments and civil society to focus on intensifying efforts to effectively deal with HIV and its related impact on ALHIV and their caregivers. In response to the HIV pandemic, the South African government proactively set up the national AIDS council (SANAC) in

2002, which among others, was mandated to advise government on HIV and AIDS and STI policy matters as well as to mobilise resources for the implementation of AIDS programmes (Government technical Advisory centre (GTAC), 2016). SANAC's advisory role to government on HIV and AIDS and STI policy has consistently been through the National Strategic Plan on HIV, TB and STIs (the NSP), which is reviewed five-yearly based on priorities.

- The NSP has consistently adopted a shift away from responding to HIV as a merely a bio-medical condition to a socioeconomic issue driven by various social and structural drivers (Department of Health (DOH), 2017). Moreover, the NSP acknowledges the vital role primary caregivers fulfil in attending to the psychosocial needs of ALHIV and advocate for programmes that are comprehensive and include the caregivers as well. The current NSP (2023-2028) (the Fifth Generation NSP), considers caregivers and adolescents to be among the priority populations and specifically set targets to among others, provide health education to children and adolescents, with a particular focus on exploitation in the absence of primary caregivers as well as to strengthen treatment literacy campaigns and psychosocial support for both caregivers and adolescents (SANAC, 2023). Although the fifth generation NSP can be applauded for such a bold move of focusing primarily on programmes that address how primary caregivers can improve their communications with and support their adolescents to prevent HIV infection, it specifically falls short on addressing programmes that are tailor-made and focus on how to support primary caregivers of ALHIV (DOH, 2017). The limitation of primary caregiver's tailor-made programs was also highlighted by the National Strategy Plan end-term review report (2023) that comprehensive, dedicated programs specifically for the holistic support of all primary caregivers (e.g., mental health, financial, and time-off support) across the various NSP goals have not been consistently highlighted as a major success.

Internet searches on engines such as Google Scholar, the Nexus database, and SABINET, as well as international journal database sites such as EBSCOhost and ScienceDirect, undertaken by the researcher to ascertain the state of knowledge around the phenomenon under investigation, did not produce any homegrown

research. On the international front, the researcher found the following studies (by no way exhaustive), related to the topic:

- Nedstadt, Lakhonpon, Pardoc, Saisaengjanb, Gopalanc, Bunupuradahd, McKay, Ananworanich and Mellinsa (2018) conducted a qualitative research project amongst social/health workers in Bangkok, with the aim of exploring the psychosocial challenges of perinatally HIV-infected adolescents and families.
- In California, USA, Kidman and Heymann (2016) reported their findings on a research project focusing on 'Caregiver supportive policies to improve child outcomes in the wake of the HIV/AIDS epidemic'. Their study analysed a gap between what is needed and what is available in 25 high prevalence countries in sub–Saharan Africa.
- Santiesteban, Castro, Calvo (2012) from the discipline of psychology, conducted psychological research among 13 Cuban caregivers with the aim of describing the 'mental health of primary caregivers for children and adolescents with HIV/AIDS' in Cuba. Their findings revealed that caregivers affected by HIV are exposed to multi-faceted life dynamics impacting negatively on their mental health, and it recommended that a comprehensive and integrated approach be implemented to improve the mental health state of primary caregivers.

Focusing on the African Continent, the researcher found the following research studies:

- In an article on integrated psychosocial, economic strengthening, and clinical service-delivery to improve health and resilience of ALHIV and their caregivers, Rosen, Phiri, Chibuye, Namukonda, Mbizvo and Kayeyi (2021) reported the findings from a prospective cohort study undertaken in Zambia. Among others, the findings were that implementing a multi-faceted, integrated service-delivery service is associated with substantial improvements in financial security and the wellbeing of caregivers of ALHIV.
- Luseno Iritani, Zietz, Maman, Mbai, Otieno, Ongili and Hallfors (2017), conducted a study in Western Kenya among 29 adolescents and 14 caregivers focusing on their experiences along the HIV continuum of care. One of the lessons from this study was the importance of family, school and health facilities

in supporting and motivating ALHIV to continue taking HIV treatment and care after diagnosis.

- Emanating from their qualitative study in which they employed focus group discussions to engage 39 ALHIV and 53 caregivers who were accessing services from HIV clinics in Western Kenya, McHenry, Nyandiko, Scanlon, Fischer, McAteer, Aluoch, Naanyu, and Vreeman (2017) published a paper on the topic of 'HIV stigma: Perspectives from Kenyan child caregivers and ALHIV'. Their findings revealed that stigma continues to be a major challenge in the everyday lives of PLHIV and those affected, by specifically hampering access to HIV prevention and treatment programmes.

On the National front, the researcher found studies conducted in the disciplines of nursing science and psychology covering aspects of the experiences and challenges of caregivers but did not find any social work-related publications dealing with support programmes and interventions aimed at this cohort of caregivers specifically. Some of these studies are as follows:

- Emanating from their internationally funded research project, Shenderovich, Boyes, Esposti, Casale, Toska, Roberts and Cluver (2021), from Oxford University in the United Kingdom (UK), under the auspices of health sciences, drew on a prospective longitudinal cohort study undertaken in the Eastern Cape in South Africa to report on 'Relationships with primary caregivers and mental health outcomes among adolescents living with HIV (ALHIV)'. Their study pointed out that open and supportive communication among adolescents and caregivers reduces depression and anxiety symptoms among ALHIV.
- Based on the voices of key stakeholders in the quest to end HIV in children and drawing on lessons from their experiences to be employed by policy makers in strengthening services, Pillay (2021), in the discipline of psychology, published a paper under the title, 'Towards an AIDS-free generation by 2030: How are South African children, adolescents, caregivers and health care workers coping with HIV?' The study found that the health system is not effectively responding to the needs of adolescents and their caregivers, who still experience stigma and discrimination on a daily basis.

- Resulting from their intercontinental and interdisciplinary research collaboration, Visser, Thurman, Spyrelis, Taylor, Nice and Finestone (2018) (in the field of psychology), published a paper describing the 'Development and formative evaluation of a family-centred adolescent HIV prevention program in South Africa'. The programme presented over 19 sessions to the caregivers and over 14 sessions to the adolescents and it was piloted with 12 groups of caregiver-adolescent dyads by community-based organisations (CBOs) in the KwaZulu-Natal and Gauteng provinces. The study found that structured family-centred adolescent HIV prevention interventions are associated with reductions in risky behaviour among adolescents rather than standard adolescent-only models.
- Casale et al. (2014) in the discipline of psychology, embarked on a research project in Kwa-Zulu Natal Province to assess the relationship between social support and anxiety among caregivers of children in HIV-endemic South Africa. The study revealed that social support needs to be incorporated as one of the mental health resources for caregivers of children regardless of whether they are facing specific stressors related to HIV or other illnesses.
- A research study conducted by Nsibandze et al. (2020) in the disciplines of nursing sciences and educational psychology, focused on 'Experiences of grandmothers caring for female adolescents living with HIV in rural Manzini, Eswatini: a caregiver stress model perspective'. It specifically pointed to the ill-health experienced by grandmothers who care for ALHIV and recommended that psychosocial and financial support should be available to ease their burden.
- Mafune et al. (2017) in the discipline of nursing (Public Health), conducted a study on the challenges faced by caregivers of children on antiretroviral therapy (ART) at selected healthcare facilities of Mutale municipality of Vhembe district in Limpopo province. The study was conducted among 16 caregivers who were caring for children on ART and revealed that the caregivers experienced financial burdens and some level of stigma against these children.
- Turning to social work practice, the researcher engaged in informal interactions with social workers employed by non-governmental organisation (NGO) funded by the South African Department of Social Development (DSD), who are

providing services to primary caregivers, children and adolescent living with HIV with the intention of finding out about any available social work practice interventions aimed at supporting primary caregivers caring for ALHIV. From the responses shared by the social workers, it was apparent that the focus of the services is directed at ALHIV as individuals and not much is done to support their primary caregivers. These revelations justified a need for a study which will culminate into guidelines for supporting interventions for primary caregivers of ALHIV, hence the problem statement: *A noticeable gap exists in the homegrown social work body of knowledge and social work practice to address the challenges of caregivers caring for ALHIV and to offer support through social work practice interventions.*

1.2.2. The rationale

According to Maree (2016), a research study's rationale is the justification for the study based on a gap in the literature that is evident. Creswell and Poth (2018) postulate that the rationale for a study refers to the reasons why the researcher wishes to conduct a specific study. The rationale serves to provide reasons about what motivated the researcher to conduct a specific study.

At the time of composing this study, the researcher was employed as a social work manager at PACTSA, which is an international organisation operating in various African countries to provide support to disadvantaged communities. In South Africa, PACTSA provides support to the DSD and DSD-funded Non-Profit Organisations (NPOs) to improve services to vulnerable children and adolescents, including those living with HIV. The researcher's main work responsibility was to manage social workers rendering services to children and ALHIV under the auspices of Gauteng DSD. Having been engaged with social workers and social auxiliary workers, it emerged that the current psychosocial interventions focus more on the needs of ALHIV, while the interventions on primary caregivers caring for ALHIV remain an area of concern. In their conceptual framework to help address the needs of HIV-affected caregivers and to prioritise policies, Kidman and Heymann (2016) advocate for the significance of making mental health and social services more widely available as they are essential to support caregiving by families of HIV-infected children. Similarly, a study by Katana et al. (2020) focusing on primary caregivers of perinatally HIV infected adolescents revealed a lack of intervention programmes for primary caregivers. These

authors further called for inclusive programmes to enable the active involvement of primary caregivers of ALHIV and therefore recommended that such programmes be strengthened. In addition, Kasande et al. (2022) in a study on the burden of caring for children living with HIV in a semi-rural South African community, accentuated that failure to have inclusive programmes may impact on primary caregiver health and may ultimately cause household dysfunctions.

In line with the constraints faced by primary caregivers, this study sought to amplify the voices of primary caregivers of ALHIV by documenting their experiences, challenges and needs from the perspectives of the primary caregivers themselves, ALHIV and the social workers who are engaged in rendering services to these service users. In addition, through the study, the researcher sought to gather some suggestions from the abovementioned participants to ultimately forward social work practice guidelines for the purpose of supporting caregivers caring for ALHIV and in so doing, address the identified gap in the body of knowledge and practice.

1.3. THEORETICAL FRAMEWORK

For the purpose of this study, the researcher adopted the strengths-based perspective and the ecological systems theory as theoretical frameworks. The above-mentioned theories were chosen with a view that they will give direction to social work practice interventions to support primary caregivers caring for ALHIV, based on the suggested support systems for caregivers caring for ALHIV by the three groups (Primary caregivers, ALHIV and Social workers) that participated in this study. Therefore, develop guidelines for supporting caregivers based on their experiences, challenges and needs in relation to caring for ALHIV. These theories will be explained in detail in chapter 2.

1.4. RESEARCH QUESTION

A research question is a specific inquiry which is of interest to the researcher and is identified through own experience or literature, to which answers should come from the collected data (Litchman, 2014). For Ratan, Anand and Ratan (2019), a research question identifies which issues are to be studied and signposts the research methodology to be followed. A good research question as opined by Barroga and Matanguihan (2021), demarcates the research topic and clarifies the objectives, scope

and limitations of the study. The research question thus refers to specific issues that the researcher is interested in and seeks to find answers to through the study.

For this study the following research questions were formulated:

- From the perspectives of social workers, caregivers and ALHIV, what are the experiences, challenges and needs of primary caregivers in relation to caring for ALHIV?
- What experiences do ALHIV have in relation to being cared for by a primary caregiver?
- From the perspective of caregivers and ALHIV, what are the current and suggested social work support services for assisting the caregivers to manage their difficulties?
- Based on the study findings, how best can guidelines for supporting caregivers, ALHIV and social workers be developed?

1.5. GOAL AND OBJECTIVES OF THE STUDY

Under this heading the goal and objectives of the study are presented.

1.5.1. The goals of the study

According to Schneider and Fuller (2018), a research goal should be specific, clear, focused on the research problem, and signify the researcher's intentions for conducting the study. Simply put, Creswell (2016) describes the research goal as what the study intends to achieve at the end of the research project. Hence, the goal of this study was set as to *develop guidelines for supporting caregivers based on their experiences, challenges and needs of caregivers in relation to caring for ALHIV, the experiences of ALHIV regarding being cared for by a primary caregiver and the current and suggested support systems for caregivers caring for ALHIV.*

1.5.2. Research objectives

Ritchie, Lewis, Nichols and Ormston (2014) state that the concept research objective refers to a clear, concise, declarative statement that gives direction to study and must be feasible and researchable through data collection. Research objectives define the specific aims of a study and should be clearly stated in the introduction of the research (Ritchie et. Al., 2014; Parahoo, 2014). These explanations resonate with the

researcher's understanding of research objectives as activities that must be executed to realize the research goal.

To achieve the study's goal, the following objectives were formulated:

- To explore the experiences, challenges and needs of primary caregivers in caring for ALHIV, from the perspective of social workers, primary caregivers and ALHIV.
- To explore the experiences of ALHIV in relation to being cared for by a primary caregiver.
- To ascertain the current and suggested social work support services for assisting the caregivers to manage their difficulties from the perspectives of caregivers and ALHIV,
- To develop guidelines for supporting caregivers, ALHIV and social workers based on the study findings.

1.6. CLARIFICATION OF KEY CONCEPTS

Concepts that are continuously used in this study are considered central. These concepts are introduced and explained in this section.

1.6.1. Adolescent living with HIV

Before the concept adolescents living with HIV can be understood in the context of this study, it is important to understand the meaning of the term 'adolescence'. According to the UNICEF (2016), adolescence refers to a stage characterised by a transition from childhood to adulthood and a time when a child develops an individual identity and independence. Accordingly, ALHIV refers to a heterogeneous population between the ages of 10 and 19 years who have acquired HIV (Falcão, Zerbe, Mellins, Mantell, Brittain, Kapogiannis, de Gusmao, Simione & Abrams, 2021). Therefore, in the context of this study, ALHIV is defined as any person between the ages of 18 and 19 who acquired HIV and is living with a primary caregiver. The age category of 18 and 19 was selected for this study because it was deemed easier for older adolescents to comprehend research information and procedural consent. In addition, they were deemed able to give consent without parental permission and therefore not coerced or influenced by parents or caregivers (Meter, Ehrenreich, Carker, Flynn & Underwood, 2019).

1.6.2. Challenges

Challenge is a difficult task that requires new or additional energy and skills in order to achieve it (Horikoshi, 2023; Rudland, Jaye, Tweed & Wilkinson, 2021). Calikoglu (2019) submits that a challenge reflects the difficult side of a task**.** In this study the concept challenge refers to the difficulties experienced by primary caregivers when caring for ALHIV.

1.6.3. Experiences

Mulelo (2016) states that experience refers to knowledge of an event or subject acquired through exposure. Malungani (2018) adds that experiences are how individuals create meaning about their lives and how they interpret their world within a given context. In this study experiences relate to how primary caregivers attach meanings to their lives and their world in caring for ALHIV.

1.6.4. HIV (human immunodeficiency virus)

HIV is an abbreviation for human immunodeficiency virus. This virus enters the human body and attacks the body's immune system or cells that help the body to fight infections, making a person more vulnerable to other infections and diseases. People diagnosed with HIV can live for a long time if they are taking medication (UNAIDS, 2025; Muchanyerei, 2015; Verma, 2020). For the purposes of this study, the phrase adolescent living with HIV (ALHIV), refers to adolescents who have been diagnosed with HIV.

1.6.5. AIDS (acquired immunodeficiency syndrome)

AIDS is an abbreviation for acquired immunodeficiency syndrome, which defines a group of infections and symptoms associated with being infected with HIV. However, if HIV is not treated, it can lead to AIDS (acquired immunodeficiency syndrome) which is the final stage of HIV (UNAIDS, 2025; Verma, 2020).

1.6.6. Perspective

Perspective refers to the different lenses through which individuals interpret the world, which is influenced by their unique beliefs, experiences, and attitudes (Gorichanaz, 2018).

1.6.7. Multi-perspective review

Robbins (n.d.) defines multiple perspectives as the incorporation of various perspectives and accurate sources based on facts for the purpose of exploring social and cultural issues. The concept 'review' is defined in the Merriam Webster Online Dictionary (n.d.) as the action of going 'over' or 'examining' a phenomenon 'critically or deliberately'. In the context of this research study, multi-perspective review' means to deliberately examine the experiences, challenges and needs of primary caregivers from more than one perspective.

1.6.6. Needs

Needs are defined as physiological or psychological requirements for the well-being and self-actualisation of an individual (Merriam-Webster, n.d.). In addition, Dove (2023) states that needs include food, shelter, clothing, health, education, work, recreation, creativity, recognition, communication, self-expression, and human relations. In the context of the study, the concept refers to the needs required by primary caregivers for the purpose of performing their duties of caring for ALHIV.

1.6.7. Primary Caregiver

According to the DOH (2016), a primary caregiver in the context of caring for adolescents is a parent, legal guardian or person responsible for providing primary care to the adolescent. Lauwereys (2020) defines a primary caregiver as a person who performs primary duties such as ensuring that the child or adolescent is looked after, fed and attends school. Primary caregivers in the context of this study refer to biological parents, foster parents, adoptive parents, grand-parents, legal guardians or or any other person who is living with and responsible for the needs of an ALHIV.

1.6.8. Social work

According to the International Federation of Social Workers (IFSW, 2014) 'social work is a practice based and an academic discipline that seeks to promote the profession's commitment to social change and development, social cohesion and the empowerment of people. Moreover, it is governed by principles of social justice, respect for diversities, human rights and shared responsibility'. Social work as a discipline is underpinned by theories of social work, humanities, social science and indigenous knowledge. Bjerge, Berggren and Anand (2020) expand the definition by asserting that social work focuses on engaging people with the intention of addressing

the life challenges they face and improving their wellbeing. For the purpose of this study, social work is regarded as an academic discipline and practice-based profession that concerns itself with individuals, families, groups, communities and society as a whole in an effort to meet basic needs and enhance the social functioning, self-determination, collective responsibility, optimal health and overall wellbeing of ALHIV and their primary caregivers.

1.7. CHAPTER SUMMARY AND OUTLINE OF THE REPORT

This chapter introduced the study by highlighting the context and background, with specific focus on the problem formulation and rationale of the study. With the main purpose being to gain a broader perspective around the subject of ALHIV and caregivers, presenting the contextual information and background was informed by a broader discussion considering the global state of ALHIV, followed by the African continental and local trends around the subject. To clarify the study scope and focus, the chapter also provided the questions, goals and objectives on which the study was based and concluded with the definitions of key terms that are central to the study.

Chapter Two focuses on a literature review around the subject of HIV and ALHIV. It outlines an understanding of the subject from global, regional and local perspectives, with specific attention given to the state of HIV in general and among adolescents in particular. The chapter also explores the impact of HIV on adolescents and their families by considering how they are affected socioeconomically, psychosocially, and developmentally. In acknowledging measures that have been in place to respond to some of the issues associated with HIV among adolescents and their caregivers, consideration is also given to available interventions. In this chapter, the phenomenon of HIV, adolescents and their caregivers is explored from a strengths-based perspective and ecological systems theory.

Chapter Three outlines how the researcher applied a qualitative research approach to investigate the research topic. In this chapter, the researcher outlines the research design, the study population and sampling procedure. The chapter continues to discuss the data collection methods, data analysis, data verification and ethical considerations applied in the study.

Chapter Four presents the key findings of the study is divided into this chapter and Chapter Five. The chapter focuses on the first set of the research findings which are the findings based on the experiences and challenges faced by the caregivers of ALHIV as well as the experiences of ALHIV on being cared for by primary caregivers. This first set of findings is presented in a form of four themes, 12 subthemes and four categories that emerged from the process of data analysis as supported by the storylines and interpreted through existing literature and the adopted theoretical frameworks.

Chapter Five offers a thorough discussion and interpretation of the second set of the research findings based on the caregivers' needs and suggested solutions associated with caring for PLHIV. This part of the findings is presented through five main themes and ten subthemes. Like the first set of findings in Chapter Four, these subthemes are discussed and interpreted through existing literature and the adopted theoretical frameworks.

Chapter Six presents the summaries, conclusions, recommendations, and limitations of the study. Regarding the summaries and conclusions, specific focus is on summaries and conclusions based on the research process, research methods as well as the study findings. With regard to the recommendations, the chapter draws recommendations from the conclusions as follows: recommendations based on the research methods and the process as well as recommendations based on the research findings. On limitations of the study, the chapter points to limitations around the methods and the research findings.

Chapter Seven is the final chapter of this thesis, and it presents the guidelines for supporting primary caregivers ALHIV based on the research findings. The structure is presented in such a way that it focuses on legislative and policy frameworks applicable to guide the development and implementations of the guidelines, followed by the general social work interventions process with particular focus on the Framework for Social Welfare Services. Lastly, the social work methods of interventions which are case work, group work and community work, of which the focus was on the primary caregivers and ALHIV.

CHAPTER TWO

LITERATURE REVIEW AND THEORETICAL FRAMEWORK

2.1. INTRODUCTION

This chapter presents literature as reviewed from studies which have been conducted on the impact of HIV from global, the African and South African perspectives, with a focus on PLHIV and particularly ALHIV. The chapter also focuses on the socioeconomic and psychosocial impact of HIV on ALHIV and their families and intervention programmes which need to be included in social interventions. Literature review of qualitative research provides an overview of the current state of knowledge around the subject of ALHIV and their caregivers (Butler-Kisber, 2018; Snyder, 2019). In addition, this chapter presents the theoretical context from which the researcher's understanding of the phenomenon of ALHIV developed.

2.2. LITERATURE REVIEW

This section presents a general global outlook on the phenomenon of HIV and AIDS among adolescents, followed by African and South African overviews. The impact of HIV is explored from socioeconomic and psychosocial perspectives, with specific attention on ALHIV. Various available interventions to respond to HIV are explored, starting with available interventions across the globe and then narrowing down to interventions in the South African context.

2.2.1. The global overview of the HIV phenomenon

According to UNAIDS (2023), HIV remains a major global public health concern, with a global estimate of PLHIV reported to be around 39 million at the end of 2022. Moreover, some countries are still reporting increases in new infections, with an estimated 1.3 million people having been infected during the period 2022 (UNAIDS, 2023). Since the start of the HIV epidemic, an estimated total of 85.6 million people have been infected, of which 40.4 million died from AIDS-related conditions. The global AIDS update revealed that in 2022, AIDS claimed a person's life every minute (UNAIDS, 2023).

Notwithstanding the bleak impact of HIV and AIDS-related deaths, access to treatment has also had some positive impact. Access to HIV treatment is key to ending HIV as a public health threat. The UNAIDS (2023) revealed that HIV treatment prevented

almost 20.8 million AIDS-related deaths. An estimated total of 29.8 million out of 39 million PLHIV, accessed ART in the year 2022. Despite accessibility, millions of people of whom 43% are children and adolescents, still miss out on treatment (UNAIDS, 2023; WHO, 2023). Besides treatments, HIV prevention measures also seem to be effective. According to the UNAIDS (2024), 39% fewer people acquired HIV in 2023 compared to 2010. Countries such as Kenya, Malawi, Nepal, Zimbabwe reported a reduction of new infections by 75% which is an assurance of the feasibility of achieving the 90% reduction of new infections by the year 2030 (UNAIDS, 2024).

When one looks at the ALHIV population for this study, the existing data from the UNICEF (2023) shows that 1.7 million were living with HIV in 2022, which represents a growing share of PLHIV worldwide. If the current trends continue unabated, it is estimated that 184 000 adolescents will be infected by HIV every year. Moreover, it is estimated that 271 children and adolescents die of AIDS-related causes daily. UNICEF therefore recommends that efforts should be directed at adolescents to reduce the number of people becoming infected with HIV (UNICEF, 2023).

2.2.2. An overview of the HIV in the African continent

The continent of Africa is not spared from this global phenomenon as the impact of HIV is alarming the world over. The African continent alone accounted for an estimated 25.6 million PLHIV at the end of 2022. Essentially, of the total estimate of PLHIV on the continent, the eastern and southern Africa regions account for an estimated 45% HIV infections in the entire continent of Africa (Shanaube, Schaap, Hoddinott, Mubekapi-Musadaidzwa, Floyd, Bock, Hayes, Fidler, Ayles, 2021; UNAIDS, 2023; WHO, 2023). In 2022, it was estimated that 660 000 people on the African continent acquired HIV while 380 000 people died from AIDS-related illnesses (WHO, 2023). In terms of people accessing HIV treatment, a total of 20.9 million PLHIV had access to ART (WHO, 2023).

On a closer scrutiny of children and ALHIV, the UNICEF (2023) reveals that approximately 87% of children (0–14 years) and 82% of adolescents (10–19 years) were living with HIV during the period 2023 in SSA. The statistics are troubling because it is estimated that 356 children and 384 adolescents are infected with HIV on a daily basis, with about 1100 children and adolescents between 0–19 years, reported dead due to AIDS-related causes annually (UNICEF, 2023). Moreover, in

comparison to adults living with HIV, children and adolescents have less access to HIV treatment (UNICEF, 2023). It is noteworthy that ALHIV in Africa represent a vulnerable population who face developmental, psychosocial and comorbidity issues while coping with a chronic and potentially stigmatising disease (Dahourou et al., 2017)

2.2.3. An overview of the HIV phenomenon from a South African perspective

South Africa as part of the global community is not immune to the phenomenon of HIV. South Africa alone accounts for 20% of new global HIV infections, globally (Ugwu & Ncayiyana, 2022). According to the Human Science Research Council (2023), approximately 7.8 million people in South Africa were living with HIV in 2022. The UNAIDS (2023) reported that as of 2022, around 90 thousand PLHIV have died from AIDS-related illnesses in South Africa alone. Despite these challenges, the country has demonstrated progress in responding to the HIV pandemic.

Although South Africa has faced major challenges in rolling out HIV treatment programmes in the past, there have been some improvements in recent years. It is estimated that 5.7 million (75%) of the 7.8 million PLHIV have access to HIV treatment, of whom 91% were 15 years and older (HSRC, 2023; UNAIDS, 2022). This indicates another layer of the challenges that children and ALHIV encounter than adults to access this lifesaving treatment. Research evidence also shows that children and adolescents face comparatively higher rates of AIDS-related deaths (UNICEF, 2023). HIV incidences remain high among adolescents and youth while access to HIV treatment differs considerably by age. These challenges continue to sustain HIV in South Africa and therefore call for an expansion of access to HIV treatment among adolescents (Zuma et.al., 2022). It was projected in 2022 that ALHIV were around 360 000 in South Africa (HSRC, 2023). Statistical evidence indicates that there has been a significant increase in HIV prevalence among adolescents across all nine provinces (Mabaso et al., 2021). In addition, a study conducted by Naidoo et.al. (2020) focusing on the lived experiences of ALHIV aged 10–19 years in South Africa, found that the KZN province has the highest prevalence of ALHIV with an estimated 97,182 infections. In addition, Gauteng was the second most affected province, with an estimated 66,754 infections.

2.3. THE IMPACT OF HIV ON ALHIV AND THEIR FAMILIES

HIV has several impacts on the individual person, their families, the communities, and many other aspects of human life. Below is an outline of the socioeconomic, psychosocial and developmental impacts of HIV on ALHIV.

2.3.1. The socioeconomic impact of HIV on ALHIV and their families

HIV does not only have devastating impact on individual health, but it also presents substantial socioeconomic challenges to individuals, families, communities, and societies. Socioeconomic status incorporates not just income, but also educational attainment, financial security, quality of life and access to opportunities and privileges (Charles, Ezja & Extension, 2024; Ismail, Kari & Kamarulzaman, 2017).

The socioeconomic status of people affected and infected by HIV is compromised because HIV creates additional needs that lead to poverty as a result of loss of work and depleted family income, the cost of caring for the sick family members and orphaned children, weakened family support systems, depleted social resources, decreased participation in formal education by adolescents and a decrease in development and economic growth of nations (de Medeiros et.al., 2017; Ismail et. al.,2017; Trapero-Bertran, Oliva-Moreno, 2014).

The socioeconomic challenges faced by families affected by HIV are further underscored by Dona, Mudiyanselage, Watts, Sweeney, Coghlan, Majmudar and Abimanyi-Ochom, (2021) in their Asian Pacific study of the burdens of non-communicable diseases like HIV affected households where they concluded that households affected by HIV have a higher socioeconomic burden compared to non-HIV households, because they experience higher expenditure on health services, more absenteeism from work due to ill health, lower wages, higher unemployment, and higher food insecurity compared to their unaffected counterparts. Segoale and Moloko (2024) emphasised that due to high rate of unemployment in South Africa, caregivers of children and ALHIV encounter significant financial burden, particularly in arranging clinic/hospital visits travel costs and providing adequate nutrition for them. Whereas Akinyemi, Fotso and Banjo (2018) added that Children and ALHIV or living in household that are affected by HIV are often vulnerable to discrimination, deprivation, victimisation, forms of abuse, school dropout, recurring household migration, and poverty.

2.3.2. Psychosocial impact of HIV on ALHIV and their families

HIV presents psychosocial challenges for PLHIV and their families. PLHIV experience numerous psychosocial and emotional challenges such as accepting and coping with being diagnosed with HIV, taking HIV treatment, disclosing their HIV status to others, making decisions about sexual activities and parenthood as well as seeking social/emotional support (De los Rios et.al., 2021). This is further confirmed by Basha, Derseh, Haile and Tafere (2019) who observed that compared to the general population, mental health problems are reported to be twice as common in PLHIV.

Due to the discriminatory nature of HIV, PLHIV often lack social support, have poor self-esteem, experience stigma and discrimination, which in turn predisposes them to psychological problems such as depression and anxiety. Moreover, Rzeszutek, Gruszczyńska, Piętaa and Malinowskab (2021) assert that living with HIV brings about long-term stress due to the life-threatening nature of the disease, treatment side effects and especially internal and external stigma associated with the disease. Moussa et.al. (2021) expand on the internal and external stigma associated with HIV, pointing to internal and external stigma eventually impact personal and social relationships and health-seeking behaviour resulting in treatment-seeking delays and poor adherence to treatment. Moreover, Internal stigma has been linked with psychosocial factors such as social isolation, low self-esteem, depression, and psychological distress (Rzeszutek, 2021, Mousa et.al., 2021).

ALHIV also experience psychosocial challenges associated with living with HIV, such as acceptance of an HIV positive status, disclosure concerns, adherence to treatment, stigma, and loss of parents. In addition, it has been reported that ALHIV suffer from mental health issues (Xiao, Lin, Li, & Ji, 2019; Nyongesa, Nasambu, Mapenzi, Koot, Cuijpers, Newton & Abubakar, 2022). Compared to other health related issues, ALHIV are reported to suffer an increase burden of mental health and other behavioural issues which in turn aggravate their general state of health (Mahlasera, 2020).

In looking at the psychosocial effects of HIV on families of PLHIV, it has been reported that they are often challenged by looking after children who have lost their biological parents as a result of HIV, which causes significant psychosocial problems. The problems encountered include depression, anxiety, loneliness, anger, fear and stigmatisation by association (Van Deventer and Wright, 2017; Mahlasera, 2020;

Nabunya, Namuwonge, Sensoy Bahar, Sentumbwe, Migadde, Mugisha, Sewamala, 2023). They also have challenges in accessing mental health-related assistance. HIV infected people often deal with psychosocial stress, ill caregivers, reduced parenting capacity, a shift in family structure, the trauma of losing a parent, stigma, and discrimination. These challenges can lead to poor emotional health and behavioural challenges in the child or adolescent (Burkholder, 2019).

The COVID-19 pandemic presented another layer of challenge which significantly affected the psychosocial well-being of PLHIV and their families, leading to increased mental health-related issues such as anxiety and depression, social isolation, increased stigma and difficulties accessing HIV treatment (ART), which collectively threatened HIV management and treatment adherence (Bondarchuk, Lemon, Medina-Marino, Rousseau, Sindelo, Sibanda, Bekker, Butler, Earnshaw, & Katz, 2025; Monroe, Kulie, Byrne, Wilbourn, Barth, Resnik, Huebner, Horberg, Castel, Greenberg, & DC Cohort Executive Committee, 2023; Devlin, Johnson, McNulty, Joseph, Hall & Ridgway, 2022).

In conclusion, support, care, knowledge, and intervention programmes that focus on the psychosocial impact of HIV on PLHIV, and their families can provide mental, economic, and social stability, and therefore decrease the stresses they face (Mahlasera,2020; Maddocks & Chetty, 2020; Nyongesa et.al.,2022).

2.3.3. The developmental impacts of HIV on adolescents

Despite prevention of mother to child transmission (PMTCT) through the administration of HIV treatments given during pregnancy, birth, and breastfeeding, paediatric HIV infections continue to be a global concern (Nichols, 2022), with an estimate of 160,000 children newly infected with HIV through transmission from mother to child (vertical transmission of HIV) in 2020 (UNICEF, 2021). Furthermore, effective HIV treatments have aided the children who acquired HIV from their mothers, and they have access to treatment to survive through to adolescence and have reduced mortality. However, they experience a range of illnesses due to chronic HIV infection and its treatments (Ndiokwelu, Uwaezuoke and Iloh, 2022; Rukuni, Gregson, Kahari, Kowo, McHugh, Munyati, Mujuru, Ward, Filteau, Rehman, Ferrand, 2020). In addition, adolescents with perinatally-acquired HIV infection (PHIV) are at high risk of impaired growth with frequent stunting (low height for their age), underweight (low

weight for age), and wasting (low weight for height), according to WHO and the Centers for Disease Control and Prevention (CDC) standard of growth (Ndiokwelu et.al., 2022; Nichols, 2022; Williams & Jesson, 2018).

Williams and Jesson (2018) add that impaired growth is a result of multiple factors such as undernutrition, chronic inflammation, opportunistic infections, gastro-intestinal illnesses and endocrine abnormalities. Additionally, Rukuni et. al. (2020) and Jesson et. al. (2019) accentuates that despite taking HIV treatments, the onset of puberty is delayed, with subsequent effects on pubertal growth, final attained height, bone maturation, and increased risk for depression and lower self-esteem. Likewise, Heany, Phillips, Myer, Zar, Stein and Hoare (2021) argue that adolescents with HIV have poorer cognitive functioning and higher prevalence of attention deficit hyperactivity disorder (ADHD) compared to their peers who are HIV-negative. This poses critical questions and additional challenges for caregivers and adolescents as well as an urgent need to develop support interventions for them.

2.4. AVAILABLE INTERVENTION PROGRAMMES FOR ALHIV

Besides the challenges associated with HIV and its impact as outlined in the preceding sections, the reality is that there have been some positive responses across the globe, regions and countries. This section discusses existing intervention programmes for ALHIV and focuses on available HIV interventions for ALHIV worldwide, in the African continent and specifically in South Africa.

2.4.1. HIV intervention Programs worldwide

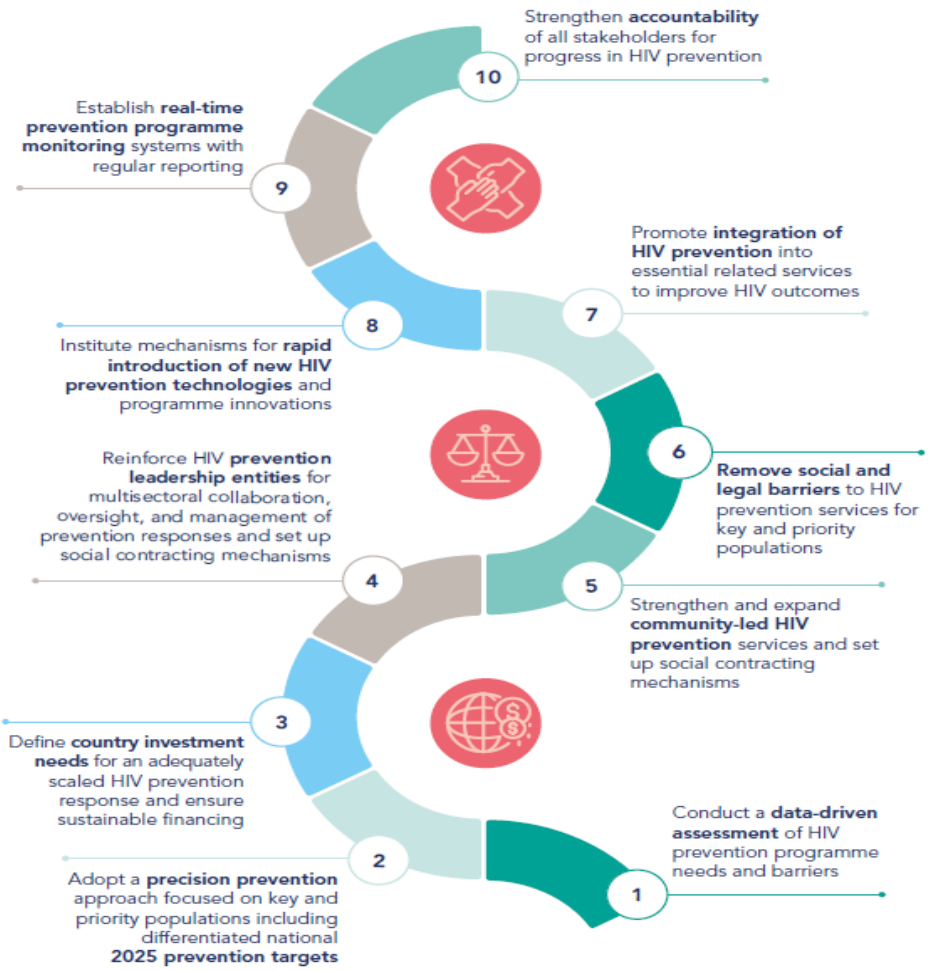
HIV still remains an incurable disease and there are still people suffering and dying from it, particularly in low-resourced settings (Rzeszutek et.al., 2021; UNAIDS, 2023). However, there has been significant efforts made by the global health community, leading governments and civil society organisations in understanding, preventing and treating HIV. These efforts have made significant improvements in people's lives through partnerships between countries, communities and donors including the United States President's Emergency Plan for AIDS Relief (PEPFAR), the Global Fund to Fight, AIDS, Tuberculosis (TB) and Malaria (Global Fund) and the private sector (UNAIDS, 2023; WHO, 2023; Lentoor, 2017). The availability and rapid scale-up of ART and the implementation of evidence-based combination prevention strategies have transformed what was perceived as an inevitably incurable and fatal disease to

a chronic, manageable condition leading to significant declines in new HIV infections and global rates of AIDS-related deaths (Cabecinha, 2022; Areri, Marshall, Harvey, 2020; Kharsany & Karim, 2016).

In ending HIV, the World Health Organisation endorsed the 2022–2030 Global Health Sector Strategy under the United Nations Sustainable Development Goal 3 (UN-SDGs-3), which aims to control the HIV epidemic and prevent HIV infections by reducing the global HIV burden by at least 50% in countries with higher HIV rates (Ugwu et. al., 2022). In addition, major breakthroughs in the prevention of HIV have been developed, and a combination of HIV prevention strategies have been employed, using a mixture of biomedical, behavioural, and structural interventions. These interventions include voluntary male medical circumcision (VMMC), the use of ART for the prevention of mother to child transmission (PMTCT), preventing transmission before exposure (pre-exposure prophylaxis) or immediately after an exposure (post-exposure prophylaxis), and suppressing the virus in PLHIV. In addition, condoms, educational awareness and health promotion programmes have been rolled out as intervention strategies (Cabecinha, 2022; Ugwu & Ncayiyana, 2022; Kharsany & Karim, 2016).

In an effort to end the HIV epidemic by 2030, the Global HIV Prevention Coalition was developed in 2017 to accelerate progress on HIV prevention, with the main focus on countries with high numbers of new HIV infections that are not showing any signs of decrease (UNAIDS, 2022). This is to be achieved by implementing large-scale high-coverage equitable and high-quality prevention programmes. Consequently, a road map (Figure 1) was developed to guide all stakeholders who are seeking to reduce HIV infections (UNAIDS, 2022). The road map (Figure1) focuses on 10 actions that guide the use of scarce resources in ways that can achieve maximum impact for HIV prevention programmes such as the use of innovative HIV prevention tools, integration of HIV prevention services to other related services, and strengthening community-led services to achieve improved HIV outcomes (UNAIDS, 2022).

Figure 1: *The HIV Prevention 2025 Road Map: Ten-Point Action Plan*



Source: Global AIDS Strategy (2021–2026)

Despite more efforts being made to end the HIV epidemic by 2030, ALHIV continue to be disadvantaged across the HIV continuum of care (from diagnosis to linkage to care and subsequent ART adherence, retention in care, and viral suppression) since they have less access to HIV treatment, poor adherence to treatment, higher rates of loss to follow-up (LTFU) and increased needs for psychosocial support and sexual reproductive health (SRH) services (Kose et.al, 2021; Armstrong et.al.,2018). In addition, compared to other populations, ALHIV are reported to be less virally suppressed since health care services are not adapted to their needs. Therefore, efforts are still needed to understand the needs and what works best for this population group (Armstrong et.al.,2018; Winskell, Miller, Allen & Obong'o, 2016)

2.4.2. HIV intervention Programs in South Africa

In looking at South Africa as one of the countries mostly affected by HIV, the government has made substantial progress in combating HIV by initiating a large-scale ART programme roll-out. In 2016, a Universal Test and Treat program was introduced with the aim of ensuring that all PLHIV have access to ART, regardless of their CD4 cell count. This has transformed HIV into a manageable, chronic condition that has led to a significant decline in new HIV infections and AIDS-related deaths (George, Maughan-Brown, Thirumurthy, 2021; Masquillier, Wouters, Campbell, Delport, Sematlane, Dube & Knight, 2020).

The South African government partnered with the United State of America (USA) in controlling the spread of HIV through a programme called PEPFAR, which aims to provide a comprehensive HIV program that focuses on prevention, care, treatment and health system strengthening. Subsequently, the country developed the National Strategic Plan for HIV, TB, and Sexually Transmitted Infections (STIs) in response to the HIV epidemic, and the country is now in its fifth generation of the NSP. The NSP has further guided the partnership between the South African government and the USA in implementing the HIV programme (USAID, 2023; SANAC, 2023). However, the relationship between the two countries have recently gone sour, with the USA withdrawing its support through the PEPFAR and the USAID. The withdrawal of this funding has resulted in service disruptions; closure of clinics that were rendering services through various HIV-related programs. The halting of these HIV-related programs resulted in significant reduction in HIV testing and treatment services, and the possibility for thousands of excess HIV-related deaths (UNAIDS, 2025; Murray & Venter, 2025). An argument submitted by Academy of Science of South Africa- ASSAF (2025) is that these cuts threatened to disrupt progress made in years in the fight against HIV in South Africa. South Africa is thus implementing the same interventions as the rest of the world by using a mix of biomedical, behavioral, and structural interventions. These interventions include VMMC, PMTCT, pre-exposure prophylaxis (PrEP), post-exposure prophylaxis (PEP) and suppressing the virus in PLHIV, in addition to condoms and educational awareness, and health promotion (Zuma et al., 2022; George et.al., 2021; NSP, 2017; Kharsany & Karim, 2016).

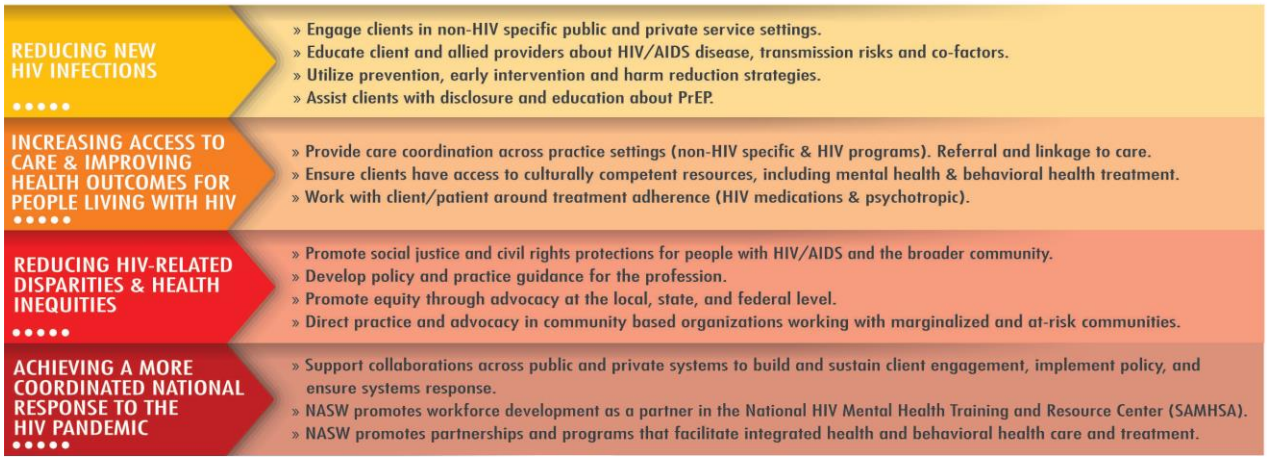
In South Africa, there are substantial gaps at each step of the HIV continuum, which led to the HIV viral suppression amongst ALHIV to be at 10% (Zanoni, Archary,

Sibaya, Ramos, Donenberg, Shahmanesh, Celum, Pettifor, Bekker, & Haberer, 2022). The reason for ALHIV to rate less on the continuum of care is because they have specific needs, which clinical and psychosocial health services and community support systems in South Africa are ill-equipped to address (Zanoni et. al., 2022; Galárraga, Kuo, Mtukushe, Maughan-Brown, Harrison& Hoare, 2020; Winskell et. al., 2016). Nevertheless, South Africa has developed and implemented the National Adolescent-Friendly Clinic Initiative, which is aimed at addressing some of the barriers to service provision, with the focus on sexual reproductive health including HIV treatment, care and management (Van Pinxteren, Cooper & Colvin, 2021; James, Pisa, Imrie, Beery, Martin, Skosana & Delany-Moretlwe, 2018).

2.4.3. Social work intervention program to ALHIV and their families in South Africa

As already stated, PLHIV and their families face various physical, emotional, social, and economic challenges that can affect their quality of life and well-being (Nyogeza et.al., 2022; Wanni et.al., 2021). Likewise, children and adolescents born from parents who are living with HIV are often left orphaned and without adult supervision when the parent dies from AIDS-related illnesses. This leaves children/adolescents vulnerable with no means of support, which means that they have extra physical and psychosocial problems (Lukelelo, 2023; Nyongesa et.al.,2022; Burkholder, 2019; Kulu, 2014). The challenges faced by PLHIV, and their families necessitate care and support from professionals such as social workers who play a crucial role in supporting PLHIV to manage emotional distress and related psychosocial conditions (Lekganyane & Manganyi, 2023). The National Association of Social Workers indicates that social work practitioners globally provide skilled interventions that support the goals of the National HIV/AIDS Strategy, and therefore contribute positively to reducing new HIV infections, increasing access to care and improving health outcomes for PLHIV (Continuum, 2015). In response to the HIV pandemic, social workers are involved in activities outlined in Figure 2 below.

Figure 2: SOCIAL WORK SKILLS & THE NATIONAL HIV/AIDS STRATEGY



Source: Continuum (2015)

A large-scale roll-out of ART in South Africa has put a huge burden on the health system, which was already facing severe human resource shortages and poor retention of health professionals and therefore prompted the government to look at additional human resources to implement the programme effectively. In addition, the NSP proposed a shift from addressing HIV as a merely bio-medical condition by emphasising the importance of considering the social and structural drivers of the pandemic. This has shifted the focus from only clinical treatment of HIV to adopting a community-based approach which include community health workers (CHWs) who provide chronic disease support and community home-based care (CHBC) and social workers who would provide social support services to PLHIV in communities and their families (Masquillier et.al., 2020; SANAC, 2017; Lekganyane & Alpaslan, 2019).

2.5. THEORETICAL FRAMEWORK

A theoretical framework is a guide that is supported by a specific theory or theories that the researcher uses to plan his or her research study and should be clarified at the inception of the study (Grant & Osanloo, 2014). Crawford (2020) describes the theoretical framework as how the research study relates to an existing theory and how the study will contribute to the body of knowledge when linked to such a theory. In short, a theoretical framework is a guide consisting of theories which assist the researcher's thinking regarding the direction to be taken in conducting a study.

In this study, the researcher adopted a strengths-based perspective and ecological systems theory.

2.5.1. The strengths-based perspective

A strengths-based perspective focuses on identifying and mobilising the resources, knowledge, wisdom, and assets inherent in every person and their environments (Pulla, 2017). It was initially developed in therapeutic contexts, as a philosophical shift from focusing on client deficits towards their strengths and resources (McCamey, 2015). According to Pulla and Francis (2015), a strengths-based perspective encourages collaboration between the client requesting services and those rendering such services, with the aim of working together to determine outcomes that draw on the strengths and assets of both parties. In the context of research, this theory suggests that researchers should develop an understanding based on collaborative relationship with their participants, with a focus on the strengths, resources, and assets. The following principles govern a strength-based perspective (Caiels, Milne & Beadle-Brown, 2021; Hammond, 2010):

- Each individual has the inborn potentials and strengths to overcome or find solutions to his or her challenges. Embedded in a strength-based perspective is the view that although ALHIV and their primary caregivers experience many challenges, they also possess inborn talents and abilities which should be considered to understand their situations and to develop intervention strategies to support them.
- A strength-based perspective is premised on the belief that change is inevitable during the struggle of confronting life challenges. In efforts to bounce back, individuals acquire skills, knowledge, resources, and abilities enabling them to endure current difficulties and eventually find solutions (Caiels et.al., 2021; Pulla, 2017). The view is that as individuals such as ALHIV and their primary caregivers face difficulties, they also develop skills and resources that enable them to overcome their challenges.
- Positive change occurs in the context of authentic worker-client relationship where clients are respected. It is therefore important that social workers treat their clients with respect. Although this principle addresses the therapeutic context, it is also applicable in research context; researchers are encouraged to respect their participants. According to Pulla (2017), believing in the inherent strengths of people involves respecting their inherent wisdom and knowledge, which leads to a rediscovery of these resources in the environments in which they live.

- Collaboration is key in starting the change process and in providing social work interventions. The researcher should see participants as collaborators in the process of co-constructing knowledge around the issues faced by ALHIV and their caregivers. It is equally important to consider the broader context in which these issues play themselves out and to explore the collaborative relations that caregivers and ALHIV engage in as they navigate through solutions.
- Resources are always available that can be employed to aid clients in challenges that face them. The general approach for researchers who are inspired by a strength-based perspective is to not only identify the challenges faced by participants such as ALHIV and their primary caregivers, but to search for resources in the environments in which these individuals find themselves. In other words, as researchers interview the participants around their challenges, they should also make use of the skills and techniques that enable them to identify resources that are available around them. Illnesses and struggles may be injurious, but they may also be sources of challenge and opportunity. The view is that researchers should refrain from focusing only on the illnesses and struggles faced by the participants but should also look beyond the struggles and difficulties.

In this study, a strengths-based perspective was adopted with the aim of enabling the researcher not to only focus on the deficits resulting from being affected by HIV, but to also search for talents, opportunities and resources that result from being affected by this condition. She adopted a strengths-based perspective in the belief that each participant possesses some strengths, wisdoms and talents that are also crucial to comprehensively understand their needs and challenges. Therefore, to fully understand the phenomenon under investigation, it was important to consider the talents, resources and competencies of the caregivers, ALHIV and social workers who are working with these categories of clients.

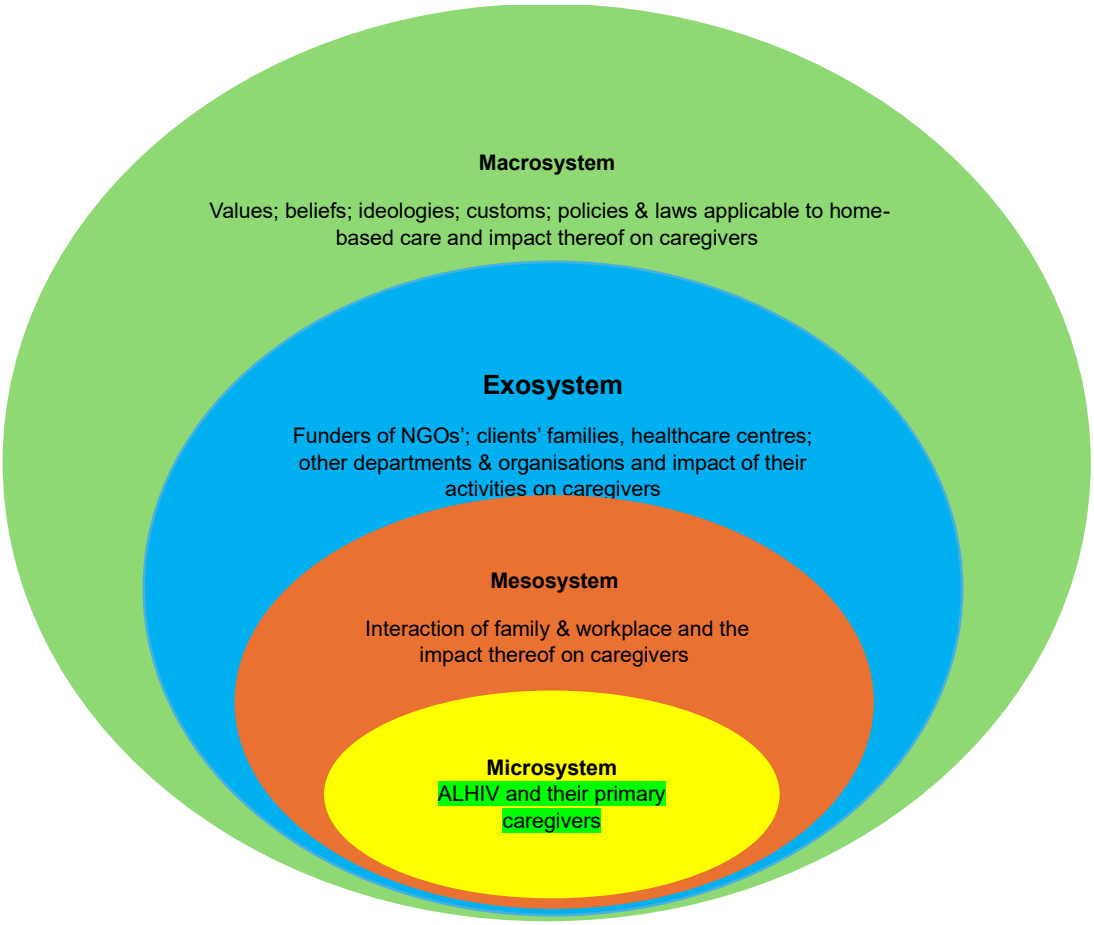
2.5.2. Ecological systems theory

Ecological systems theory is the brainchild of Bronfenbrenner (1994), a developmental psychologist. It focuses on the interaction and interdependence that occurs between people and their social and physical environments (Teater, 2014; Crawford, 2020). Ettekkal and Mahoney (2017) submit that human beings function in more than one ecology; their ecosystem comprises interrelationships and a collection of different

ecologies. Consequently, ecological systems accentuate the importance of understanding individuals and their behaviour through their environments. Simply put, a person's environment and his or her experiences, help to define how they view the world and how they respond to it (Teater, 2014).

According to the ecological systems theory, human development is influenced by interactions and interpersonal relationships crosscutting multi-dimensional and multifaceted levels, differentiated as the microsystem, the mesosystem, the exosystem and the macrosystem (Ettekkal & Mahoney, 2017). Figure 3 below indicates how these systems interact with each other:

Figure 3: An adapted Bronfenbrenner's Ecological Systems theory



Source: Ettekkal & Mahoney (2017)

The **microsystem** is a system which is close to the individual and the one with which the individual has direct contact and interaction. It includes daily interactions with family members, peers, teachers, and others (Navarro & Tudge, 2023; Crawford, 2020; Ettekkal & Mahoney, 2017). A person's life is shaped by immediate environments such as schools, homes or workplaces, which have the potential to influence their psychological and behavioural development (Crawford, 2020; Ettekkal & Mahoney, 2017). Additionally, factors such as socioeconomic status and resources within the family can shape an individual's experiences within the system (Crawford, 2020; El Zaatari & Maalouf, 2022). In the context of this study, the microsystem included the family, inclusive of ALHIV as members thereof, and the work environments and socioeconomic circumstances of their primary caregivers. Similarly, how the primary caregivers live their lives and develop experiences is influenced by their immediate environment.

The **mesosystem** is about the relationship between a person's specific microsystems and how they influence each other, which may also influence the individual positively (when working together) or negatively (when not working together). A mesosystem includes the relationships between family members, teachers, peers, and other social groupings (Navarro & Tudge, 2023; El Zaatar & Maalouf, 2022; Ettekkal & Mahoney, 2017). Furthermore, the family, as a microsystem is regarded as the closest most strong and influential part of a mesosystem (Crawford, 2020; Ettekkal & Mahoney, 2017). In focusing on this study, the challenges faced by ALHIV (frequent illness, failure to take medication regularly, feeling stigmatised, disclosure challenges and more), have both direct and indirect negative effects on primary caregivers.

The **exosystem** refers to the broader social and environmental contexts in which the person is not an active participant, but nevertheless affected by social activities or decisions. It includes community resources, government policies, and the availability or non-availability of social services (El Zaatar & Maalouf, 2022; Crawford, 2020; Ettekkal & Mahoney, 2017). Navarro and Tudge (2023) highlight the fact that even though individuals may not have direct contact with these factors, they still influence their development. For the purpose of this study the availability or lack of and access to resources such as employment, health care and social services influences how

primary caregivers react or perceive the challenges they experience in caring for ALHIV.

The **macrosystem** is a set of overarching beliefs, values and norms as reflected in the cultural, religious and socioeconomic environment (Crawford, 2020; Ettekkal & Mahoney, 2017; Bronfenbrenner, 1994). The macrosystem encompasses broader factors such as cultural beliefs, social norms, customs and value in families, which might have impact on the individual development (El Zaatar & Maalouf, 2022; Liao, 2016). This is the broader spectrum of culture to which the primary caregivers or the ALHIV subscribe, which shapes the needs and challenges they face. It is therefore essential for the researcher who aspires to understand the plight of ALHIV and caregivers to understand their macrosystem.

Crawford (2020) states that ecological systems theory shifts the focus of treatment from the individual's personality and behaviour to their interrelation with the family, community and other systems, by using the resources that are available in the systems and by employing them to aid them in resolving their challenges. In this way, the ecological systems theory ties in with a strength-based perspective, because the former provides the context for the latter to operate by demonstrating how an individual is part of a larger environment. The ecological systems theory highlights a "person-in-environment" perspective, which means that to understand an individual's strengths and challenges, one must consider the various systems that influence them (family, community including its components and culture). The strengths-based approach then uses this understanding to identify and influence an individual and their environment (Caiels et.al., 2021; Chapin, 2017; Ettekkal & Mahoney, 2017). In this study, the ecological systems theory emphasises the importance of understanding how ALHIV and their primary caregivers perceive and experience the various sub-systems (including social workers and their services) in their environments and how these systems influence their overall functioning and well-being, regardless of how problems or concerns may appear. In addition, in rendering their services, social workers consider the interrelations between these systems (the individual, families, policies, communities and cultures) and identify the strengths and weaknesses emanating from these relationships (Chapin, 2017; Darling, 2007).

2.6. CHAPTER SUMMARY

This chapter presented a literature review. It outlined the phenomenon of HIV and ALHIV from global, African regional and South African perspectives. The impact that HIV has was explored in consideration of socioeconomic, psychosocial and developmental impacts. The researcher acknowledged that alongside the challenges associated with HIV, ALHIV and their primary caregivers, there have been positive initiatives made by role players such as the government and private sector to mitigate against and prevent some of the impacts. The chapter examined the various interventions from global and country level perspectives. Attention was also given to specific interventions by social workers designed for ALHIV and their families. Finally, the two theoretical frameworks adopted for the purpose of this study, namely strengths-based perspective and ecological system theory, concluded the chapter.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1. INTRODUCTION

This chapter focuses on the research methodology adopted for this study. It outlines the philosophical orientation upon which the study is grounded and then presents the selected research methodology. Qualitative research is introduced and explained as a research approach that guided the study, followed by the research design and the methods applied, namely the population, sampling, the data collection instruments, the data analysis strategies and how rigour or trustworthiness were ensured. Given the significance of research and the involvement of human participants in it, the chapter gives an account of the ethical principles that were considered.

3.2. PHILOSOPHICAL AND METHODOLOGICAL GROUNDING OF THE STUDY

There are several research paradigms, and qualitative researchers select paradigms that are theoretically aligned with their views (Gretschel, Ramugondo & Galvaan, 2023). A research paradigm is a philosophical framework that guides the research process. It comprises abstract beliefs and principles that shape how researchers see the world, and how they interpret and act within that world (Kivunja & Kuyini, 2017; Rehman & Alharthi, 2016). Examples of social research paradigms are positivism, realism, interpretivism, objectivism, subjectivism, pragmatism, functionalism, radical humanism and radical structuralism (Rahi, 2017; Rehman & Alharthi, 2016).

This study adopted an interpretivist paradigm (Junjie & Yingxin, 2022; Wilson, 2015; Ormston, 2014). In simple terms, Kivunja and Kuyini (2017) explain that researchers operating from an interpretivist paradigm, make efforts to get into the participants' heads and to understand and interpret what they are thinking or what meaning they are making of the context. Interpretivism assumes that reality is subjective, multivarious and constructed by the meanings attributed by research participants to phenomenon under investigation (Junjie & Yingxin, 2022; Rehman & Alharthi, 2016). Applying the assumption to this research meant that the realities of primary caregivers in terms of how they experience caring for ALHIV and the accompanying challenges as well as the experiences of ALHIV on being cared for by a primary caregiver were subjective and multivarious. Interpretivism allows researchers to employ a qualitative

research approach, (Alharahsheh & Pius, 2020; Rehman & Alharthi, 2016). This approach enabled the researcher to gain knowledge about the relevant social work practice interventions required to support the primary caregivers who care for ALHIV.

In addition, interpretivism relies on the subjective relationship between the researcher and participants to explore the phenomenon under study in depth. Building rapport with participants is therefore vital and engaging them in one-on-one interviews is favoured (Polit & Beck, 2022; Carpenter, Coughlan & O'Connor, 2018). This allows researchers opportunities to probe participants' thoughts, values, prejudices, perceptions, views, feelings and perspectives, which result in a broader understanding of the phenomena under study (Majeed, 2019; Pham, 2018). In this study, the researcher interacted with participants and observed both their verbal and non-verbal communication to arrive at an understanding of the phenomenon being investigated. These purposeful conversations were facilitated through posing explorative, open-ended and probing questions to the participants (the primary caregivers, ALHIV and social workers) about the experiences, challenges and needs of caregivers in caring for ALHIV, the ALHIV' experiences regarding being cared for by a primary caregiver, the kind of social work support available for primary caregivers, ALHIV and social workers, as well as to develop the guidelines for supporting social workers, primary caregivers and ALHIV(Busetto et al., 2020; DeJonckheere & Vaughn 2019).

3.3. RESEARCH METHODOLOGY

Research methodology is a process initiated by the researcher to conduct a research project, which includes steps and methods used which led to collecting data as well as the actual data collection methods (Brynard, Hanekom & Brynard 2014; Patel & Patel, 2019). Putting it differently, Sileyew (2019) describes research methodology as playing a crucial role in directing the path undertaken by the researcher in formulating the research problem and objectives and interpreting and presenting the research results obtained from the collected data. There are three types of research methodological approaches, namely qualitative research, quantitative research, and mixed methods (Creswell, 2016; Snyder, 2019). For the purposes of this study, a qualitative research approach was used. The discussion below provides a description and the rationale for using this approach.

3.3.1. Qualitative research approach

This study adopted a qualitative research approach because it is human-centered and focuses on people's experiences by searching for deeper meanings of such experiences. Applying a qualitative research approach enables the researcher to study people's actions directly from their own experiences and perspectives (Rubin & Babbie, 2014; Given, 2015). This means that a qualitative research approach gives the researcher first-hand information from the perspectives of the participants. In practical terms, the primary caregivers were afforded an opportunity to reflect on and describe their lived experiences, challenges and needs in relation to caring for ALHIV. It allowed ALHIV and social workers to share their perceptions about their challenges and needs and to put forward suggestions on how social workers can support caregivers caring for ALHIV.

The following are the main characteristics of qualitative research through which this study evolved (Moser and Korstjens, 2017; Malagon-Maldonado, 2014):

- **Qualitative research is conducted in a real or natural setting.**

It is crucial to study behaviours as they happen in a natural setting since human experiences are inclined to be influenced by the settings in which they occur (Moser & Korstjens, 2017; Marshall & Rossman 2016). Similarly, qualitative researchers strive to understand socially constructed meanings by entering the social environment of the research participants and reconstructing these meanings in scientific language (Bell, 2017). According to Yegidis et al. (2018), the scope of the interpretations is determined by the natural context in which the phenomenon occurs. The researcher immersed herself in the natural environment of the participants and with the individuals whose ideas and perspectives she explored. She conducted the study and collected data about the participants' daily living experiences (primary caregivers and ALHIV) and the working environments (social workers) through individual semi-structured face-to-face interviews in the municipal areas of Tshwane, Johannesburg, Ekurhuleni and Sedibeng which were the residential sites for the participants and where they were free to express themselves. As a result, the researcher was able to better understand their social settings and experiences.

- **Researchers in qualitative research are the main instruments of data collection**

Qualitative researchers develop data collection tools such as interview guides, negotiations and gain entry into the field to identify and recruit participants. In addition, they schedule and conduct interviews, analyse the data and ultimately report on the findings. In other words, what is collected as data is filtered through the researcher's eyes and ears (Creswell, 2014). However, this does not mean that qualitative research is biased; it rather means that qualitative researchers, according to Creswell (2016), are self-conscious researchers who are aware that their values, beliefs and attitudes are all elements in the collection process. This is beneficial because it ensures that these features are integrated into their research reports through reflexivity, which is a process affording researchers the opportunity to declare their personal background and reflect on how their own values, assumptions and personal experiences shape their interpretations (Creswell, 2014; Darawsheh, 2014). In short, qualitative researchers do not only pay attention to the factual nature of their research, they also pay attention to their own thinking and backgrounds during the unfolding research process.

For this study the researcher was the main data collection instrument. As already stated, she used individual semi-structured face-to-face interviews and observations. The interviews were supported by an interview guide which consisted of open-ended questions directly related to the study questions, aim and objectives. She also employed open-ended questioning, probing and clarifying questions. In administrating the interview guide the researcher also paid attention to her own thinking and reflected on how her own values, assumptions and personal experiences (working in the HIV field as a social worker for more than 20 years) assisted in probing deeper, all of which assisted in getting rich and detailed responses from the participants in terms of the experiences, challenges and needs of the caregivers in caring for ALHIV or how ALHIV experience being cared for by their primary caregivers. To ensure reflexivity the researcher documented her own thoughts, feelings and experiences, which assisted in shaping her interpretations during the data verification.

- **Qualitative research allows the researcher to use multiple data sources**

In qualitative research, it is common to use multiple data sources such as interviews, observations and documents, rather than a single method to gain deeper understanding of the topic that is researched (Pyo, Lee, Choi, Jang, & Ock, 2023; Cypress, 2015). In this study, individual semi-structured face-to-face interviews were the primary data collection method. During the interviews, the researcher also observed and noted non-verbal behaviours and considered the environment in which the interviews were conducted. She made use of a diary to document her experiences and reflected on the research process as the study unfolded. She listened attentively to responses while reflecting on whether the questions were understood the way they were intended, used follow-up questions to probe further and if questions were understood, posed clarifying questions to the participants to get more detailed information.

- **In qualitative research, data is collected from the viewpoint of the individual participants**

In qualitative research, data is collected from the perspectives of individual participants and described, analysed and interpreted using 'thick description' to further explore their experiences and perspectives (Kostova, 2017; Cypress, 2015; Koch, Niesz & McCarthy, 2014). Malagon-Maldonado (2014) adds that the purpose of qualitative research is to describe, understand, and interpret different phenomena as perceived by the research participants. Correspondingly, Riese (2018) emphasize that qualitative research intentions are applied to comprehend the realities in which people find themselves. In this study, the researcher approached the interviews with an open mind which enabled her to learn from the participants. She collected, analysed, and interpreted data based on the caregivers' experiences, challenges and needs in caring for ALHIV and how ALHIV experience being cared for by their primary caregivers. She refrained from imposing her assumptions on the study. Lastly the challenges and needs of primary caregivers in caring for ALHIV were also considered from the perspectives of social workers.

- **Qualitative research works inductively, and themes are derived from the participants**

Qualitative research focuses on an in-depth investigation and understanding of the meaning individuals or groups attribute to a social or human problem. The research process comprises emerging questions and procedures, data collected in the participants' setting, data analysis inductively building from particular to general themes, and the researcher's interpretations of meaning attached to the data collected (Moser & Korstjens, 2017; Creswell, 2014). These meanings and ideas are then reported in the form of quotations that represent the voices of the participants (Creswell, 2016). In other words, the researcher works inductively and derives themes from the information that emerges in the participants' accounts. For the purpose of this study, the researcher approached the research field with an attitude of learning from the participants (primary caregivers, ALHIVs and social workers) in their environments (homes, workplaces and NPOs) in order to do an in-depth investigation and to understand the patterns, themes, and relationships which emerge from the data. She adopted an inductive approach to developing themes and ensured that when reporting, the participants' accounts are supported by the extracts from the interview transcripts.

- **Qualitative research is complex and multifaceted**

Creswell (2016) describes qualitative research as 'a complicated subject with components that are on motion. The complexity of qualitative research calls for multiple methods to be used, while, at the same time, taking note of how personal backgrounds shape the understanding of the participants (Pyo et. al., 2023; Creswell, 2016). It is through qualitative research that the complexity of human life and multiple themes can emerge in the data analysis derived from the participants' multiple voices (Creswell, 2016; Cypress, 2015). The researcher developed a whole or complex picture of the study rather than focusing on certain parts only. In this study, the complexity consisted of multiple layers of research participants (primary caregivers, social workers and ALHIV) who are unique with different experiences and whose experiences occurred in environments characterized by different challenges.

- **Qualitative research is flexible**

It is critical to note that qualitative research is conducted in a fluid environment that requires flexibility and adaptability of plans (Yegidis et al., 2018; Fain, 2017). Qualitative researchers should be receptive to changes that may arise at any stage in the research process, which might require modification of the original plan to acclimatise it to the dynamic fieldwork environment (Litchman, 2014). The researcher's approach to qualitative research is therefore determined by various contextual factors (Malagon-Maldonado, 2014). Flexibility guided the application of this study. The researcher embraced the idea of an emergent design giving her the flexibility to adapt to any change that may occur when she entered the field or collected the data. In some instances, this meant changing meeting times to accommodate the participants, particularly the ALHIV because they were schooling. Therefore, some of the interviews were conducted late in the afternoon or over weekends. In addition, because of fear of being stigmatized due to lack of privacy at home, a total of nine interviews had to be moved to the NPO offices and some to the clinics where primary caregivers and ALHIV were taking their medication.

3.3.2. The rationale for using qualitative research approach

One of the reasons for the researcher adopting qualitative research is that it allows the researcher an opportunity to study the phenomenon in its natural setting (Marshall & Rossman, 2016; Flick, 2018; Creswell & Poth, 2018). In this study, qualitative research approach afforded the researcher the opportunity to collect data where participants were experiencing the problem or the issue, which were their primary residences or at the NPO where they were receiving psychosocial services. As already mentioned, some of the primary caregivers and ALHIV preferred to be interviewed at an NPO or clinic due to fear of being stigmatized by their communities and/or families. Furthermore, the social workers were interviewed in their offices which are places where they would normally render services to primary caregivers and ALHIV.

Qualitative research contributes to professional knowledge about the understanding of participants' lived experiences and/or the perspectives from which their lived experiences can be perceived, which is important in understanding and addressing social issues or problems (Koch et.al., 2014; Busetto, Wick & Gumbinger, 2020). Creswell and Poth (2018) add that problems or issues need to be explored by focusing on participants' perspectives, the meanings they attach to the phenomenon under

investigation and their multiple subjective views of this. The main interest in this study was to understand primary caregivers' lived experiences, the challenges they face and the needs they have in caring for ALHIV. The study further explored the experiences of ALHIV in regard to being cared for by their primary caregivers as well as suggestions for supporting the caregivers and social workers working with ALHIV and their caregivers.

It is crucial to highlight that in qualitative research, researchers seek to discover or enhance a deeper understanding of the social relationships by avoiding their own prior knowledge and are open to learn new things from the participants and the context in which the study is conducted (Creswell & Poth, 2018; Islam & Faraj, 2022). In other words, in this study, the willingness to learn new things from the participants was important. However, this does not suggest that the study lacked focus; the interview guide was prepared to guide the semi-structured interviews, and the researcher ensured that the responses provided by the primary caregivers, ALHIV and social workers remained within the parameters of the study. In addition, observations were made by the researcher in relation to the context of the study (how HIV affects the participants and how they navigate life and their living conditions) and the way in which the participants expressed themselves in relating their experiences (Busetto et.al, 2020). In fact, the researcher tried to see things with openness and from the participants' perspectives even in instances where it was not the first time, she came across certain issues since she has been working in the HIV field for a while.

3.3.3. Research design

Research design is a guide to assist researchers on how to plan and conduct their studies (Creswell, 2016; Creswell & Poth, 2018). It affords the researcher an opportunity to make sense of issues by investigating them in their specific contexts together with the meanings that participants attach to them (Asenahabi, 2019). Qualitative research designs produce data that is not quantifiable using open-ended questions. Marshall and Rossman (2016) argue that a qualitative research design comprises interconnections and interactions between various design components and does not have a rigid commencing point; nor does it continue through predetermined orderly steps. In other words, the research design is a plan on how the study will be conducted; and the plan is not fixed but it can be flexible to enable modifications, especially in a situation where the researcher is confronted with unexpected

circumstances that may require modification of the original research design. Ravitch and Riggan (2016) add that a research design is shaped by the research questions. To achieve the set goals and objectives of this study and to answer all the research questions, the research design deemed suitable was a phenomenological research design supplemented by explorative, descriptive, contextual and intervention research designs.

3.3.3.1. Application of phenomenological research design

Employing a phenomenological research design as a commonly used qualitative strategy of inquiry, is fitting when the researcher's intention is to explore or to find out how participants experience a phenomenon in their 'live world' (Nieuwenhuis, 2016; Creswell, 2014). Pathak (2017) highlights that phenomenological research design attempts to understand people's perceptions and understanding of a specific phenomenon. In phenomenological research, the role of the researcher is to extract the fundamental experiences of participants through a reductionist process or put between brackets (Pathak, 2017; Litchman, 2014). In this study the central focus was on the lived experiences of primary caregivers in caring for ALHIV and the ALHIV on being cared for by the caregiver and how they translate these into the meanings they attach to them in an effort to interpret the linkages between the scientific world and their everyday life events (Korstjens & Moser, 2017; Bakanay & Çakır, 2016). Phenomenological research design afforded the researcher an opportunity to investigate the lived experiences of the participants and to describe the meanings they attached to these experiences (Neubauer, Witkop, and Varpio, 2019). In addition, by using a phenomenological research design, the researcher set aside her preconceived ideas, judgments and biases to better understand the lived experiences of participants. She also offered participants an opportunity to share their experiences without fear of judgement or misrepresentation (Alase, 2017).

The researcher ensured that the lived experiences were captured by the way the interview questions were posed to the participants. For example, attention was paid to the way the caregivers expressed their challenges to gain full understanding of the likelihood or the seriousness of the challenges. Additionally, the participants were prompted to share examples of their lived experiences (e.g. a question directed at primary caregivers would be: Tell me what it is like to stay and care for an ALHIV - which then prompted one primary caregiver to respond by saying, *It is difficult because*

she is not like other children, she needs extra care, always sick, you need to take her to the clinic). The researcher also probed for more information by asking participants how they reacted/felt about certain things or asking them what they did in response to such things (e.g. one primary caregiver was asked: You mentioned that he was sick; what symptoms were displayed by your child - and he responded by saying, *He was coughing, had sores and diarrhea, then they said he has TB and later I think it was in 2009 or so when he started taking HIV treatment*). The researcher also applied communication skills such as active listening, non-verbal communication such as nodding, and summarising key points to capture the participants' lived experiences (Kapur, 2018).

3.3.3.2. Application of explorative research design

According to Yegidis et al. (2018), the researcher needs to start a research inquiry with less insight into the phenomenon under investigation. This means that researchers should not bring their prior knowledge about the phenomenon into the study; they should rather be open to learn from the participants. This is further emphasized by Swedberg (2020) who argues that explorative research aims to increase knowledge or uncover new ideas of a specific phenomenon. Exploratory research design was applied through conducting individual semi-structured face-to-face interviews comprising open-ended questions. To further explore their experiences, the participants' responses were followed by probing questions for the purpose of clarifying what was shared and also to understand the participants from their own perspectives. In this way, the researcher was able to gather more information and insight into the lived world of the participants.

3.3.3.3. Application of descriptive research design

The purpose of descriptive research is to describe a phenomenon under investigation as it is in nature (Fain, 2017; Siedlecki, 2020). This means that the different ways in which participants experience or perceive the phenomenon are interrogated, and the researcher can describe the rich details they provide about their environments, interactions, meanings and their daily lives (Yegidis et al.,2018; Doyle, McCabe, Keogh, Brady & McCann, 2020). In this study a descriptive research design aided the researcher to collect data by giving participants time to describe their experiences and opinions in relation to the phenomenon being studied. The individual semi-structured face-to-face interviews gave primary caregiver participants an opportunity to describe

their lived experiences, challenges and needs in relation to caring for ALHIV. In addition, the ALHIV were invited to share their lived experiences regarding being cared for by a primary caregiver while social workers described the needs and challenges of primary caregivers and suggestions on how they as social workers working with caregivers and ALHIV, can be supported. These aspects were then interpreted and further described by the researcher as findings, supported by detailed narratives from the interview transcripts (See Chapters Four and Five in this regard).

3.3.3.4. Application of contextual research design

Qualitative research considers the contextual circumstances in which individuals and groups function (Moser & Korstjens, 2017). Ritchie et. al. (2014) state that contextual research involves identification of what exists in the social world and how it manifests. The researcher had a desire to gain more insight into the phenomenon under study and its manifestation. Contextual research design was therefore used to gain more insight of the participants in consideration of their social contexts. Interviews were conducted in the primary residences of the primary caregivers and their ALHIV and the offices where social workers render services to them. Hennink, Hutter and Bailey (2011) caution researchers to be cognisant of the context surrounding the issues they investigate. They distinguish between various contexts that must be taken into consideration, during the planning and execution of the research and when reporting the research process and findings namely the subject context, theoretical context, cultural context, physical context, methodological context and context of issues (Hennink, et al., 2011). These contexts are explained in the table below.

Table 3.4: Types of contexts

Subject context	The subject context relates to the nature of the research topic and what has been written about it. In this study, social work is the central disciplinary angle from which the subject was explored. However, the subject of ALHIV have been documented from other disciplines such as health studies, psychology, medicine and the researcher did refer to some of these studies to explain it.
Theoretical context	This refers to the theoretical framework adopted for the study. The researcher employed strength-based and ecological systems perspectives to consider the subject of investigation from this theoretical context.

Cultural context	The cultural context refers to the socio-cultural characteristics surrounding the research participants and the phenomenon under investigation. In conducting this study, consideration was given to cultural dynamics that can enhance an understanding of the phenomenon of ALHIV and their caregivers. For example, the ethnic background of the participant was deemed essential to enhance diverse experiences from a cultural contextual perspective, hence the biographical questions required participants to indicate their ethnicity.
Physical context	The physical characteristics of the study refer to the sites where the data was collected. During the interviews with the participants and through observation, the researcher was able to obtain the physical features enabling her to provide a description of the study site. The study was conducted in Gauteng's four municipal areas: the cities of Johannesburg, Sedibeng, Tshwane and Ekurhuleni. This gave the researcher an opportunity to observe their home circumstances in support of their narratives (i.e. such as their concerns about shelter).
Methodological context	This speaks to the methodology that was used to guide the study including the data collection and the background and experience of the researcher in relation to the topic. In this study, a qualitative research approach was adopted, with individual semi-structured face-to-face interviews used for data collection. The open-ended questions were used to gain insight into the experiences, challenges and needs of primary caregivers caring for ALHIV.
Context of issues	This refers to the issues raised in the findings and reflected in the participants' responses about their experiences, challenges and needs and those of primary caregivers. Several issues emerged in the form of eight themes, twenty-two subthemes and four categories.
Context of implications	This relates to the study's implications either for practice, research or education and training. The recommendations reflected in the last chapter of the thesis account for the context of implications.

3.3.3.5. Intervention research design

The researcher also used the intervention research design by employing the design and development model (D&D) since it involves the development of human service interventions (Rothman & Thomas 1994), including the guidelines for supporting caregivers caring for adolescents living with HIV. Intervention research is a study of purposeful action that involves change strategies, and which include interventions that are defined by practice principles, goals and activities (Fraser & Galinsky, 2010; Richman, Galinsky & Day, 2009). Rothman and Thomas (1994) regard D&D as a problem-solving process that seeks effective intervention and tools to deal with human and social difficulties, of which in this study guidelines will be developed with a purpose of supporting primary caregivers of ALHIV in managing challenges they face when caring for ALHIV. The development of the guidelines for supporting caregivers caring for ALHIV is the intended practical outcome of this project (De Vos & Strydom, 2011). In line with the components of D & D intervention research model, the project was structured in the following steps as outlined by Rothman and Thomas (1994):

- **Phase 1: Problem analysis and project planning**

The first step entailed selecting and studying a specific problem by developing an understanding of such a selected problem from a variety of systems, perspectives, establishing a specific goal for the purpose of developing an intervention (Richman et.al., 2009). In addition, researchers select a population with whom to work in partnership with, and whose issues and problems are of current or emerging interest to the clients themselves, researchers and community (Rothman and Thomas,1994).

- **Phase 2: Information gathering and synthesis**

In this step the researcher focuses on conducting and exhaustive literature review and which includes review of existing programs or intervention to avoid replication of already created intervention or program, then the researcher adds to an already exiting program/ intervention or develop an entirely new intervention or program (Richman et. al., 2009; Rothman and Thomas, 1994).

- **Phase 3: Design of intervention**

Phase 3 focuses on the design of the intervention of which for this study was the guidelines for supporting caregivers caring for ALHIV. According to Richman et al.

(2009), the main task during this step is converting theoretical generalization into programmatic intervention.

- **Phase 4: Early development and pilot testing**

Phase 4 consists of implementing a pilot test of intervention. Rothman and Thomas (1994) accentuated the importance of pilot testing which should occur in real-world settings.

- **Phase 5: Evaluation and advanced development**

In this step, intervention and its outcome are assessed. According to Rothman and Thomas (1994) phase 5 encompasses four main aspects of the evaluation and advanced development which are selecting an experimental design, data collection and analysis, replicating the intervention in real life situations and refining the intervention.

- **Phase 6: Dissemination**

This is the last step which entails dissemination of research findings and intervention. Dissemination of findings is done through publication of the intervention in academic journals, community organizations and other target audiences.

For the purpose of this study, these steps were not followed rigidly, they rather served as guidelines to the project process (De Vos & Strydom, 2011). Due to time and financial constraints inherent to intervention research (Fraser et al., 2009), the current project ended at the design phase (phase three). It was impossible for the process to proceed into pilot testing, evaluation and advanced development. However, one of the forwarded recommendations is to ensure that the remaining steps are completed to ensure accuracy thereof. In the context of this study, implementation of the D & D Intervention Research Model was guided by the following process:

In **phase one**, the focus was on the problem identification and project planning. This step entailed conducting preliminary literature review around the phenomenon which led to the drafting and submitting research proposal describing the research methodology and research approach, activities, project phases, timeframes, outputs and budget. It also involved identifying the population, which is primary caregivers caring for ALHIV, the ALHIV themselves as well as social workers, and the scheduling of interviews with them.

In **phase two**, the researcher started the process of collecting data through the individual semi-structured face-to-face interviews and analysing it to identify key components and themes essential for the guidelines for supporting caregivers caring for ALHIV. This entailed interviewing primary caregivers, ALHIV and social workers and a review of literature relevant for the envisaged guidelines.

Lastly, **phase three** entailed designing the first draft of guidelines for supporting caregivers caring for ALHIV. The draft was based on data collected from interviews conducted with all categories of participants (the primary caregivers of ALHIV, social workers and ALHIV) as well as the literature reviewed during phase two. Although these guidelines were not pilot tested, one of the recommendations is for these guidelines to be pilot tested, evaluated and be developed further in line with Rothman and Thomas' approach.

3.4. THE RESEARCH METHODS

In this section the researcher outlines the strategies and/or tools used to collect, analyse and verify the data for this study.

3.4.1. The study setting, population, and sampling techniques used.

The concept study setting means the physical or social context in which the researcher conducts a study (Majid, 2018; Busetto et al., 2020). This study was initially planned to be confined to three municipalities located in Gauteng province, namely Johannesburg, Ekurhuleni, and Tshwane (another municipality, Sedibeng, was later added to enhance data saturation). The specific sites of the study were communities that were served by DSD-funded NPOs in these municipalities. The motivation for choosing the above-mentioned settings was influenced by time and financial constraints, as well as the HIV prevalence in Gauteng province. As reported by Naidoo et. al. (2020), Gauteng province was found to be the second most affected province with an estimated total of 66,754 adolescents reported to be living with HIV, followed by Mpumalanga as the third affected with an estimate of 62,931, and Northern Cape being the lowest affected with an estimated total of 2,333.

Population is defined as all individuals, families, groups or organisations and communities of interest to the researcher who are likely to contribute to a research topic and from which the researcher can draw conclusions (Majid, 2018; Babbie, 2014). Majid (2018) and Shukla (2020) note that the characteristics of the research

participants are critical in order to conceptualise the study's population, inform the study setting, the eligibility criteria of the participants and the sampling strategies. For Marshall and Rossman (2016), well-formulated research questions signpost what a study population should consist of. To determine the study population, the researcher started by revisiting the research questions. She had to find appropriate participants who would answer the research questions and provide the best answers, in addition to rich information about the topic (Marshall & Rossman,2016). Based on the research questions of this study, the following three population categories were targeted:

- All primary caregivers caring for ALHIV living in Gauteng Province
- All ALHIV in the care of a primary caregivers living in Gauteng Province
- All social workers rendering social work services to ALHIV and their primary caregivers through DSD-funded NPOs situated in Gauteng Province.

Upon entering the field, the researcher realised that the number of possible participants in this area would not be large enough to achieve data saturation, which therefore implied that she would not have an opportunity to adequately explore the scope of the topic under investigation. She then decided to widen the boundaries of the study area from Johannesburg, Tshwane and Ekurhuleni to include Sedibeng. It is noteworthy that data saturation was reached after the eight interviews, with each of the three categories (primary caregivers, ALHIV and social workers) of this study. This was when the information gathered from these participants became repetitive without any new information being forthcoming (Vasileiou, Thorpe, Barnett & Young, 2018; Merriam & Tisdell, 2016).

Due to the impracticality and impossibility associated with time and money constraints, samples were drawn from the respective population groups. Sampling is conducted when researchers have no time or resources to analyse an entire population and therefore use sampling techniques to reduce the number of cases to be researched (Taherdoost, 2016). This is a process through which individuals from the whole population are selected to be studied with the aim of obtaining information and drawing conclusions about the whole population (Martinez-Mesa, Gonzalez-Chica, Duguia, Bonamigo &Bastos, 2016).

In qualitative research, the tendency is to look for and recruit participants by employing purposive sampling. This sampling method involves identifying and selecting

individuals or groups of individuals that are information-rich or experienced about a specific phenomenon under study (Palinkas, Horwitz, Green, Wisdom & Hoagwood, 2015). Researchers deliberately select people whom they believe will provide relevant and best data to answer the research questions formulated at the outset of the study (Andrade, 2021). To assist in the process of purposefully finding participants, the researcher had to establish inclusion and exclusion criteria as outlined under Table 3.5 below.

Table 3.5: Inclusion and exclusion criteria used to recruit participants

Inclusion criteria for primary caregivers	**Exclusion criteria for primary caregivers**
Primary caregivers were expected to- • have ALHIV in their care • be from different households with an ALHIV participating in the study[1] • know the HIV-positive status of the ALHIV in their care • be willing to participate in the study • be service users of DSD-funded NPOs rendering services to orphans and vulnerable children, adolescents and youth (OVCA&Y) within the Cities of Johannesburg, Sedibeng, Tshwane and Ekurhuleni municipalities. • be of any gender from any race group, aged between 40 years and older[2], and • be conversant in English, Setswana and /or Isizulu, as these are the languages the researcher is conversant in. The interviews were mainly to be conducted in	**Primary caregivers -** • do not have an ALHIV in their care • care for ALHIV where the caregiver and ALHIV are from the same households • are not aware of the HIV-positive status of the ALHIV • are not service users of the DSD-funded NPOs that are rendering service to OVCA&Y in the Cities of Johannesburg, Sedibeng, Tshwane and Ekurhuleni and • are not conversant in the languages the researcher can converse in.

[1] The researcher decided not to interview the primary caregiver and the ALHIV from the same household in order not to compromise the caregiver-adolescent relationship and to allow for honest reflections from all parties concerned.

[2] This age range was decided upon as the research from Chauhan, Rai, Kant, Lodha, Kumar, Singh (2016) estimates the mean age of caregivers caring for ALHIV to be 40 years of age.

English, but the researcher undertook to translate the questions in either Setswana/Isizulu, in order the enhance the participants' comprehension of the questions	
Inclusion criteria for ALHIV	**Exclusion criteria for ALHIV**
Adolescents living with HIV had to- • know their HIV-positive status • be between the ages of 18 and 19 years • be in the care of a primary caregiver • be willing to participate in the study • have reached out to DSD-funded NPOs rendering services to OVCA&Y in the Cities of Johannesburg, Sedibeng, Tshwane and Ekurhuleni • be of any gender from any racial group • be conversant in English, Setswana and /or Isizulu, as these are the languages the researcher is conversant in.	**Adolescent living with HIV who:** • are not aware of their HIV-positive status • are younger than 18 or older than 19 years • are not in the care of a primary caregiver • have never been service users of the DSD-funded NPOs that are rendering service to OVCA&Y in Gauteng Province in the city of Johannesburg, Ekurhuleni, Sedibeng and Tshwane. • reside with primary caregivers in the same households and • are not conversant in the languages the researcher can converse in.

Social workers

Inclusion criteria	Exclusion criteria
Social Workers had to be- • employed at NPOs rendering service to OVCA&Y in the Gauteng Province in the cities of Johannesburg, Ekurhuleni, Sedibeng and Tshwane • providing social work services to primary caregivers caring for ALHIV through a DSD-funded NPO • willing to participate in the study • of any gender from any racial group and any age group, and • conversant in English, Setswana and /or Isizulu, as these are the languages the researcher is conversant in.	**Social Workers who:** • are not employed at the DSD-funded NPOs that are rendering service to OVCA&Y in Gauteng Province in the cities of Johannesburg, Ekurhuleni, Sedibeng and Tshwane • are not providing social work services to primary caregivers caring for ALHIV and ALHIV through a DSD-funded NPO, and • are not conversant in English, Setswana and /or Isizulu.

The researcher started by identifying DSD-funded NPOs rendering services to ALHIV and their primary caregivers through the assistance of an organisation called HIV South Africa (HIVSA), which works in collaboration with DSD-funded NPOs that are rendering services to OVCA&Y, including ALHIV and their primary caregivers. HIVSA linked the researcher with relevant DSD-funded NPOs, from which she requested permission to conduct a study through their managers. The DSD-funded NPOs' managements were considered 'gatekeepers' for the purposes of obtaining access to participants (Dempsey, Dowling, Larkin &Murphy, 2016).

A request for permission as stated above was formally made through a letter (see Appendix 2) which was sent to managers of NPOs via an email. The letter detailed the purpose of the study, its benefits, the procedures to be followed and the ethical protocols to be observed. Once permission was granted, the researcher followed up with phone calls and scheduled meetings with different managers from these DSD-funded NPOs to formally introduce herself and further discuss the contents of the letter and her specific request to access the participants. The DSD-funded NPOs were requested to provide 'insider assistance' by actively assisting in identifying and

recruiting potential participants (primary caregivers and ALHIV) who met the inclusion criteria, by means of passing on the information about the research to the relevant employees who were mostly community caregivers. They were also requested to provide identifying particulars and contact details of potential participants who expressed an interest in participating in the research project, and who indicated their intention to give consent to be contacted.

Once consent was obtained to contact potential participants, the researcher received assistance from community caregivers who were working closely with potential participants (primary caregivers and ALHIV) to arrange meetings with interested parties for the purpose of explaining the nature, aims and process of the study and to obtain consent for the interviews. Meetings were mostly arranged at the participants' homes or at the offices of these DSD-funded NPOs. The researcher also obtained contact details of social workers from the managers of the DSD-funded NPOs that render services to orphans, vulnerable children and adolescents including ALHIV and their primary caregivers. She contacted them telephonically to obtain consent and to schedule convenient dates for interviews. The recruitment process was not easy due to the sensitivity of the topic. A total of 24 participants agreed to be interviewed, eight of which were primary caregivers, eight ALHIV and eight social workers.

3.4.2. Preparation for data collection

In planning a research project, researchers need to prepare for data collection by ensuring that their data collection plans are defined, sample strategies are selected, interview-guides are well-formulated and suitable participants are recruited and informed about the purpose of the research (Moser & Korstjens, 2017; Winsome & Travis, 2014). Data collection in qualitative research is a process of collecting information about participants' realities to better understand their experiences and to eventually answer specific research questions (Barret & Twycross, 2018). Busetto et al. (2020) submit that observations, interviews and focus groups discussions are commonly used methods of data collection in qualitative studies.

To prepare for data collection, the researcher contacted DSD-funded NPOs that render services to ALHIV and their primary caregivers through the assistance of HIVSA, to seek permission for conducting the research. The DSD-funded NPOs that granted permission assisted with the recruitment of potential participants. The latter were

recruited, informed about the purpose of the study and asked to sign consent forms prior to data collection. The researcher also developed an interview guide tailor-made for each of the three research population groups, namely the primary caregivers, ALHIV and social workers (See attached Appendix 6 for a sample of data collection tool.

3.4.3. Method of data collection

According to Busetto et al. (2020), interviews and focus group discussions are commonly used methods of data collection in qualitative studies. In this study, the researcher used individual semi-structured face-to-face interviews based on interview guide**.** The aim was to gain a detailed understanding of participants' subjective experiences, perceptions and accounts on a research subject, and to facilitate the discussion using open-ended questions (Busetto et al., 2020; Barrett &Twycross, 2018). Individual semi-structured face-to-face interviews allow the researcher some flexibility. In the interviewer-interviewee relationship, participants are regarded as key informants or experts on the subject, and they are given maximum opportunity to tell their stories (Ruslin, Mashuri, Rasak, Alhabsyi & Syam, 2022; DeJonckheere & Vaughn, 2019).

In this study 24 qualitative interviews were conducted with three categories of research participants, namely the eight primary caregivers, eight ALHIV and eight social workers. The interviews lasted between 40 minutes to one hour. Ayton, Tsindos, and Berkovic (2024) highlighted that semi-structured interview seeks to expand on knowledge and that such interviews may last no longer than 30 minutes, or up to one hour. Mwita (2022) added that the length of qualitative interviews should depend heavily on the research goals, the depth required, and the participant's comfort. Semi-structured interviews are more similar to guided conversations than structured inquiries (Yin, 2014). The decision to use this method of data collection was informed by the research questions, goal and objectives. This method also afforded the participants an opportunity to speak freely and authentically about the topic. Busetto et al. (2020) submit that individual semi-structured face-to-face interviews permit participants to talk from their own subjective experiences and freely share meanings which are familiar to them. Moreover, due to the sensitive nature of the topic of this study, the interviews were permitted to flow naturally based on information obtained

from the participants, as supported by Horsfall, Eikelenboom, Draisma and Smit (2021).

The interview guide was tailor-made for each of the three research population groups, namely the primary caregivers, ALHIV and social workers (see Appendix 6). Jamshed (2014) defines semi-structured interview as a set of questions used by the researcher with the purpose of exploring the experiences of various participants in a systematic and comprehensive manner. Although the questions are phrased in the same order in which they are put to the participants, the responses made by the participants enable flexibility when the researcher asks follow-up questions. In addition, the questions are neutral and supplemented by follow-up probing questions (DeJonckheere & Vaughn, 2019; Jamshed, 2014). A similar approach was followed in this study as the interview guide was not rigidly applied, but the researcher was flexible in order to respond appropriately to what was shared by the participants. In the interviewer-interviewee dyad, the researcher was both a participant and an observer and therefore remained empathic, non-judgmental, and non-directive whilst actively building and maintaining a trusting relationship with the participants (Moser & Korstjens, 2017).

The researcher also applied the interview skills of active listening and probing to clarify what participants described and to build rapport with them, which enabled the interviews to unfold naturally. Horsfall et al. (2021) emphasise the importance of the interviewer showing interest, supporting and understanding the interviewee in order to build rapport.

3.4.3 Data Analysis and Interpretation

Data analysis is the process of collecting, describing and interpreting data gathered by using qualitative techniques to bring structure and meaning to it (Lester, Cho & Lochmiller, 2020; Ravitch & Riggan, 2016). For Sutton and Austin (2015), the most important part of data analysis is for the researcher to be true to the participants by ensuring that their voices are heard, interpreted, and accurately reported. In qualitative research, data analysis entails preparing and organising data from multiple sources such as transcripts and then grouping it into themes and subthemes through a process of coding (Busetto et al., 2020). Akinyode and Khan (2018) state that to better analyse and present qualitative data in a logical manner, it is important to conduct a step-by-

step approach. In this study the researcher analysed the data by employing the steps below as proposed by Tesch (cited in Creswell, 2014):

- **Step 1: The researcher prepared and organised raw data**

The data analysis process started with raw data, which was audio-recorded during the interviews. Ravindran (2019) emphases that in conducting data analysis, every item of recorded data should first be written down and edited. In this study the recorded interviews were transcribed word-for-word, which sometimes required the researcher to go back and forth in listening and capturing to reflect exactly what the participants had conveyed during the interviews. To make sense of what the participants related, the researcher made notes on a separate page during and after the interviews, and once more during the data analysis phase.

- **Step 2: The researcher familiarised herself with the data**

Maguire and Delahunt (2017) emphasise that one of the ways in which researchers familiarise themselves with data is by reading through the transcripts repeatedly while jotting down the ideas that come to mind. In this study, once the data was fully transcribed, the researcher read through all the transcripts to obtain a general idea thereof. At the same time, she took notes of interesting ideas reflected in the actual interviews and thoughts that came to mind based on what was in the transcripts.

- **Step 3: Transcripts were studied to search for underlying meanings**

In this step, the researcher familiarised herself with what was shared by the participants and selected an interesting interview with rich information from each category of participants (primary caregivers, ALHIV and social workers). Subsequently, she repeatedly read through the transcripts to identify and comprehend the underlying meanings and recorded them. Ravindran (2019) and Mayer (2015) argue that reading and re-reading interview transcripts provides understanding and gives meaning to context, situations, events and actions related to the phenomenon under investigation. The same step was applied to the remaining 21 interviews.

- **Step 4: The topics identified were clustered together**

In this phase the researcher looked for emerging common issues. These were listed as topics and grouped with similar topics. For example, one of the identified topics was the needs of primary caregivers in their caring roles.

- **Step 5: The topics were abbreviated as codes**

Coding refers to the process of identifying topics, similarities and differences that are narrated by research participants and interpreted by the researcher (Maguire &Delahunt, 2017; Sutton & Austin, 2015). Data coding and categorising are some of the ways used by the researcher to organise and prepare data analysis (Ravindran, 2019; Mayer, 2015). All the allocated topics were grouped and given unique abbreviations based on their similarities. The abbreviations were placed in the transcripts next to the matching data segments and then rewritten into themes. Finally, the researcher drew lines between categories that corresponded to demonstrate shared relationships. This exercise was meant to remind her of the common categories during the recategorisation stage.

- **Step 6: Converting chosen topics into themes**

In this step, the researcher began to sort grouped topics into potential themes. The themes and their respective subthemes and categories are presented in Chapters Four and Five respectively. DeSantis and Ugarizza (in Nowell Norris, White & Mules 2017), define a theme as a non-observable object that brings meaning and identity to a repeated experience and its different indications. In this conversion process a total of eight themes, twenty two subthemes and four categories were generated. These themes, subthemes and categories are introduced and explained in Chapters Four and Five.

- **Step 7: Alphabetising the final themes and performing a preliminary analysis**

In step seven, the researcher chose descriptive words for the themes, cut and pasted them under their appropriate themes and then arranged them into subthemes and categories. She chose abbreviations for each theme and alphabetised them. Lastly, she performed a preliminary analysis.

- **Step 8: Data was recoded**

All the relevant data was recoded, as recommended by Tesch (in Creswell, 2014), and the recoding process was repeated to make sure that all the data material is appropriately placed under the correct themes and that no useful data was discarded. Finally, the research findings were reported.

Data analysis is linked to trustworthiness or rigor, which is the next section of discussion.

3.5. ENSURING RIGOUR OR TRUSTWORTHINESS

As this study was approached from an interpretivist paradigm, Kivunja and Kuyini (2017) advise researchers to use Guba and Lincoln's classical criteria to ensure rigour by establishing consistency, accuracy in the methods used and trust or confidence in the findings of the study (Elo, Kääriäinen, Kanste, Pölkki, Utriainen & Kyngäs, 2014; Stahl & King, 2020). The criteria for credibility, dependability, confirmability, and transferability as introduced and explained below, were employed to ensure trustworthiness and authenticity (Merriam & Tisdell, 2016; Nieuwenhuis, 2016).

3.4.1. Credibility

Credibility entails establishing the truth-value of the research findings based on the participants' views (Mohajan, 2018; Korstjens & Moser, 2018). A research study passes the test for credibility if the findings represent the participants' accounts (Nieuwenhuis, 2016; Stahl & King, 2020). The researcher established confidence in the truth of the findings through the use of the following strategies:

- **Iterative questioning**

  The researcher employed iterative questioning and probing to elicit detailed information from the participants. She made a conscious effort to probe for clarity and where necessary, re-phrased previously posed questions to allow exploration of the topic in greater depth and breadth from the vantage point of the participants (Busetto et al., 2020). Probing was one of the skills used. For instance, one question would be re-phrased differently for a participant to enable in-depth responses and to confirm the meaning of what they shared, or to assess if the participant understood what was asked (e.g. one of the probing questions directed at social workers was: *What do you mean by community stigma*?). In some instances, the participants were encouraged to support their responses with examples (e.g. ALHIV: *There are a lot of things that I would like to ask her but I cannot, because I am scared to see her reaction. I think social workers can help us talk and clear both our chests, that is the thing that I can say is the problem.* Researcher**:** *How do you want social workers to help you in this regard*?).

- **Engaging honestly with the participants when collecting data:**
  For a study to be credible, participants should be honestly informed about the study. They have to be informed, that participation is voluntary and that they have a right to refuse to participate and to withdraw at any time if they so wish. This ensures that data collection only occurs with willing participants who share their experiences freely and without coercion (Creswell, 2016). Due to the sensitivity of the study, the researcher ensured that all participants were honestly informed about the purpose of the study, its aims and objectives as well as the possible risks and benefits involved (see Appendix 4). Furthermore, participants were afforded opportunities to ask questions related to the study prior, during and at the end of the interview if they so wish.
- **Peer scrutiny of the research project:**
  Various scholars (Anney, 2014; Nowell et al., 2017) assert that peer scrutiny is crucial in data verification because it allows peers to challenge assumptions made by the researcher whose subjective involvement in the research project may be biased. As required, the researcher presented her research plan (proposal) to the UNISA Departmental Scientific Review Committee and the College Research and Ethics Committee to assess the methodological and ethical soundness of the study. This committee found the plan to be ethically acceptable and granted ethical clearance (See attached Appendix 1). Furthermore, the researcher regularly engaged with her supervisor and fellow colleagues who were also busy with postgraduate studies, as well as colleagues from HIVSA and PACTSA who have expertise in both qualitative research and the field of HIV/AIDS. The purpose of these engagements was to subject her process to peer scrutiny and critique.
- **Authority of the researcher:** The researcher was employed as a social work manager at PACTSA, and amongst other duties, was responsible for training and research in the field of HIV. Furthermore, she has more than 10 years working experience in the field of HIV specifically rendering services to PLHIV and their families. The researcher also has experience in conducting qualitative research, which began in the year 2000 when she was a fourth-level student social worker. She also followed a qualitative research approach during her studies towards a master's degree in social work, with the focus on the

perceptions, expectations, fears and needs of chemically dependent youth in a rehabilitation centre, about being reintegrated into their family systems. This experience and expertise positioned the researcher as properly qualified to execute a study of this nature at a doctoral level.

- **Triangulation of data sources:** This refers to the use of different sources of data collection, comparing theories against one another to confirm data and its interpretation in order to ensure that all aspects of a phenomenon are properly understood (Campbell, Goodman-Williams, Feeney & Fehler-Cabral, 2020; Bans-Akutey & Tiimub, 2021). By combining theories and methods in a research study, researchers ensure that fundamental biases arising from the use of a single method and theory are eradicated (Noble & Heale, 2019). In this study triangulation of data sources was used by means of interviewing primary caregivers, ALHIV and social workers from different organisations, different age groups, both genders and primary caregivers and ALHIV from different households. It also involved the use of diverse literature sources (i.e. literature from different disciplines), different theories (a strengths-based perspective and ecological systems theory) and methods (i.e. supporting the individual semi-structured interviews with observation).

3.5.2. Transferability

Transferability is a method through which the findings of a study can resonate with or be applicable to other contexts, situations or populations that were not part of the study (Korstjens & Moser, 2018; Schloemer & Schröder-Bäck, 2018). It gives the researcher an opportunity to transfer the research findings to similar situations, circumstances and contexts (Mohajan, 2018). In order for transferability to occur, a study needs to be supported by rich thorough description of the context, site, and experiences of the participants. Moreover, the researcher needs to remain transparent in relation to the analysis and trustworthiness of the study (Connelly, 2016; Korstjens & Moser 2018).

Thick description reflects the quality of time spent with participants, the description of behaviours and experiences of participants and the contexts in which such behaviours and experiences occurred in order to be meaningful (Korstjens & Moser 2018; Hamilton & Finley, 2019).The researcher in this study applied thick description by presenting a detailed explanation of how the process evolved as well as the decisions made and the reasons for making such decisions.

During the interviews the researcher ensured that she asked follow-up questions and probed for more information to gather as much data as possible from the participants while observing non-verbal messages and making notes. An example is when one of the participants (a primary caregiver) was asked to share her experiences in caring for her sister's children after the sister's passing, and she discovered that they were HIV positive. While she was narrating her experience, it was apparent that she was deeply hurt and even shed tears (She said: "*It's painful but what can I say I have to be strong and accept that my sister passed on, yes they are 4, I mean my sister children and 3 of them are HIV positive except 1 I don't even know how he survived, and he is a boy and I am definitely sure that the one who passed on was also HIV positive."* See Subtheme 3.1*)*. The participants' own voices were captured during the interviews as well as descriptions of the physical and social conditions under which the interviews were conducted.

3.5.3. Dependability

Dependability in research refers to the consistency and reliability of research findings and how the research procedures were documented in order to allow someone outside the research to conduct an audit and critique the process (Moon et.al., 2016). Nowell et al. (2017:3) stress that to achieve dependability, researchers need to maintain logical, traceable, and clearly documented research process. In this study, the researcher ensured the viability of a dependability audit by keeping a detailed record of the entire research process including how the data was collected, recorded, coded and analysed in the study, for someone outside the study to identify any changes that occurred during the process (Anney, 2014). A detailed account of how this was done is presented below.

- **Data collection and recording**: A detailed description of the methods used in collecting data is the main focus of this chapter. Individual semi-structured face-to-face interviews with an interview guide tailor-made for the three categories of research participants, namely the primary caregivers, ALHIV and social workers were administered. Each interview was recorded and transcribed word for word prior to analysis.
- **Data analysis**: The data was analysed according to the steps proposed by Tesch (cited in Creswell, 2014), as explained earlier in section 3.4.3. The

researcher and the supervisor conducted data analysis independently and later on met for consensus discussion in order to ensure dependability.

3.5.4. Confirmability

In this study the researcher ensured confirmability by keeping accurate records of all the details which emerged during the research process, including the experiences she had with participants and meetings held with gatekeepers (Cope, 2014; Mohajan, 2018). The researcher audio-recorded the interview sessions through the participants' permission (i.e. when some of the participants (ALHIV) had difficulty explaining how they got to know about their HIV status and others (primary caregivers) and narrated their difficulties in raising a child living with HIV). Confirmability also requires the researcher to maintain an audit-trail for an audit to be conducted to show how the research process was executed, how interpretations were made and conclusions drawn (Moon et al., 2016; Nowell et. at., 2017). The strategies for confirmability included triangulation sources, peer-debriefing, thick description of the research process and the research methodological decisions taken. It also involved presenting the findings inclusive of vivid descriptions of the participants' accounts. In presenting the findings, the themes and subthemes generated were supported by direct quotations from the interview transcripts together with detailed demographic profiles of each participant (See Chapter Four Section 4.2.1; 4.2.2 and 4.2.3 for demographical profiles of the participants in particular and Chapters Four and Five for the research findings in general).

3.6. APPLICATION OF THE ETHICAL PRINCIPLES

In this section, the researcher describes how ethical principles were upheld in the study. The focus is on informed consent, confidentiality and anonymity, avoiding harm, beneficence, debriefing the participants and managing the data.

3.6.1. Obtaining informed consent.

Research participants have a right to be given adequate information about a study, full understanding of the implications and the possibility of discomfort due to self-disclosure, which should enable them to make informed decisions on whether or not to participate in a study (Moule, 2018; Green & Thorogood, 2014; Babbie, 2014). For this purpose, the researcher took time to ensure that the participants are fully informed about the study. She began by making individual appointments with them where she

took time to explain the purpose of the study, the nature, procedure, potential benefits, and anticipated inconveniences of participation as explained in the information sheet (Appendix 4), which included the following:

- Participants' rights to-
    - participate voluntarily
    - exit the study at any time; and
    - know that refusal to participate in the study will not affect their access to services or their employment conditions in any way.
- Possible risks and benefits associated with the study
- Participation conditions (being involved in an interview where they will be requested to respond to demographical questions and data collection questions about the subject of research).
- Aspects of confidentiality, anonymity and the confidential management of information.

Upon informing the participants about the nature, process, objectives, risks and benefits of participating in this study, the opportunity was then given to them to ask questions or raise any concerns they had about the study. The researcher provided them with a consent form (Appendix 5) so that they could go through it at their own time and decide if they still wanted to continue with the study. The participants were also asked to share their telephone numbers for the researcher to do follow-ups.

A follow-up telephone call was made with primary caregivers and ALHIV to find out if they were willing to continue with the study and to schedule individual meetings with those who agreed to participate so that they can sign consent forms and proceed with interviews. During these individual meetings, the researcher went through the information sheets and the consent form once again and gave participants the opportunity to ask questions. This was an opportunity for the researcher to address any concerns that were raised (e.g. one of the primary caregivers took this opportunity to alert the researcher that she did not want her landlord to know about her grand-daughter's HIV diagnosis). During these scheduled meetings, participants who showed interest in continuing with the study were given the opportunity to sign the consent forms prior to the interviews. All participants agreed to continue with the study.

3.6.2. Ensuring confidentiality and anonymity.

Data obtained from research conducted with human subjects can be shared with other researchers or archived, but prior to such sharing it must be anonymised, and sensitive information must be removed. Anonymity in the research context means that participants' identities cannot be known by other people, except the researcher (Given, 2015). It means that the identifying details of participants cannot be linked to the research data. In this study the researcher ensured that the participants' identities were kept anonymous by using pseudonyms. According to Quick and Hall (2015) pseudonyms are considered the best method of ensuring anonymity during research. The participants in this study were not referred to by their real names but by pseudonyms which were used throughout (for example one of the primary caregivers was named C-MJ, an ALHIV named ALHIV-JP, while one social worker was called SW-VM). The researcher also refrained from using the participants' residential addresses or the health facilities where the ALHIV were accessing health services as this could have easily enabled their identities to be traceable. All the interviews were audio recorded with permission from the participants and were shared only with the supervisor. The participants were informed that the audiotapes and transcripts of the interviews would be kept safe in a locked drawer in the researcher's office at home and only the researcher would have access to them (Kennan & Markauskaite, 2015). They were also assured that the collected data will only be used for the purpose of this study and nothing else. Moreover, given the sensitivity of the research topic, the researcher assured the participants that any confidential or personal information would be kept to herself and not be shared with anyone without their knowledge and permission, except with her supervisor who was part of the study.

3.6.3. Avoiding harm to participants and ensuring beneficence

Researchers have an obligation to protect participants and refrain from harming them, even when they gave consent to participate in the research (Buchanan, & Warwick, 2021; Favaretto, De Clercq, Gaab & Elger, 2020). The principle of no harm in research context forms the foundation of all the ethical considerations since it guarantees protection to study participants. As highlighted by Posel and Ross (2014), researchers should not only avoid harm to research participants, but they also need to respond to it in cases where it prevails. In a research context harm means anything that may negatively affect the rights, safety, or welfare of research participants. This may

comprise psychological, social, physical, financial or economic factors (Buchanan & Warwick, 2021; Human Research Ethics Committee, 2021). Court (2018) reports that ethics in research must not only safeguard participants from harm, but researchers should also ensure that research is conducted in a socially responsible manner.

Beneficence is the ethical responsibility for researchers to maximise benefits and minimise risks in research (Barrios, Levy, Díaz-Anzaldúa & Camarena, 2022; Pieper & Thomson, 2016). In this study, cognisance was taken of the fact that HIV is a sensitive topic, and that it may even enable the participants to be stigmatised. The principle of no harm to participants was diligently implemented throughout the study by informing all participants about the aim of the study from the inception of the study. Prior to starting any interviews, the researcher first assessed the mood of the participants and enquired about their general wellbeing. In addition, she assessed whether the ALHIV knew their HIV status and if the primary caregivers and ALHIV were comfortable to discuss how they got to know about the ALHIV's diagnosis. Lastly, she always asked participants directly if they were comfortable to start and proceed with the interview.

In instances where harm could occur, the researcher arranged for the services of a qualified social worker to provide the necessary counselling and debriefing session should such a need arise (see Appendix 12). However, the services were never required.

3.6.4. Debriefing of participants

Debriefing is the process of discussing the overall purpose of the study and its implications after the data has been collected, with research participants (McMahon & Winch, 2018; Sharf & Kimonis, 2015). Picardi and Masick (2014) suggest that debriefing should ensure that participants are not harmed in a negative way as a result of participating in a study. Due to the sensitivity of the research topic, the researcher anticipated the possibility that the participants might be affected subsequent to participating in the study. She therefore planned for the services of a qualified social worker to provide the necessary counselling and debriefing where necessary. A qualified social worker with experience in trauma counselling and working with PLHIV and those affected, was always on standby to provide the participants with debriefing where necessary. The agreement between the researcher and the social worker was

the former to identify participants who needed debriefing and to refer them telephonically for debriefing. Likewise, the researcher ensured that she observed the participants throughout the study to identify any signs of discomfort or discussion during interviews that evoked strong emotional responses or distress. The services of the social worker were never used since no participant needed them. However, one primary caregiver was referred to the department of South African Social Security Agency (SASSA) regarding application for social grant for her granddaughter, which she indicated a need during the interview (see chapter for section 4.3.3. Theme 3).

3.6.5. Managing data

Managing research data involves the organisation, documentation, storage, and preservation thereof (Kanza & Knight, 2022; Surkis & Read, 2015; Corti, Van den Eynden, Bishop & Woollard, 2014). Data management in research is determined by relevant legislation and codes, national and institutional policies and the procedures and guidelines that have implications for the collection, storage, and transfer of research data, and it is vital that researchers familiarise themselves and comply with these regulations (Kanza & Knight, 2022; Kennan & Markauskaite, 2015; Ritchie et al., 2014). Court (2018) postulates that researchers, in order to maintain confidentiality and anonymity, should either erase or store interview recordings in a safe place and use pseudonyms. In this study, all the documents that participants signed, where personal information such as names can be identified, were kept in a locked drawer in the researcher's office at home and only the researcher had access to them. All the electronic data was password-protected.

3.7. SUMMARY OF THE CHAPTER

In this chapter, an outline of the philosophical orientation upon which the study is grounded, and the adopted research methodology were presented. Qualitative research was introduced and explained as a research approach that guided the study, followed by the research design and the methods such as population sampling, data collection instruments and data analysis strategies. Furthermore, trustworthiness of the study and the ethical considerations that were adhered to throughout the study were explained from a conceptual and applied perspective. The next chapter presents the first set of the research findings based on the experiences and challenges of caregivers caring for ALHIV.

CHAPTER FOUR

RESEARCH FINDINGS: THE EXPERIENCES AND CHALLENGES ASSOCIATED WITH CARING FOR AN ALHIV

4.1. INTRODUCTION

In the previous chapter, a detailed presentation of the research methodology and how it was applied was provided. Among others, qualitative research approach was introduced as an approach adopted for this study as well as the research designs that were applied. Based on the aim of the study as presented in Chapter One, was to (1) develop an in-depth understanding of the experiences, challenges and needs of primary caregivers in relation to caring for ALHIV; (2) understand the experiences of ALHIV regarding being cared for by a primary caregiver; (3) explore the kind of social work support for caregivers caring for ALHIV; and (4) develop guidelines to support social workers, primary caregivers and ALHIV, this chapter presents the first set of the research findings which are the findings pertaining to the experiences and challenges associated with caring for ALHIV. In presenting this chapter, the researcher begins by introducing the demographical findings based on the participants who took part in this study, namely the social workers, primary caregivers, and adolescents. The presentation of the participants' demographical data will then be followed by the main themes, subthemes and categories that emerged from data analysis as supported by the interview extracts or the storylines. In presenting both demographical and the main findings, literature control will be performed by analysing the findings using existing literature and the adopted theoretical frameworks. The chapter will conclude with a chapter summary.

4.2. PRESENTATION AND DISCUSSION OF FINDINGS

The findings of this study are presented in Chapter Four and Chapter Five. This chapter focuses on the findings based on the experiences and challenges associated with caring for ALHIV. These data upon which the findings were based was drawn from a total of twenty-four (24) participants comprising eight social workers, eight primary caregivers and eight adolescents. This section gives the demographical profiles of all three categories of participants, starting with the primary caregivers, followed by the ALHIV and then the social workers.

4.2.1. Demographic profiles of the research participants (primary caregivers)

A total of eight primary caregivers who met the inclusion criteria set out in Chapter Three Table 3.5 participated in this study. It is essential to present the demographic data of participants, because their backgrounds assist in providing rich context to the study and therefore enhance a comprehensive understanding of the phenomenon of caring for ALHIV. Table 4.1 below presents the demographical features, namely age, gender, ethnicity, employment status, education level, relations to the ALHIV, how they discovered the HIV-positive status of the ALHIV and the duration of caring for ALHIV. Further below the table is a reflection on each of the demographical features in the relevant literature context.

Table 4.1 Demographic particulars of primary caregivers

Participant	Age	Gender	Ethnicity	Employment status	Education qualifications	Relations to the ALHIV	How discovered the HIV status of the ALHIV	Duration caring for an ALHIV
C-MJ	46	Female	Tsonga	Unemployed	Grade 11	Aunt	When sick	From birth
C-ID	41	Female	Zulu	Unemployed	Grade 7	Biological child	When sick	From birth
C-ES	60	Female	Swati	Unemployed	Grade 5	Grandmother	After the passing of the mother	4 years
C-VS	56	Male	Tsonga	Unemployed	Grade 5	Biological child	When diagnosed with TB	From birth
C-SF	53	Female	Xhosa	Unemployed	Grade 11	Biological child	When sick	From birth
C-TB	57	Female	Zulu	Employed	Grade 8	Grandmother	When sick	9 years
C-DA	53	Female	Xhosa	Employed	Grade 11	Biological child	When sick	From birth
C-MJ	46	Female	Pedi	Self employed	Grade 11	Aunt	After sister passed away	11 years

As indicated above, the *ages* of the primary caregivers ranged from forty-one to sixty years. This age range seems to support some of the previous studies. Chauhan et.al. (2016), for example, found that the mean age of caregivers caring for ALHIV was forty years. In slight contrast to the current study, a South African study conducted by Nathaniel, Pamela and Takalani (2024) on caregiver experiences in disclosure of HIV positive status of children living with HIV, the ages of the sixteen caregivers who took part in the study ranged from 28 and 60 years. In a Ugandan study seeking to explore the experiences of caregivers of ALHIV, by Kasande et al., (2022), the participants' ages varied. Of the fifteen participants, nine were in their forties, two were in their fifties and four were in their thirties. In northern Ghana, a similar study with nine caregivers by Atanuriba et al. (2021) found that five were in their forties, two were in their thirties and two were in their twenties. Their study did not have caregivers in the age categories of fifty or sixty. Assessing the findings in the context of existing literature, it is therefore inconclusive to precisely determine the average age of caregivers of ALHIV.

In terms of *gender*, seven of the eight participants were females, and one was a male. In a South African a quantitative study seeking to address aspects of adolescent-caregiver relationships that promote mental health among adolescents living with HIV, Shenderovich et al., (2020) found that out of a total of 926 caregivers who participated in their study, 509 (55%) were females and 417 (45%) males. In Uganda, Kasande et al. (2022) found that eleven of the fifteen caregivers were females and four were males. In a Ghanaian study by Atanuriba et al. (2021), two of the nine caregivers were males. In a Cuban study seeking to describe the general mental health characteristics of primary caregivers of Cuban children and adolescents with HIV/AIDS from across the country, Santiesteban et al., (2012) found twelve of their thirteen caregivers to be females, with only one male. These findings show disparities in gender for caregivers of ALHIV and as supported by findings in the literature, they alert researchers to draw conclusions with caution.

Regarding *race and ethnicity*, all the participants were Black Africans. A Baltimorean study of the quality of life of caregivers of PLHIV by Knowlton, Nguyen, Isenberg, Tseng, Catanzarite, Mitchell and Cruz-Oliver (2021), found that the majority (88.4%) of the caregivers who took part in their study were black (African American). A study focusing on the racial/ethnic disparities of youth born to women living with HIV in the

United States of America by Bather, Williams, Broadwell, Smith, Patel, Garvie, Karalius, Kacanek, Mellins, Malee and Pediatric HIV/AIDS Cohort Study (2021), found that 72% of caregivers were black. Based on these studies, which correlate with the findings from this study, blacks seem to dominate as research participants in this context.

Regarding the educational levels of the participants, all of them completed less than Grade 12. This maps onto the findings of other researchers in the same context. In a Cuban study of mental health among primary caregivers of children and adolescents with HIV for instance, Santiesteban et al. (2012) found that out of thirteen caregivers who took part in their study, four had completed junior high school, seven secondary high school and only one had a university qualification. In South Africa, Bejane, Havenga and van Aswegen (2013) found in their study of the challenges of primary caregivers in relation to caring for children living with HIV in a semi-rural area, that two of the eight caregiver participants had no schooling, three had primary schooling and three had secondary schooling.

For participants who took part in a Ghanian study of the experiences of caregivers caring for children living with HIV by Atanuriba et al. (2023), the participants' educational backgrounds were found to be slightly contrary to the current study as well as the findings made by Santiesteban et al. (2012) and Bejane et al. (2013) above. Out of the nine caregivers, four had tertiary qualifications, three did not have any educational qualification and two had secondary education.

From Table 4.1 above, five of the primary caregivers found out about the positive HIV status of their ALHIV during birth, two specified that they found out after the passing of an ALHIV's mother, and one indicated that he found out when the ALHIV was diagnosed with TB. The table also shows that five primary caregivers have been staying with their ALHIV since birth which correlates with them being biological parents of the former, and three primary caregivers indicated that they had been residing with the ALHIV for four, nine and eleven years respectively.

The findings of this study in terms of when primary caregivers found out about the HIV-positive status of their ALHIV, correlate with Kasande et al.'s (2022) study in which participants also indicated they discovered that their children were living with HIV during birth, while others discovered the HIV-positive status when the child was sick

and taken to hospital. In some cases, the participants did not have knowledge of their child's HIV status until they went for testing. Similarly, in Bejane et al. (2013), one of the findings was that primary caregivers of children living with HIV came to know about their children's HIV-positive status when the child was sick, while others explained that they came to know during testing. In a South African study by Matebese (2014) it emerged that the primary caregivers were initially not aware of their children's HIV-positive status and only found out later that they had contracted HIV in different ways (some were born with HIV, some got infected through sexual abuse, and some got infected through sexual activities during adolescence). Although the researcher cannot state with certainty given a very small sample size of the current study, the possibility that, in most cases, primary caregivers gain knowledge of their children living with HIV during birth and testing, cannot be ruled out.

4.2.2 Demographical profiles of ALHIV

Below is a presentation of the demographic profiles of the eight ALHIV who participated in the study after meeting the inclusion criteria set in Chapter Three Table 3.5. Their profiles emerged from their answers to the six demographic questions pertaining to age, gender, ethnicity, educational qualifications, duration of living with HIV and relationship with the caregiver (see the attached data collection tool in Appendix 6). Table 4.2 below gives a summary of the profiles.

Table 4.2 Demographic particulars of ALHIV

Participant	Age	Gender	Ethnicity	Education qualification	Duration living with HIV	Relations to the primary caregiver
ALHIV-AK	19	Male	Tswana	Grade 9	4 years	Mother
ALHIV-AD	19	Female	Pedi	Grade 12	6 years	Aunt
ALHIV-JP	18	Female	Zulu	Grade 11	Born with it	Uncle
ALHIV-VS	18	Male	Sotho	Grade 9	Born with it	Mother and stepfather
ALHIV-TM	19	Female	Pedi	Grade 12	Born with it	Mother
ALHIV-TN	18	Female	Zulu	Grade 10	Born with it	Mother
ALHIV-AM	19	Male	Xhosa	Grade 11	3 years	Aunt
ALHIV-NM	19	Female	Xhosa	Grade 10	Born with it	Sister

It is clear that the ALHIV who took part in this study were in the age groups of 18 and 19. Of the eight participants, five were nineteen years old and the remaining three were eighteen. In this category of participants, six out of the eight were females and only two were males. According to Karim and Baxter (2019), in SSA 80% of HIV infections occurs among adolescent girls between the ages of 15 and 19, and adolescent girls are also twice as likely to live with HIV than boys of the same age. According to the UNAIDS (2023), during the year 2022 an estimated 1.9 million adolescent girls were living with HIV, compared to 1.2 million adolescent boys. In addition, globally, 46% of all new HIV infections were among women and girls (all ages) in 2022. Nabunya, Byansi, Muwanga, Damulira, Brathwaite, Namuwonge, Bahar and Ssewamala (2021) submit that adolescent girls have up to 8 times higher rates of infection than their male counterparts in SSA. Although the researcher cannot state with certainty because of the small sample size of her study, the possibility that the gender disparity in these findings reflects the general pattern of HIV infections in society cannot be ruled out.

All the participants were black Africans. This conformed the findings of a South African study conducted by Mabaso, Makola, Naidoo, Mlangeni, Jooste and Simbayi (2019), where it was revealed that HIV prevalence was significantly higher among both black African males and females compared to other races. In addition, according to a report by Statistics South Africa (2022), black Africans are estimated at 81.4% of the South African population, which indicates that they are a dominant population group in South Africa. Two of the ALHIV were Zulu-speaking, two were Xhosa, two were Pedi, one was Sotho and one Tswana speaking, thus representing five ethnic groups.

In terms of *educational attainment,* six of the participants had attained less than Grade 12 (school leaving certificate) and only two were in Grade 12, which correlates with the findings of a study conducted by Toska, Cluver, Orkin, Bains, Sherr, Berezin, and Gulaid (2019) on the educational experiences and needs of ALHIV in South Africa, which revealed that living with HIV in adolescent was associated with poorer school attendance, educational delay due to regular sickness and cognitive difficulties. Moreover, five of the participants indicated that they were born with HIV, and three discovered that they were living with HIV at the ages of 13, 15 and 16 respectively. This indicates that effective HIV treatment has aided children who acquired HIV from their mothers to survive through to their adolescence stages (Ndiokwelu et.al., 2022; Rukuni et.al., 2020).

On *relationships* with the caregivers, four of the participants were the biological children of the primary caregivers, while three related to their primary caregivers as nieces and one of the primary caregivers was a biological sister.

4.2.3 Demographical profiles of social workers

The demographic profiles of the eight social workers who participated in the study are presented in Table 4.3 below.

Table 4.3 Demographic particulars of the participants (social workers)

Participant	Age	Gender	Ethnicity	Highest educational qualification in social work	Duration as a social worker	Duration providing services to ALHIV and primary caregivers
SW-VM	53	Female	Tswana	BA social work	25 years	17 years
SW-MJ	38	Female	Zulu	BA social work	6 years	17 years (started as a SAW)
SW-PF	27	Female	Zulu	BA social work	5 years	9 years (started as a SAW)
SW-MP	48	Female	Venda	BA social work	8 years	18 years (started as a SAW/HIV Coordinator)
SW-JM	42	Female	Sotho	BA social work	7 years	5 years
SW-RZ	45	Female	Xhosa	BA social work	7 years	7 years
SW-ZM	41	Female	Zulu	BA social work	12 years	6 years
SW-AM	37	Male	Tsonga	BA social work	5 years	5 years

Table 4.3 above shows that the *ages* of the social workers ranged from 27 to 53 years. Seven of the eight participants were female and one participant male. According to this analysis, social work as a profession is dominated by females. This finding is supported by Zastrow (2017) who indicates that gender-bias exists in social work, with females holding leadership positions in this field. Although Makhanya (2023) submits that social work is constructed to be a female-dominated profession in South Africa, Hicks (2015) argues that even though social work is described as a female-dominated profession, men disproportionately occupy more senior roles than women.

In terms of qualifications in social work, all eight participants have bachelor's degrees in social work. This part of the finding was expected, since according to the National

Association of Social Workers (2024) to qualify as a social worker, one has to have a degree in social work from an accredited college or university. In addition to a Bachelor's degree, a social worker in South Africa is required to register with the South African Council for Social Service Professions (SACSSP). The SACSSP is a statutory body which falls under the Professional board for Social Work and the Professional Board for Child and Youth Care Work (SACAP, 2024; SACSSP, 2024). Wolgemuth, Erdil-Moody, Opsal, Cross, Kaanta, Dickmann and Colomer (2014) state the importance of considering the number of work experience of participants in reporting the research findings. Therefore, the work experience of all social workers from the current study ranged from a minimum of five to a maximum of 25 years.

Lastly, in terms of the *duration of providing services* to ALHIV and their primary caregivers, three social workers indicated that they had more than ten years' experience working in the field. They all started out as social auxiliary workers prior to qualifying as social workers. Five participants had work experience ranging from 5 to 17 years. The work experience of participants as a demographic aspect in HIV studies is broadly linked to the view that social workers have been involved in the health care of individuals, families and communities, particularly PLHIV since the early days of the epidemic (Zerden, Lombardi & Jones, 2018; Lekganyane & Alpaslan, 2019). The researcher took cognisance of the fact that the participants with longer working experience in the field of HIV would have more insight into the phenomenon under investigation.

4.3. THE MAIN RESEARCH FINDINGS

This section introduces the main research findings in the form of eight themes, twenty-two subthemes and four categories. Whereas a detailed discussion of theme one to four pertaining to the experiences and challenges of primary caregivers in relation to caring for ALHIV as well as the experiences of ALHIV regarding being cared for by a primary caregiver are discussed in detail in this section, the remaining themes (theme five to eight and its subthemes) are discussed in chapter five.

Table 4.4 Themes, Subthemes and categories that emerged from the process of data analysis

Themes	Subthemes	Categories
1. Primary caregivers' experiences of caring for ALHIV	1.1. Caregivers' concerns in relation to caring for an ALHIV	• Concerns regarding regular monitoring of ALHIV who are always sick • Concerns about failure by ALHIV to comply with their treatment • Concerns about the general behavioural issues of ALHIV • Concerns regarding academic challenges faced by ALHIV
	1.2. Coping well with ALHIV	
2. The experiences of ALHIV being cared for by a primary caregiver	2.1. ALHIV enjoy supportive relationships with the primary caregivers	
	2.2. Lacking the necessary support from primary caregivers	
	2.3. Having overprotective caregivers	
3. The socioeconomic-related challenges of caregivers caring for ALHIV	3.1. Financial burden leading to inability to meet basic needs	
	3.2. Lack of proper nutrition and other means	
	3.3. Stigma and discrimination associated with caring for ALHIV	
4. The psychosocial challenges faced by primary caregivers of ALHIV	4.1. Perceived psychological stress among the primary caregivers	
	4.2. Perceptions that primary caregivers are struggling with disclosure of HIV positive status	
	4.3. Perceived parenting-related challenges	
	4.4. Perceived lack of support for caregivers to manage HIV-related challenges	
	5.1. Food and clothing	

5. A need for material support	5.2. Shelter	
	5.3. Financial support	
6. A need for employment		
7. Social workers' supportive roles for caregivers of ALHIV	7.1. Assistance with disclosure of HIV positive status	
	7.2. Support with adherence to HIV treatment and appointment reminders for clinic visits	
	7.3. Linking caregivers with resources for support	
8. A need for psychosocial support	8.1. A need for social support networks	
	8.2. A need for counselling	
	8.3. A need for peer support programmes	
	8.4. Support groups for caregivers	

The first four themes with their related subthemes and categories (where applicable), supported by direct storylines from the transcripts, are introduced and discussed below. The supporting storylines have been interpreted using some parts of the available literature, and where necessary, the adopted theoretical frameworks.

4.3.1. Theme 1: Primary caregivers' experiences of caring for ALHIV

An individual with lived experiences in a particular aspect of life is the only one qualified to tell his or her story for the researcher to gain full insight (McCall, Shallcross, Wilson, Fuller & Hayward, 2021; Kgadima, 2017). This theme emerged from the information voluntarily provided by the participants to the researcher's question regarding their experiences when caring for an ALHIV. The primary caregivers' experiences were explored, and their reflections were clustered into two subthemes, namely *concerns in relation to caring for an ALHIV* and *coping well with ALHIV.* The subtheme concerns in relation to caring for an ALHIV is introduced and explained in the next section.

4.3.1.1. Subtheme 1.1: Caregivers' concerns in relation to caring for an ALHIV

This subtheme was subdivided into four categories. These include regular monitoring of ALHIV who are always sick, concerns about failure of ALHIV to comply with their treatment, concerns about the general behavioural issues of ALHIV and concerns regarding academic challenges faced by ALHIV. The categories are introduced and discussed below:

- Category 1.1.1: Concerns regarding regular monitoring of ALHIV who are always sick

Regarding concerns about caring for ALHIV, the participants declared that it was generally difficult to monitor those who are always sick. This emerged from the interviews conducted with five caregivers, extracts of which are provided below.

C-VS was one of the caregivers who alluded to the challenges regarding monitoring of her child who was always sick. This is what she told the researcher:

> *"It was difficult, but I managed I use to ask for leave from the part time jobs I worked, I have 4 children at home, but he is the only one who is taking ARVs."*
> *"Where I worked, I always told them that I have a child who is HIV and I need to take him to the clinic, so I explained that the mother passed away, so I am the mother and father. I will tell them that I am going to the hospital and when I go back to work, I always bring a medical certificate. What I can say it is difficult to*

look after a child who is HIV because sometimes you want to give him his medication and he is still playing and now he is a teenage it is more difficult because sometimes he doesn't want to take his medication, I will say it is difficult to look after such a child."

Similar sentiments were uttered by another primary caregiver **C-MJ** who felt that regular clinic visits affected his day-to-day functioning:

"No really those are the challenges I am experiencing, just frequenting clinics, which is time consuming that is the reason I had to stop working so that I can be able to attend her clinic visits."

C-MJ added:

"It is difficult because she is not like other children, she needs extra care, always sick, you need to take her to the clinic. So, you take care of her more than other children and you must ensure that you give her medication all the time and with extra caution so that she can be like other children".

C-MM also shared her view about regular sickness that requires monitoring in adolescents. According to her:

"He got sick, eish when he was born, I didn't know that I have HIV, when he was born, he couldn't walk, so I took him to traditional healers thinking that he is bewitched, but it never helped, and my mom suggested that we take him to the clinic. Yeah after taking him to the clinic that is how we found out that he is sick and they started giving him medication, then he couldn't walk anymore, they took him to hospital, you know that time he was no longer staying with me because my mother took him to a children home. So, when he got there, he stopped taking his treatment and he started getting very sick, then he was taken to Baragwanath hospital, then they operated him on his legs."

C-SF's adolescent child was always vomiting and required regular monitoring. She stated:

"Yeah, the problem is now she is vomiting, she has been vomiting for the past 3 years, all of a sudden, she started vomiting we don't know what is causing it. She started in 2020, and she became weak because she vomits until her stomach is empty. We went to the clinic and at the clinic they gave us a note so she could

go to the hospital, at the hospital the Dr did an x-ray scan, nothing could be seen, but later the Dr saw something that looked like a warm, the Dr asked if she felt pain. She said yes, but sometimes it disappears. The vomiting and pain were affecting her school, but I encouraged her to continue focusing on taking the medication."

These research findings are consonant with a study conducted by Kasande et al. (2022) on the experiences of caregivers in caring for a child living with HIV. Their burdensome roles include ART clinic visits plus regular sickness and psychological care. Some participants found it difficult to juggle the needs of their ALHIV and their employment, which in turn compromised their employment duties. A Ugandan study by Osafo et al., (2017), focusing on the experiences of caregivers of children living with HIV, also revealed the challenges of having sufficient time to spend on income-generating activities, which resulted in some of them being fired.

Considering this from the ecological systems theory adopted in this study, it is essential to remember that human development is influenced by interactions and interpersonal relationships across micro-, meso-, exo-, system and macrosystems (Ettekkal & Mahoney, 2017). Considering HIV from this theoretical perspective, the microsystem includes challenges brought about by HIV which places demands on both the ALHIV and their family members including the primary caregivers, whose functioning are also affected by spending time on regularly monitoring ALHIV as opposed to their employment and other related duties. The mesosystem considers the interactions between primary caregivers, employers and healthcare systems. Due to the regular illnesses by ALHIV and regular clinic or hospital visits, the primary caregivers find themselves continuously monitoring the ALHIV, resulting in their daily functioning and duties such as employment being at risk (Lekganyane & Manganyi, 2023; Crawford, 2020; Ettekkal & Mahoney, 2017).

- Category 1.1.2: Concerns about failure by ALHIV to comply with their treatment

Primary caregivers aired their constant worries about the refusal of ALHIV to take their HIV treatment as prescribed and properly. What made them more concerned was that failure to take treatment might increase poor health and have extreme repercussions. Participants' narratives in relation to this are presented below.

C-TB was one of the participants who reported the difficulties of adolescents in adhering to treatment. Her concerns are reported below:

"It is because her mother failed to monitor her, she was just saying to her take your pills and she will throw those pills away, ya that is how she stopped taking her treatment. Ya so when I usually visit, I decided to check (said the name of the granddaughter) clinic card and I saw the date on the card, got worried and I asked the mother when did (said the name of the granddaughter) go to the clinic and my daughter said why are you asking is there a problem. Then I told my daughter the card shows that she is not going to the clinic. My daughter said but she still has medication. When I ask my granddaughter, she will say I drink my pills but sometimes I forget."

C-ID who was also concerned about ALHIV failure to adhere to treatment, had this to say:

"My worry was acceptance of her HIV status, not wanting to take her medication, coming late from school and fail to take her medication on time. but as time goes on, she adjusted and started taking her medication."

Caregivers **C-SF** and **C-MM** reported that their ALHIV experienced treatment fatigue and ended up stopping treatment**:**

"It was hard because we started the medication when we got here in Joburg, because at home my mother couldn't afford to run around and go to the clinic with a sick child while I'm busy looking for work. So, I decided to come to Johannesburg with my child and I brought her here to the clinic, here at the clinic they did everything, and the child started taking the medication and treatment in 2014. When she becomes an adolescent, she didn't want to take the medication, she will say these things are bad, they make me vomit and I am tired. I told her that she needs to be strong we will report this at the clinic."

Then caregiver **C-MM** added:

"He was 16 years, but he didn't understand, sometimes he will say that I am tired of taking these pills, so my mom is also HIV positive, and she is taking these pills, so she will tell him that you can see that I am also sick and taking these pills, so if you don't take them you will get sick and die. Sometimes he will stop taking his medication and he will start developing a rush all over his body and the face, so

we will explain to him that if he continues to stop taking his medication his face will get worse with this rush. You know sometimes he doesn't want to take the medication saying that it chokes him and can't pass through his throat, so we have to give him sweets to be able to take them."

This category seems to find support in studies such as one conducted by Kasande et al. (2022) in Uganda based on the experiences of caring for adolescents living with HIV. The interviews revealed that ALHIV are sometimes disrespectful and intentionally refuse to take their HIV medication which results in failure to attend clinic visits, leading to poor adherence to anti-retroviral therapy (ART). Despite the successful roll-out of this therapy and numerous other interventions implemented to improve adherence, ALHIV in South Africa have also been reported to poorly adhere to anti-retroviral therapy compared to adults and children. This is supported by the findings of a study by Brittain et.al. (2018) on the association of adolescent and caregiver, which reported antiretroviral therapy adherence to HIV viral load among perinatally-infected South African adolescents. Among the reasons for adolescents' non-adherence to HIV treatment was poor with reported barriers being forgetfulness, needing a break from taking medication and not wanting to be reminded of HIV. The above corroborates the findings of this study where primary caregivers indicated that ALHIV are also tired of HIV treatment, with some also complaining that the treatment does not taste nice.

- Category 1.1.3: Concerns about the general behavioural issues of ALHIV

The primary caregivers reported significant challenges with ALHIV in relation to unacceptable behaviour often expressed as rebellious acts and having a know-it-all attitude because they seek independence. The participants also expressed concerns about risky sexual behaviours sometimes displayed by their ALHIV.

In relation to this category, **C-TB** stated:

"You know the stage where they start getting smart, yes adolescent stage, eish I have to always reprimand her. When she has to come back home from school she comes back late, and when I ask, she will say she was with her friends, I keep on reprimanding, but she will change for few days and go back to her old ways. She loves friends but a boyfriend I am not sure yet, but it is worrying me because eish you know living with this illness is a problem, because people talk and you will end up telling people your stories and they judge you, ya so I worry when she spends time with friends."

Another caregiver who reported behavioural issues on part of the ALHIV was caregiver **C-MJ** who had this to say:

"Eish they are difficult, they don't understand, they think they know it all and on top of it she has HIV so she can't just date anyone she needs to understand that she can infect others with HIV. But she is blaming me."

C-ID also contributed to the narrative around problematic ALHIV behaviours by saying:

"When it comes to school and on how to cope better in future with having a child who is HIV positive. You know especially when they start being adolescent, they are troublesome because they start dating and they don't know that they are HIV positive."

Similarly, **C-MO** reported the following*:*

"She is now 16 years old, you know in December she went to visit his father in Phalaborwa and she came back pregnant and I worry that she give birth to a child who has HIV."

For **C-VS,** the problematic behaviour of her ALHIV took the form of even being reminded to take a bath. She reported:

"Yes, it is difficult you experience a lot of challenges like even taking a bath, if you don't remind him, he will stay for 2 days without bathing, and he sometimes stay until late and when you ask him he will say he was with his friends, but I worry if he now has a girlfriend and he might infect the other child without thinking about it or make her pregnant."

C-DA, reflecting on problematic behaviours, reported:

"Mistakes like going to be with a friend and come home late after sunset. The sun shouldn't set on a female child not being home. Sometimes she goes playing; she grew up being a child that loves to play, she just stopped playing on the streets last year, yeah she still played on the streets for a while. When she is playing sometimes, she forgets that she must wash dishes, she is not that child that just goes missing and no one knows where she is, boys she is not fast with that if she does have one, I don't know anything about it. She is secretive, she doesn't want anything to do with being embarrassed and if she does have a boyfriend, she is the only one that knows about it, we don't know anything about it."

These behavioural concerns expressed by the primary caregivers align with some previous studies. Several scholars found that ALHIV are likely to have behavioural and social problems and/or multiple risky health behaviours, which impact negatively on their wellbeing and cause significant risks and burdens to their families (Ezenwoko, Raji, Oche, Oladigbolu and Kwaido, 2024; Kemigisha, Zanoni, Bruce, Menjivar, Kadengye, Atwine & Rukundo, 2019; Matebese, 2014). Zgambo, Kalembo and Mbakaya (2018) in a study of the risky behaviours among ALHIV in SSA, found that the latter were engaging in risky sexual behaviours and abused alcohol and substances while not adhering to HIV treatments. Apart from the negative impact of these behavioural issues on their own wellbeing, they also cause psychological stress and added burdens to their primary caregivers.

- Category 1.1.4: Concerns regarding academic challenges faced by ALHIV

The fourth category concerns the academic challenges faced by ALHIV. This category emerged from the narratives of several caregivers who expressed significant concern about ALHIV's academic performance and educational experiences. In this regard, **C-MJ** shared the following**:**

> *"I also assist her with schoolwork because sometimes she is slow compared to other kids and sometimes missed school because of her illness."*

C-MM echoed these sentiments:

> *"Sometimes he gets sick, my child is now 18 years, and he is still in grade 8, I think he is slow I don't understand. I was referred to a social worker in town and they promised to remove him from the current school to a new school and also at school they say he is not coping well."*

C-ES also suggested that the loss of parent(s) contributed to poor school performance**:**

> *"Yes, she wasn't coping at all after her mother's passing, sometimes she will just be at school and cry, not do her homework or even sometimes not complete her schoolwork, and at school they had to take her to a lower grade."*

C-SF's daughter experienced academic challenges when she started falling sick. She had this to share:

> *"When she was doing Grade 11, she failed because she started getting sick, you know the vomiting issue but because she liked going to school, she insisted even when she is sick. She lost focus on her schooling because of being sick…"*

For **C-TB** and **C-MO,** behavioural problems were primarily responsible for school performance among their ALHIV. **C-TB** had this to say:

> *"Yes, at school, she once gave a problem, she would go to school and not get into the school yard for 3 weeks, she will sit at the park near school. So, I received a call from the school saying she hasn't been to class for 3 weeks. I called her mother who went straight to school to get more information. When we asked (mentioned the granddaughter's name) she would say there is a man who stand by the school gate and tells her not to go inside the school but go to the park, then she mentioned that she will go there and sleep until school is out."*

For **C-MO**, the main concern was her boy who would bunk classes and not do his schoolwork. She explained:

> *"You know I have a brother who is also sick and doesn't even want to go get treatment, so I decided to accompany him to take his treatment. While busy with my brother I received a call from school that my sister's younger child is absconding at school, and they want to see me and when I confront him, he says at school they got the wrong person. So, I followed up the following day at school, the teacher informed me that he comes to school, but he never gets to class, and they have been sending call letters, so it means they never reached home. It was difficult because all the teachers say he never gets to class, never does his homework or schoolwork and give them an attitude. You know children have 2 characters at home he is the sweetest boy but at school he gives teachers attitude, disrespect the teachers and they want to chase him from school."*

ALHIV are more likely to experience cognitive difficulties because of the neuropsychiatric effect of HIV infection on their brain functioning. They may develop mental health-related issues resulting in academic challenges including general school performance (Nxumalo, van Rensburg & Jacobs, 2024; Merville, Puangmala, Suksawas, Kliangpiboon, Keawvilai, Tunkam, Yama, Sukhaphan, Sathan, Marasri &

Rolland-Guillard, 2021; Kimera et.al., 2019). A South African study by Toska et. al. (2019) on the educational needs and experiences of ALHIV, confirmed that living with HIV is associated with school absenteeism and delays in education. Living with a chronic illness causes cognitive difficulties and mental health challenges like depression and stigma which impact on the school performance of ALHIV (Cluver et al.,2019), Likewise, Merville et al. (2021) suggest that ALHIV, particularly those that have been infected perinatally, experience difficult living circumstances such as parental loss, poverty, and stigmatisation and other health-related problems which negatively affect their educational achievements and school attendance. These findings demonstrate the impact of a meso-system of the ecological systems theory, particularly the relationship between the person's specific microsystems (in this instance the school), chronic illness and healthcare facilities and how they influence the individual positively by working together or negatively by working against each other (Bronfenbrenner, 1979; Navarro & Tudge, 2022; El Zaatar & Maalouf, 2022).

4.3.1.3. Subtheme 1.2. Coping well with ALHIV

Despite the challenges in caring for ALHIV, two of the primary caregivers, namely **C-ES** and **C-SF** reported positive experiences.

C-ES reflected on her pleasant experiences in caring for ALHIV as follows:

> *"It's okay, now I can say it's even better because when she arrived from Pretoria, she had stomach problems and when we went to the clinic, they said the pills that they were giving her were not right for her. They then changed her prescription, that's when she started feeling better."*

Another caregiver who reported positive experiences was **C-SF** who indicated that she was lucky to have her ALHIV since she is focused on school. Below is her reflection**:**

> *"Yes, I am lucky, when she was doing Grade 11 she failed because she started getting sick, you know the vomiting issue but because she liked going to school, she insisted even when she is sick, she is good child."*

This part of the research heeds the call by Afful et.al. (2019), for researchers to also explore the positive experiences of primary caregivers caring for ALHIV because they may contribute useful information that could also be shared with those who have children recently diagnosed with HIV. In the responses above, it is apparent that some participants' experiences were positive and that they adapted well to the challenges.

This aligns with a Chinese qualitative study of the experiences of Chinese informal caregivers for PLHIV by Zhang, Liu, Han, Tian and Xin (2024), which revealed that despite facing numerous psychological, physical and economic challenges, caregivers of ALHIV also have positive experiences in their caring roles. Similarly, another Chinese study conducted by Bonavitacola (2024) focusing on the positive and negative experiences of caregivers of PLHIV, concluded that despite primary caregivers of PLHIV reporting being burdened by psychological and physical stresses, some also had positive experiences and even indicated that they had more intimate relationships, gained knowledge in understanding HIV, and were more optimistic and hopeful.

Drawing from the responses of the participants of the current study as well as some research studies, it is evident that individuals have inborn potential and strengths to overcome and find solutions to challenges, which is one of the principles of the strength-based perspective (Caiels et.al., 2021; Hammond, 2010). Moreover, the strength-based perspective states that change is inevitable in the struggle of life challenges. In bouncing back from these challenges individuals acquire skills, knowledge, resources and abilities that enable them to endure their difficulties and find solutions (Poteat & Logie, 2022; Caiels et.al., 2021; Pulla, 2017). Despite the psychological and physical stresses associated with caring for an ALHIV, primary caregivers seem to use their innate strengths and potential to draw positive experiences from caring for ALHIV.

4.3.2. Theme 2: The experiences of ALHIV being cared for by a primary caregiver

This theme emerged from the data provided by ALHIV to the researcher's question regarding their experiences of staying with a primary caregiver. Their reflections were in this regard, clustered into subthemes, namely supportive relationships with primary caregivers, having overprotective caregivers, and lacking the necessary support from primary caregivers. These subthemes are explained below:

4.3.3.1. Subtheme 2.1: ALHIV enjoy a supportive relationship with primary caregivers

ALHIV experienced staying with their primary caregivers as a positive experience, characterised by support. Among the participants whose narratives supported this

subtheme were ALHIV-AK; ALHIV-AD; ALHIV-VP; ALHIV-TN and ALHIV-TM as presented below.

ALHIV-AK reported a positive and supportive relationship with the caregiver as follows:

> *"She is supportive, she does not show it, but you can tell through her actions that she supports you, she does not talk too much, she is just a quiet person who is just paying attention to her own matters."*

ALHIV-AD stated that she regards her primary caregiver as a mother figure and was happy with the treatment that she was receiving*:*

> *"It is nice living with my aunt, I regard her as a mother figure, even when my mother was still alive, my aunt was supposed to adopt me, I even asked my mom to go live with my aunt but unfortunately, she passed away before the year I was supposed to go live with my aunt in 2017."*

ALHIV-VP also highlighted the positive and supportive aspects of the relationship with her mother and stepfather with whom she was staying with and who treated her well:

> *"It's OK they both (mother and stepfather) treat me well. Like everything I want they buy for me unless I want a last-minute thing then they don't buy me they tell me to wait for month end."*

ALHIV-TN indicated that her mother was also on treatment, and they had a supportive relationship***:***

> *"It's OK, my mom treats me well, she is also on HIV treatment. We always remind each other to take treatment because it is only the 2 of us who take HIV treatment at home."*

The findings of this study correlate with findings of a study conducted by Mabasa, Skaal and Mothiba (2024) on the social support experiences of ALHIV in rural Limpopo, where the ALHIV reported positive social support experienced within their families. Likewise, Wowolo, Cao, Bosomtwe, Enimil, Tarantino, Barker and Galárraga (2022) in a study focusing on different parental figures and their impact on ALHIV, indicated that ALHIV have increased experiences of social support from their primary caregivers, and if the caregiver is of their own gender, there were increased feelings of mutual trust and shared understanding. Although the

researcher could not find evidence to support her understanding of the findings, it may be possible that the dynamics such as cultural norms, which encourage females to be cared by female caregivers, could be playing a role in enhancing these support systems.

4.3.3.2. Subtheme 2.2: Lacking the necessary support from primary caregivers

Besides the ALHIV who reported that they had positive and supportive relationship with their primary caregivers, there were some who reported that such relationships did not exist. Their responses were clustered into a subtheme called lack of support from primary caregivers. Among these participants were ALHIV-NM, ALHIV-JP and ALHIV-AM, whose extracts are presented below.

ALHIV-NM was stressed by the fact that her stepmother discriminates against her because of her HIV positive status**:**

> *"There was a conflict with my stepmother, she was originally not told that I am HIV positive and when she found out, you know, a lot of stereotypes surrounding HIV, you know like I will infect them, and I should stop playing with her kids because they will get HIV from me and what not. So, there was a lot of conflict surrounding that, which basically led to my sister stepping in and taking me to live with her. It's ok but we fight a lot, but I understand where she's coming from, Yeah, it's a bit hard. I grew up with my dad, living with my dad and his wife, so it's a bit hard on that end. We don't always seem to see eye to eye with a lot of things. Umm (paused) Things like, staying out late, things like going to my friends for a sleeping over, things like you know how I dress."*

ALHIV-JP also reported lack of support from the primary caregiver:

> *"Hmmm my aunt is sometimes moody and wake up not talking to me and obvious if someone is not talking to me, I won't force them, but I always greet her and she will ignore me and not respond, then I told my uncle, and he said he will talk to her. My aunt will get angry, she will just get angry for nothing. It makes me sad and lonely because I don't know what I did to her I try my best to respect and do my house chores, sometimes she is happy but sometimes she is moody."*

For **ALHIV-AM**, it was initially hard, because her primary caregiver was not supportive. However, things seem to have changed. She said:

> *"She is supportive now, but it was hard before, remember I said I was pregnant, so she stayed for a while not talking to me because she was angry with me because I got pregnant while I know I am still young and taking HIV pills."*

This part of the findings tends to reflect some existing literature, with researchers such as Mabasa et.al. (2024) reporting that ALHIV experience lack of emotional and social support within the family, particularly if the primary caregiver is not a biological parent, but one of the family members. A study conducted by Atanuriba et.al. (2021) highlights that the stigma and misconceptions surrounding HIV result in family dissension and problems result in limited support for ALHIV. A Ghanaian study by Doat, Navab and Sadat Hoseini (2021) on the experiences of ALHIV, reported stigma and rejection from friends and some family members as they struggle to adjust to HIV. Similarly, a Swaziland study of the experiences of female LHIV by Nsibandze et.al. (2021), revealed lack of support from family members as well as stigma and discrimination. Considering this subtheme, it is essential to remember that the microsystem in ecological systems theory consists of the immediate, most intimate and closest people to an individual. The ALHIV make use of family support systems such as primary caregivers and significant others in the family, and support at this level help them to cope better with HIV-related issues. If they lack support at this level, their lives may easily be disrupted leading to dysfunctionality within the families (Muller-Kluits & Slabbert, 2020; Ettekkal & Mahoney, 2017).

4.3.3.3. Subtheme 2.3: Having overprotective caregivers

Another subtheme that emerged was overprotection from primary caregivers, which ALHIV did not like it. They reported that in some instances, they were treated like children and therefore not trusted to make good decisions, particularly in relation to their sexual activities and future.

ALHIV-TM was among those who reported feeling overprotected primary caregivers:

> *"You know they think I will sleep with boys, and I know about these things they teach us from school and also here at Friends for life we talk about them, so I know what to do and now my school is more important."*

ALHIV-AD expressed similar sentiments*:*

"My aunt has been supportive and sometimes she is [over protective] and treats me like a child, you know I am now 19 years of age, she should realise that I am an adult and I am capable of making decisions, she always tells me that I should know that I am not like other children so I should take extra care so that I don't get sick and doesn't want me to spend time with my friends or go to parties with my friends she will always calls to remind me that I need to come back home and I know I need to come back home on time and also to take my medication on time."

ALHIV-TM felt that although her relationship with her mother was good, it was the overprotectiveness that bothered her:

"Yes, I have a good relationship with mother but sometimes eish she can be too protective. (she laughed) my mom doesn't trust me she things I am dating, she is always screaming if I come back home late, you know she always think I am busy with boys, and she doesn't understand that I know these things and more focus on school."

ALHIV-VP also expressed frustration about the overprotective behaviour of her parents***:***

"It's OK they both (mother and stepfather) treat me well, but very protective and sometimes it exhausts me because they don't trust me. They think I will get pregnant while still at school and they don't realise that I know what I want in life, and I know I still need to finish school. I know I am delayed a bit at school because I was always sick but now, I am healthy and more focus on school."

Overprotective by primary caregivers as is the case in the current study, was also found in some of the previous studies. A South African study conducted by Mukwevho, Maputle and Ramathuba (2023) on the transition experiences from adolescence to adulthood at selected primary health facilities in the Limpopo province, found that some of the ALHIV felt they were not trusted by their caregivers in terms of sexual maturity and intimate relationships. Their primary caregivers on the other hand were worried about their ALHIV's early sexual debuts and poor decision-making which aligns with the findings of Kasande et al. (2022) whose caregiver participants

expressed concerns about their ALHIV engaging in early sexual relationships and immature decision-making because they were adolescents.

An Indian study by Verma, Kota, Bangar, Rahane, Yenbhar, and Sahay (2023) focusing on the emotional distress experienced by ALHIV reported strong parental control as one of the major themes, with ALHIV not even allowed to visit friends. The controlling behavior of primary caregivers results from their fear of risky behaviour by the adolescents and their need to maintain secrecy about their HIV-positive status in order to protect themselves from the community stigma and discrimination (Tarantino, Guthrie & Armistead, 2020; Verma et.al., 2023). As much as ALHIV still needs to be protected, it may have negative consequences such as emotional distress with the potential to affect family relationships.

4.3.3. Theme 3: The socioeconomic-related experiences of caregivers caring for ALHIV

The primary caregivers looking after ALHIV have a vast of experiences, some of which are socioeconomic in nature. On a question requiring primary caregivers to share their experiences in caring for ALHIV, they provided various responses that were rearranged according to three subthemes, namely financial burden leading to inability to meet basic needs; lack of proper nutritional and other means; stigma and discrimination associated with caring for ALHIV. These subthemes are introduced and explained below.

4.3.3.1. Subtheme 3.1: Financial burden leading to inability to meet basic needs

The subtheme of the financial burden experienced by caregivers emerged from the interviews with all the categories of participants. The caregivers who contributed to this subtheme were: C-MO, C-TB, C-ES, C-MM and C-SF.

C-MO stated**:**

> *Yes, I do, you know sometimes it is difficult financially, but you know sometimes we will not be having money for bread, but God grace someone will come and help. Especially when we get to the 15th of the month it is hard, but we are grateful that we are alive. You know we are many in total I have 7 children, 4 are for my sister and 3 are mine, so we live on foster care grant, but now I am worried that*

(she mentioned the name of ALHIV) after giving birth she will be removed from the foster grant, ya but we will cross the bridge when we get there.

C-MO added that she was burdened because she is also looking after her deceased sister's children and she said the following:

"*It's painful but what can I say I have to be strong and accept that my sister passed on, yes they are 4, I mean my sister children and 3 of them are HIV positive except 1 I don't even know how he survived, and he is a boy and I am definitely sure that the one who passed on was also HIV positive. Yes the one who is HIV negative when we test him, he always test negative and the oldest passed on this month. She was 23 and I am sure he was also positive, so now I am left with 2 who are HIV positive."*

C-VS had similar sentiments:

"Ya it is difficult you might find out that he has lot of needs that you are unable to meet like he might need money…"

C-TB is a grandmother of the ALHIV, also concerned about the financial burden:

"*I am struggling my granddaughter needs money to buy lunch at school and the school is far, so she also needs transportation. Transport to school is R30 a day so if I don't have, I have to make a plan, and she always says granny I get hungry at school so I need to give her that money and it is bad I don't have it."*

C-ES said the following***:***

"I was referring to the fact that we don't have money, food and that my granddaughter doesn't have enough school uniform, you know it is hard without money to take care of a child who is sick, sometimes no money to visit the clinic when she is sick, and her mother passed away so sometimes she becomes emotional, and his father is Pretoria. I do not get a pension yet, so I recently registered, and I am not working so getting adequate food for her is a problem more especially since my son stays in Pretoria."

C-ES added that she is also struggling to access her granddaughter's grant because her maternal grandmother took the documents, and she said the following:

"Yes, because her grandmother, the person who gave birth to her mother, took all the necessary documents, you know she gave me my granddaughter birth certificate and her mother death certificate, but came back later and took it saying that she needs it to be able to claim money from burial society. When I wanted them back, she kept on telling me stories, claiming that when she receives the grant money, she will send it to me, I am still waiting even today".

C-MM indicated that financial difficulties sometimes resulted in them going to bed on empty stomachs*:*

"Eish ya, like I said at home were too many so sometimes we sleep without eating, so I must go hassle and look for food, so that he can eat and have money to buy lunch at school, at school the is a food scheme program so they give them food for free, but he is unable to eat it because he vomits, so I must make sure that he has R10 to buy fat cakes and he will be fine."

C-SF needs to be able to provide her ALHIV with healthy food so that she can take medication. However, due to financial difficulties she finds this challenging*:*

"I will be happy if I can be able to provide for her and give her healthy food so that she can be able to take her medication and be strong. Lack of money is also a problem because I am struggling sometimes to get her school uniform or to take her to a private doctor and end up going to the clinic. You know girls like to look beautiful and I can't afford to buy her expensive clothes, and I hate to always ask from family members, I should be able to provide for my children, I need money, and working will make a difference in my life and I will stop begging".

Financial burdens and the resultant inability to meet the basic needs of the ALHIV also emerged from the interviews conducted with ALHIV. The ALHIVs who specifically contributed to this subtheme were ALHIV-AD; ALHIV-JP; ALHIV-VP; ALHIV-TM; ALHIV-AM; and ALHIV-NM.

ALHIV-AK believes that when children are sick, it is the responsibility of the caregiver to provide the necessary assistance and take the child to medical facilities which, however, requires money and this is not always available:

"I think when the child is always sick, and they have to take her to the hospital it needs money and they might not have it."

ALHIV-AD gave her views regarding financial difficulties experienced by the primary caregivers:

"She was raising her kids and her sister's kids, and in total we are 7 children, and she is not working so sometimes she can't afford to buy us food, which I think it is burdensome to her."

ALHIV-JP sometimes needs things that require money, and this is a challenge because her caregiver does not always have money. She said*:*

"You know sometimes I want my uncle to buy me staff or I want to go out because I am teenager, or sanitary pads you know female staff, toiletry, things like that, and it is hard for him to buy them all and also school staff and I will tell him to pay and he will say he doesn't have money you know so I must ask my father, I know that it is waste of time because he doesn't do anything for me, he is just a father and never do anything."

ALHIV-VP stressed that lack of employment is the reason why her aunt fails to meet some of her needs:

"Another challenges I can think of is the fact that she is not working is a problem. Eish, you know sometimes it bothers her when she cannot provide some of the things I need and she will be stressed, but at least my stepfather is there to assist."

ALHIV-TM said there are some items that she needs, and her caregiver cannot always provide them due to financial challenges:

"You know sometimes I want her to buy me staff or I want to go out because I am teenager and want to look beautiful, ya those things and it is hard for my mom to buy them all and also school staff and I will tell her to pay for a school trip and she will say she doesn't have money you know so I must ask my brother but he is always saying he doesn't have money. Yes money is the most important, I think if she can start working to assist my brother it will really help because now I no longer receive a grant which was helpful, ya also sometimes she doesn't have money to give me when I need to go to the clinic, the clinic is not far but sometimes you stay the whole day there and you get hungry."

ALHIV-AM reported her perceptions about her caregivers' financial difficulties as follows:

"I think for my aunt it is hard because she is working part-time, so sometimes food is a problem, she tries so that we always eat, you know she tries but it is hard. When I get sick or the child is sick, even my clinic visits so it needs money and sometimes she doesn't have it and the father of my child is not willing to assist, so all the money problems are my aunt responsibility."

ALHIV-NM stated that her aunt has her own children to care for financially:

I would say definitely the biggest one is, she is struggling to support us financially because she does have her own kids, so it is hard supporting everyone in the family, financially she is struggling. Now she works part-time, she lost a permanent job a few months ago, so money has been really tight on that end and sometimes in the new job she doesn't get paid or get paid late which is a problem.

The social workers also pointed out that they mostly work with primary caregivers from poor communities and that their poverty results in financial burdens leading to stress because they cannot meet some of the basic needs of the ALHIV such as nutritious food. This specifically emerged during the interviews conducted with SW-ZM, SW-AM and SW-VM:

SW-ZM had this to say*:*

"Yes, I think also the challenge that primary caregivers are experiencing beside the virus is external factors like unemployment, poverty, which also contributes to the stress, or the challenges that they have because It's really difficult to take medication with an empty stomach, they believe so and also going to the clinic to get medication sometimes they don't have money. So, it's also one of the challenges that affects the primary caregivers caring for ALHIV and ALHIV themselves."

Social worker **SW-AM** highlighted the financial burdens and poverty experienced by the caregivers:

"Yes, sometimes it could also be structural you know, such a poverty because I've noticed that most of the primary caregivers are living in impoverished communities and sometimes poverty becomes a challenge because it is not easy

to care for adolescent living with HIV, meanwhile you are struggling in terms of employment, or you are struggling in terms of having a proper diet."

SW-VM added to this issue of financial challenges that impose pressure on the livelihoods of caregivers and their families:

"The main other problem finances, sometimes family members might be appointed as guardians and they sometimes abuse the grant, you know they don't utilise it correctly. They don't buy winter clothes, they buy whatever, just use it for their own needs, you find that the child is here in Alexander, but the money is being earned by somebody's aunt or whoever's in Eastern Cape or KZN and is not sending them money, then the guardian is struggling. So then in that way, we have to make sure that we intervene and see how we can help the guardian to access the grant here in Gauteng rather than in Eastern Cape. Others you find that its child headed household or caregiver is not working, you know there's issues of food in the house."

Financial burden as one of the challenges in the context of the current study was not a new phenomenon it was also reported by Nasuuna et al. (2019) and Mafune et al. (2017) who reported that primary caregivers' financial difficulties include transport costs to visit clinics to comply with follow-up dates. Financial challenges further hamper the provision of food, clothing, and pocket money for school. Maddocks and Chetty (2020) in a study focusing on the burdens of caring for children living with HIV in a semi-rural South African community, confirm that caregivers are constantly identified as vulnerable to economic challenges. Carries Mkhwanazi, Sigwadhi, Moshabela, Nyirenda, Goudge, and Govindasam (2023) conducted a study in South Africa focusing on the economic incentive package for the wellbeing of caregivers of ALHIV during COVID-19. They found that financial resources to support the needs of ALHIV was one of the main barriers to the wellbeing of primary caregivers. As observed by Carries et al. (2023), financial strain experienced by primary caregivers of ALHIV is compounded by the fact that many of them are unable to work full-time because of their caregiving responsibilities.

The above difficulties are linked to employment, mental health and the general state of poverty among the caregivers. Muller-Kluits and Slabbert (2020) also point out that primary caregiver's experience 'caregiver burden, which covers employment and

financial concerns that negatively impact their mental and physical health. The specific findings on social workers regarding the primary caregivers living in poverty and in impoverished communities which poses a challenge for them to meet financial needs of ALHIV, confirms reports by Mafune et. al. (2017), that caregivers live in poverty and debts due to unemployment. Kasande et.al. (2022) alluded that primary caregivers of ALHIV who are experiencing financial burden are predominately in low-income communities with inadequate healthcare facilities, making it difficult for caregivers to access the necessary medical services and medications for ALHIV.

Abubakar et. al. (2016) found in a study conducted in Kenya focusing on the financial challenges faced by ALHIV, that poverty results in lack of proper meals, clothing, and school fees for ALHIV. Kimera et.al. (2019), found financial stress affects ALHIV who were perinatally infected, with the loss of one or both parents who were financially supportive to them increasing the burden on primary caregivers who are not their biological parents (Kimera et al., 2019). As a result, ALHIV end up not attending their clinic appointments and collecting their ART medication because of lack of transport money.

What emerged from this subtheme is also a reflection of ecological systems theory. According to this theory environmental factors such as socioeconomic status of primary caregivers and lack of resources such as transport money to go to school or clinic or even food to eat in the family may negatively impact the health of ALHIV and the primary caregiver (Crawford, 2020; Zaatari & Maalouf, 2022). Drawing from the above narratives, it is evident that primary caregivers experience financial challenges that hamper their capacity to provide basic needs such as food, clothing and more to their ALHIV.

4.3.3.2. Subtheme 3.2: Lack of proper nutrition and other means

Participants expressed challenges in relation to meeting material and basic needs such as nutritional food to provide for ALHIV. They stated that this challenge is heightened by the fact that ALHIV have special needs. Among those who contributed to this subtheme were **C-ES, C-VS, C-SF, C-TB** and **C-MM.**

C-ES stated***:***

"Sometimes when she eats some of the food disturbs her stomach, so I always need to ensure that she eats healthy food and that won't upset her stomach. Her tummy will run, she will have diarrhea so I make sure that I don't give her milk and oily food, but you know how children are she will sometimes eat chips and all the wrong food."

C-VS expressed that failure to meet the needs of the ALHIV who does not understand, results in him becoming angry***:***

"Yes, it is difficult you might find out that he has lot of needs that you are unable to meet like he might need money, food, ya healthy food or clothes and you don't have money, so he becomes angry at you."

C-SF contributed to this subtheme and said:

"I will be happy if I can be able to provide for her and give her healthy food so that she can be able to take her medication and be strong. You know girls like to look beautiful and I can't afford to buy her expensive clothes, and I hate to always ask from family members, I should be able to provide for my children, ya that will be all I need money and working will make a difference in my life and stop begging."

C-TB shared her experiences regarding nutritious food:

"I mean it is difficult in terms of getting food, particularly from the middle of the month, eish my daughter buy food for R2000 but you know children misuse the food, they misuse the food shame. Ya it is difficult and frustrating, so sometimes I go look for money from illegal money lenders, ya it is difficult."

For **C-MM,** the issue was not nutritious food but just basic food because of the number of people in the house. This is how she explained the situation:

"Yes, food is a problem because we are 6 at home, but my son is getting a grant, a foster care grant. So, it is not enough but my mom and I try to add but the food won't be enough to finish the month. My brother is wasteful when it comes to food, and he end up controlling us and telling us he is owner because he is boy."

Lack of food for ALHIV also emerged from the interviews conducted with ALHIV. The ALHIV who contributed to this subtheme were **ALHIV-AD** and **ALHIV-AM.**

ALHIV-AD explained her views about lack of food on a large household:

> *"She was raising her kids and her sister's kids, and in total we are 7 children, and she is not working so sometimes she can't afford to buy us food, which I think it is burdensome to her."*

ALHIV-AM gave her perceptions of the caregiver's difficulties in meeting her nutritional needs:

> *"I think for my aunt it is hard because she is working part-time, so sometimes food is a problem, she tries so that we always eat, you know she tries but it is hard."*

Food insecurity is a significant and difficult challenge in this subtheme. Matebese (2014) in her study of primary caregivers' experiences of caring for HIV infected adolescents indicated that one of the challenges experienced by primary caregivers in their caring role is meeting the basic needs of the whole family and the children living with HIV. This problem as revealed by Matebese, was compounded by the special needs of ALHIV to remain healthy. In Atanuriba et al. (2021), one of major challenges experienced by primary caregivers caring for children living with HIV was also found to be food insecurity. Likewise, Heany, Phillips, Myer, Zar, Stein and Hoare (2021) in their study of the physical development and mental health of perinatal ALHIV and their caregivers in terms of household food insecurity, found that primary caregivers of ALHIV had a high level of food insecurity. The complexity of the role of caregivers of ALHIV was also highlighted by Onono, Sheira, Frongilio, Odhiambo, Wekesa, Conroy, Bukusi, Cohen and Weiser (2025) who among others, pointed to demands for food, educational and healthcare needs for all adolescents, with failure to meet such needs leading to emotional stress and therefore potential disruption of family relationships. In conclusion, lack of or inadequate economic means for meeting nutritional or basic needs of ALHIV has the potential to expose both caregivers and the adolescents to emotional distress, which might in turn lead to disruption of family relationships.

4.3.3.3. Subtheme 3.3: Stigma and discrimination associated with caring for ALHIV

One of the subthemes that emerged from further analysis of the theme **pertaining to the socioeconomic-related challenges of caregivers** was that caring for ALHIV often attracts stigma and discrimination. Caregivers expressed fear of being stigmatised which they often experience during the disclosures of HIV-positive status by ALHIV, as well as when they visit the healthcare facilities for treatment.

As demonstrated below, the participants whose narratives supported this subtheme were **C-ID, C-MJ** and **C-ES**.

C-ID indicated that she is scared of going to the clinic because of the stigma:

> "Y*es, and sometimes I would feel ashamed and start asking myself what people were going to say about my child. but I realised that this thing is normal, anyone can have it so I had to accept."*

C-MJ also had concerns about stigma and discrimination:

> *"I meant fear that she will disclose her status to other children, when she was still young she use to know that she has germs that are making her sick and she is taking medication and she shouldn't tell anyone, but later I was assisted by Friends for life to tell her that she is HIV positive which was difficult because she was angry with me and even stopped taking her medication. This was very difficult and stressful to me. You know now she is a teenager, and she might want to start dating and how will she disclose her status and also I am scared that she will infect others with this virus."*

C-ES strongly felt that her ALHIV should keep her HIV-positive status secret and not share it with anyone due to the fear of stigma:

> *"She must not mention that she takes HIV medication, not even to her friends. She even brings it up sometimes and even reminds me that she must take her medication, but eish I am worried that when she starts dating it will be a problem…my worry is she might infect the other children and she might also find it difficult to tell her partner about her HIV status and I worry that they will hurt her or even tell everyone about her HIV status, and this will be very traumatic to her. You know I love her so much and I will do everything for her, and I don't want her to get hurt especially now that she doesn't have a mother."*

The stigma and discrimination of caregivers on the basis of their involvement in caring for ALHIV was also reported by social workers, with social workers such as **SW-MP**, also mentioning the stigma and discrimination experienced by primary caregivers:

"The issues of stigma, that there's still a stigma in the family without even going to the community, the family member who will know that their granddaughter or grandson is living with HIV, will start stigmatising them, saying we do not associate with somebody who is HIV positive because we might get it ourselves. Yes, this is caused by lack of knowledge, because they think when you are HIV you are going to die and you might infect them, without knowledge it is also a challenge because it can lead to stigma and those having HIV being isolate from other children in the family, on even denied some basic needs."

SW-JM stated the following regarding stigma:

"You know in the community we know each other, we know each other's business, so you find out that the primary caregiver doesn't want neighbours to know that they are taking care of a child who is HIV positive or have a parent who died of HIV because to neighbours it might means that they were not looking after themselves maybe they had too many relationships. Also, the child who is living with HIV will pass it to their children so they have this fear that their children will be rejected by the community you know and/or labelled and treated differently from other children in the community. which makes it difficult for the primary caregivers to disclose their status due to fear."

SW-RZ reported that caregivers feel isolated. She explained as follows:

"They never trust anyone and feel isolated, they don't have the confidence to do something for themselves, and also for their child, because they've failed even from the beginning. While other people have healthy children, but then they have this child that's just going to take medication for the rest of their lives, also have this negativity within themselves. Yes, I am referring to stigma, you know they have self-judgement, and they carry it within themselves you know. It's something that is playing in their mind, in their ears. What I mean, they will say "I'm HIV, my child is HIV". They judge themselves so much and tend to isolate themselves from the community that is the stigma I'm referring to and fear that

the community and family will judge them, saying they have too many partners that is the reason they have HIV and they don't want to be infected by them."

According to **SW-ZM,** despite all efforts that are taken by the government to educate people about HIV and AIDS, there seems to be a need for more, particularly because PLHIV and their caregivers are still subjected to stigma and discrimination. This is how **SW-ZM** expressed it:

"As much as the government is trying to work on educating people about HIV and AIDS, but we can't really say people have accepted. We still have that stigma within our communities because you will find that a caregiver or adolescent would not want to talk freely about their HIV status, even within the family, we still have the stigma within the family. You'll find that adolescent is taking the medication, but as soon as one relative visits, then the medication will be interrupted, because they don't want that aunt or uncle to know that the child is HIV positive. So there is still stigma within families also and also fear caregivers have since they don't know how best they can support the adolescents living with HIV. Yes, they worry that they will be regarded as also HIV positive, what I mean is they stop going to collect medication for their children at the clinic because they are scared that their neighbours are going to see them, you know in our community the people who work at the clinic the stay in the same community, so they are scared that they will tell everyone and then they stop taking their children for treatment."

Another social worker who mentioned stigma and discrimination towards primary caregivers of ALHIV was **SW-PF,** who said:

"Even issues of stigma because when you go for a home visit, they are always scared that others will ask questions and sometimes they are not welcoming because they have this fear what is hidden will be revealed, you know HIV status."

According to Nabunya, Namuwonge, Bahar, Ssentumbwe, Migadde, Mugisha and Ssewamala (2023) HIV is a stigmatised disease, and caregivers of ALHIV are experiencing the negative effects because of their association with an HIV-infected family member, an adolescent. This stigma is demonstrated through gossip, name-calling, rejection and isolation, loss of social support, and harassment (Nabunya et al.,

2023; Atanuriba et al., 2021). Moreover, stigma results in lower quality of life, poor mental health and parental stress among primary caregivers (Robinson, Cooney, Fassbender & McGovern, 2023; Nabunya, Byansi, Bahar, McKay, Ssewamala & Damulira, 2020). Mofokeng and Green (2017) observed that HIV-related stigma has a severe impact on those infected (ALHIV) or affected (primary caregivers) by the virus and can eventually lead to internalised stigma which in turn leaves them with the less likelihood of seeking support because of fear of rejection and isolation.

Stigma can manifest in different forms, enacted by people such as family or community members. *Anticipated stigma* is the fear of potential discrimination and *internalised stigma* refers to person's own negative beliefs and attitudes about themselves because of their HIV-positive status (Nabunya et al., 2020; Turan, Budhwani, Fazeli, Browning, Raper, Mugavero & Turan, 2017).These forms of stigma can impact severely on the mental health and wellbeing of ALHIV and their primary caregivers (Schweitzer, Dišković, Krongauz, Newman,Tomažič & Yancheva, 2023; Kip, Udedi, Kulisewa, Go & Gaynes, 2022; Fauk, Hawke, Mwanri & Ward, 2021).

Whereas ALHIV may experience enacted stigma directly in the form of being excluded, stereotyped, or even discriminated against because of their HIV-positive status, internalised stigma is directly related to psychological distress for PLHIV and their families (Kip et al., 2022). In a Malawian study focusing on stigma and discrimination among ALHIV and those with depression, it was found that the main drivers of HIV-related stigma are fear of HIV transmission, inaccurate knowledge, associating HIV with death and the negative attitudes that may results in insults, physical and social isolation, leading to reduced adherence to HIV treatment and missed clinic appointments.

The ecological systems theory is concerned with the interaction and interdependence of individuals with their surrounding systems (microsystem, mesosystem, exosystem and macrosystem). Some of these systems carry negative factors such as HIV-related stigma and discrimination influenced by a variety of social, political, economic, and cultural factors (Lekganyane & Manganyi, 2023; Placek, Nishimura, Hudanick, Stephens & Madhivanan, 2019; Ettekkal & Mahoney, 2017). It therefore becomes important to protect caregivers and ALHIV from stigma and discrimination from both

within their immediate families, their communities, their schools and other settings where they interact with their significant others.

4.3.4. Theme 4: The psychosocial challenges faced by primary caregivers of ALHIV

The last theme reported in this chapter involves the psychosocial challenges faced by primary caregivers of ALHIV. Here ALHIV were of the view that their caregivers experience psychological stress as a result of HIV disclosure and not having the necessary support to manage their challenges. The four subthemes: perceived psychological stress and perceptions that primary caregivers are struggling with disclosure issues, perceived parenting-related challenges, and perceived lack of support for caregivers to manage HIV related challenges were then developed from this theme and they are explained below.

4.3.4.1. Subtheme 4.1: Perceived psychological stress among the primary caregivers

According to ALHIV, their primary caregivers are experiencing psychological stress due to caring for them. This stress as described by ALHIV, often stems from fear that they will engage in sexually risky behaviours and fall pregnant. They also felt that their primary caregivers were stressed about how to navigate through relationships, with some blaming themselves since they believed that they infected their children (the ALHIV) with HIV.

Among the participants who alluded to this were **ALHIV-AD** who mentioned that their primary caregivers are worried that they will engage in risky behaviours and fall pregnant:

> *"My aunt is raising a total of 7 children, most of us are girls so she says girls are a problem because if one gets pregnant then another one will follow and my aunt told us she won't take anyone to the clinic for contraceptives, if someone wants to have a child then it will be from their own will, yes she stress about that."*

In another interview, **ALHIV-TN** said*:*

> *"She doesn't have any problems I can look after myself now I am old, and we always remind each other when it is time to take medication. Yes but after she found out I was dating she was not happy and telling me that I must look after myself and not bring a child."*

In the case of **ALHIV-AK,** she stated that his primary caregiver is stressed about him and how he will navigate relationships because of his HIV status:

"Even if they do not ask you, they ask themselves where you got it and how, they want to get that closure, but they won't tell you. They also think about how you are going to survive with this illness and relationships."

ALHIV-TM said that her primary caregiver is worried about disclosure of her HIV positive status and also stressed that she may not adhere to her HIV medication:

"Another challenge she is always worried that I will have a boyfriend and since I have HIV how will I tell my boyfriend about my status and also she worries a lot and always reminds me to take medication. I think she thinks I will die or something and that won't happen, I look after myself."

ALHIV-NM stated that it is sometimes hard for her primary caregiver to provide for her needs because there are other children who also need her attention:

"I would say, dealing with my HIV. Yeah, I need, there's sometimes where You know, obviously I need more care and her other kids, so it might be harder for her to since she has three of her children."

Another adolescent, **ALHIV-VP** reflected on the mental health-related experiences of her primary caregiver and said her mother feels guilty and thinks that she has infected her with HIV:

"She feel bad because she infected me and because I'm young and taking pills. Yes, it pains her so much and she blames herself that it is her fault that I must take ARVs every day."

Perceived psychological stress among the caregivers also emerged from the interviews conducted with the social workers who thought the primary caregivers lacked knowledge around HIV and as a result, developed emotional and psychological stress.

SW-PF, one of the social workers, reported perceptions regarding lack of knowledge of HIV among the primary caregivers, which then led to stress. This is what she said:

"I think another challenge is primary caregivers lack information about HIV, so they have this fear that if they look after an ALHIV they might also be infected.

This is caused by the fact that they do not have enough information about how HIV is transmitted."

Lack of knowledge around HIV among the caregivers also emerged during an interview with **SW-MP** who reported as follows*:*

"The other challenge is also lack of knowledge about the illness. Some particularly the grandmothers they fear that they will get infected by the child they are looking after who is HIV positive, because they don't have knowledge, mostly they just know that this is HIV, you take medication if you don't take medication you die. They don't know what the purpose of the medication is that at the end viral load is suppressed and these are the benefits for that child and when she grow up she won't infect the partner when she is married so they don't have that knowledge, what they have is just fear."

Another Social worker **SW-MP** had the following to say about primary caregivers' lack of knowledge in HIV-related matters:

"… the case that I once had the primary caregiver was afraid that the child will start to have a relationship, so the primary caregiver feared that if this child has a relationship maybe she won't disclose to that person that she is HIV positive. The fear she has was misinformed, she was saying because she is HIV positive, she is not supposed to date. Like I said she did not have the knowledge that the girl can date but she always needs to use condoms, and the partner can use prep, so she didn't have education about HIV. She also said what if this child gets pregnant and her child will be HIV positive like my granddaughter, yes they don't know that it is possible that the mother can have an HIV negative baby you see."

SW-RZ was of the view that it was not only knowledge that caregivers lacked, but also support about where such knowledge can be acquired. She said:

"Another challenge is they lack knowledge. They lack support and they don't know where to get it and became stressed and it end up affecting the child. Yes, they do blame themselves and even believe that since you are living with this HIV, your future is finished. They still believe the is no future for them and their children because they believe they are going to die soon and the is no future for their children so they never what to plan anything for the future. Also, the stigma, that is out there in our communities. Those are the challenges that I have come

across. Yes, with their health, they worry about the children's health because some of the HIV positive children are always sick and have to go to hospital. Sometimes they work and the is no one to look after the child or sometimes they are the ones who are sick which causes stress to them. You know, sometimes after taking medication they react which causes problems because sometimes they don't know where to get help."

SW-AM confirmed that caregivers do not have the necessary information about where to access resources. She also stated that provision of information is essential to protect themselves from also acquiring HIV:

"It's lack of information to start with, Yeah, that's the challenge, because most of the primary caregivers, they are unaware of the resources that are around them for example information related to adherent support, or even reaching out for assistance to get care and treatment. Information related to how they can prevent themselves from being infected from contracting HIV and for the clients who are infected with HIV, how can they protect themselves, so I think that's the challenge that I thought of."

Another Social worker **SW-MJ**, had the following to say about the lack of knowledge among caregivers of ALHIV*:*

"Sometimes even the lack of information from the primary caregivers…find that most of them do not have the right information when it comes to HIV and AIDS, they are scared of it. They are the ones who are more scared of it and they get that mindset of if I tell the child they will take it the wrong way."

For **SW-JM,** lack of knowledge among caregivers of ALHIV leads to fear of being infected by HIV. This is what she said:

"I think another challenge is [that] *primary caregivers lack information about HIV, so they have this fear that if they look after an ALHIV they might also be infected. These is caused by the fact that they do not have enough information about how HIV is transmitted."*

What is revealed by this part of the findings corroborates the findings by Kasande et al. (2024) whose study indicates that primary caregivers experience psychological stress because when ALHIV reach adolescent stage, they start asking questions such as why they were born different from other children and why they have to take pills

every day. In Thailand, Wattradul and Sriyaporn (2014) conducted a study focusing on caregiver experiences in healthcare and the social support for school-going children living with HIV. They also found that primary caregivers needed more knowledge. Reading into this part of the findings from the ecological systems theory, it is essential to remember that activities and relationships of individuals within the microsystem are affected by the dynamics of other systems. Lack of or inaccessible educational programmes within the communities might result in lack of knowledge around issues of HIV among the caregivers which then has the potential to strain their relationships with ALHIV, who may desperately wish to know certain things about their conditions, while their parents are unable to provide answers because they do not have the necessary knowledge. The manifestation of intense emotions such as fear, guilt and grief alongside the HIV-related stigma and discrimination as well as lack of familial support, signal some dysfunctionalities in the microsystem, with the potential to negatively affect other systems (schools, work, community) because a dysfunctionality in one system may extend to other systems and impose further complications (Lekganyane & Manganyi, 2023; Kasande et al., 2022).

Toromo, Apondi, Nyandiko, Omollo, Bakari, Aluoch, Kantor, Fortenberry, Wools-Kaloustian and Vreeman (2022) emphasise the need for support and more HIV-related knowledge by caregivers and how to manage it effectively in caring for ALHIV. This means, among others, providing counseling on how to provide children with age-appropriate and accurate information about their health and HIV treatment and to support adolescent-caregiver communication and relationships. Strengths-based theory stresses the importance of collaboration as key in starting the change process. Therefore, in providing HIV counselling and support to primary caregivers it is important to include education and adherence support to reduce emotional and psychological stress. This will eventually improve adolescent-caregiver communication and relationships (Caiels et al., 2021; Pulla & Francis, 2015).

4.3.4.2. Subtheme 4.2: Perceptions that primary caregivers are struggling with disclosure of HIV positive status

In addition to the perceptions held by ALHIV regarding the psychological stress among their caregivers, some participants felt that their caregivers were struggling when

coming to disclosure of HIV-positive status. This subtheme specifically emerged during interviews conducted with social workers.

As revealed in the following extract, **SW-VM** felt that the difficulties which primary caregivers have with disclosure, among others, reflecting their fears in relation to the possible reaction of ALHIV and their possible struggle with acceptance of their HIV positive status*:*

"Disclosure is a big challenge because as children grow up, the caregivers say they don't want the child to know, trying to keep them safe and stress free. But, you know, at the end once they find out, it's a challenge and other teenagers also research for themselves and find out their status by mistake. We had a case where a child was not disclosed to, but you know they google and tried to get information about their treatment, by the time they tried to do disclosure, the child already know and now causes conflict between a guardian and a child, they became rebellious and stop taking treatment or run away from home so that is one of the challenges we experience in our community."

***S*W-MJ** reported as follows*:*

"I think the challenges that most of them face is the issue of telling the child that they are HIV positive because most of the adolescents who are HIV positive, were born with it, you find that the primary caregivers find it difficult to tell the children that they are HIV positive so most of them don't even know today that they are HIV positive, they just know that "I am taking treatment for my chest, they just tell them something else."

SW-PF indicated that primary caregivers fear stigmatisation and rejection by the community:

"OK, the most challenge for primary caregivers is disclosure, the community finding out that they are living with a child/adolescent who is HIV positive. Even to go to the clinic to collect medication it is a challenge, because they think the HIV status of their children will be uncovered, and community members will know. You know in the community we know each other, we know each other's business, so you find out that the primary caregiver doesn't want neighbours to know that they are taking care of a child who is HIV positive, sometimes the parents of that child have passed away so they will think it means they were also HIV positive

and also they were promiscuous, they had too many relationships. Also, the child who is living with HIV will pass it to their children so they have this fear that their children/adolescents will be rejected by the community and will be treated differently from other children in the community."

SW-JM stated that primary caregivers do not disclose to their ALHIV due to fear of rejection. She told the researcher:

"I think the challenges that most of the guardian's face is telling their children that they are HIV positive more especially mothers, because they are scared that they will be rejected. Some of them say that it is like telling my child that I was careless or promiscuous hence now you are sick because of my behaviour. From my experience the grandparents, aunts, uncles or so for them disclosure is not a serious problem like parents because most of them can be able to tell them because they don't blame themselves like the biological parents. I think to the parents, they are scared that when they tell their children, how the children are going to take it, what if the child decides to hurt him/herself or something like that, they are just scared of the aftereffects, not being sure what is going to happen."

SW-MP also pointed to the difficulties experienced by primary caregivers around disclosure. This is what she said*:*

"Disclosure, they don't disclose that their children are living with HIV. For example, if it's a grandmother or an aunt caring for a child living with HIV or teenager living with HIV, they fail to disclose to other family members, so it's difficult because you can't tell others or you can't debrief on something that you haven't shared with family members or with somebody who's closer to you."

SW-ZM indicated that caregiver failure to disclose is because of lack of knowledge*:*

"I will say most of caregivers are experiencing a fear of disclosing to the adolescents, I think that fear is caused by a lack of information or lack of knowledge, because most of the time you'll find that when you are talking to a parent or a caregiver, they haven't disclosed yet. When you ask the reason for not disclosing, they'll tell you they don't even know where to start, how to start. They feel the child is still young, mind you we're speaking about an adolescent here, maybe they are 15- or 16-year-old, but the caregiver will still feel the child is still young, to be disclosed to. But as soon as you intervene or empower them

on disclosure processes and how to begin with disclosing that's when you can see that the fear was because of lack of information from the caregiver side. Also, it's the fear of stigma in the community."

The findings of this study, pertaining to the challenges associated with disclosure, points to the critical complexity of caring for ALHIV. Disclosure of HIV-positive status is not only necessary for ALHIV to properly manage their health but is also important to prepare them to accept their health situation. This means the time and procedure of disclosure is important. A South African study focusing on caregiver experiences in disclosure of HIV status to children living with HIV by Nataniel et al. (2024) revealed that, caregivers lack the knowledge regarding the correct time and age to disclose an HIV positive status to the child and how to facilitate such a disclosure process.

Madiba and Mokgatle (2015) conducted a qualitative study focusing on the views held by the health care workers regarding the disclosure of HIV-infected children and established that most of the reasons cited by health care workers for primary caregivers delaying disclosure of HIV positive status to their children, was fear of hurting the child, fear of HIV-related stigma. Furthermore, some primary caregivers felt compelled to disclose HIV positive status because ALHIV were starting to enquire about the medications they were taking; a finding which closely linked with responses from social workers in the current study.

Likewise, an Ethiopean study by Abegaz Walle and Tilahun (2019) on disclosure of a HIV-positive status and its associated challenges among children living with HIV in pediatric ART clinics in Gondar public health facilities, revealed that primary caregivers who had some form of education are more likely to disclose to their children compared to caregivers who are illiterate. Their findings were in line with what social workers in the current study expressed as one of the challenges for failure to disclosure HIV status by primary caregivers. Several other scholars indicate that among the reasons given for failure to disclose the HIV status of the ALHIV is the primary caregivers' fear of emotional disturbances and the potential stigma and discrimination that ALHIV may experience from other siblings in the family and members of the community (Nathaniel et.al., 2024; Yiryuo, Kpekura, Osman, Kukeba, Mumuni, Mwinbam & Dery, 2024;

Sarkar, Selvaraj, Krishnamurthy, Balasundaram & Lakshminarayanan, 2018; Mafune et al., 2017).

4.3.4.3. Sub theme 4.3: Perceived parenting-related challenges

Another subtheme that reflected the psychosocial challenges among primary caregivers was perceived parenting-related challenges. This subtheme was accounted for by three social work participants as outlined below.

SW-VM reported that ALHIV may adhere poorly to treatment due to behaviour related to their adolescent stage:

> *"As they reached the teenage stage they start to date and some don't adhere to treatment. You know, they are busy with their boyfriends. They come back late, then the time to take pills already past. You know, sometimes they don't come back home, they sleep over at their boyfriends. This causes lot of stress on caregiver because they need to keep on monitoring and now, they have boyfriends or girlfriends whom they didn't even disclose to."*

SW-JM stated that the behavioural challenges displayed by ALHIV stresses primary caregivers:

> *"I think I mentioned that regardless of taking treatment in which they do not know what it is for, they still go around getting boyfriends, they do not sleep at home, things like that frustrate the guardian. From my experience, it is disclosure, and their behaviour is just like other children's and the girls also fall pregnant while HIV positive and others find out that they are HIV positive during pregnancy, whilst all along she did not know that she was HIV positive. It is luck for the guardian when the child finds out that they are HIV positive by themselves, so they won't ask the guardian a lot of questions because she will think she got the sickness on her own but the ones who find out before having sex, it becomes a problem for the guardian because they start asking the guardian a lot of questions, which makes it difficult for the primary caregivers to disclose their status due to fear."*

The social worker **SW-JM** expressed her views as follows:

> *"I think other challenges, (paused like she is thinking) I think caregivers have worries about their children because as adolescents they go around getting boyfriends or girlfriends, they do not sleep at home and things like that."*

This part of the research findings supports a Kenyan study of health-related quality of life among primary caregivers of exposed uninfected adolescents, conducted by Mwangala, Ssewanyana, Mwangi, Chongwo, Nasambu, Kagonya, Scerif, Newton and Abubakar (2022), which revealed that primary caregivers are stressed and burdened by risky behaviours associated with the adolescent stage such as active sexuality, forming relationships, and how to manage the potentially elevated risk of HIV-associated psychosocial problems, including pressure to disclose the young person's HIV-positive status. **SW-VM** and **SW-JM** confirmed that primary caregivers encounter challenges in the adolescent stage which are associated with risky sexual behaviours, falling pregnant, having romantic relationships and non-compliance with treatment.

4.3.4.4. Sub theme 4.4: Perceived lack of support for caregivers to manage HIV related challenges

Another subtheme that emerged from data analysis relates to the perceived lack of support to enable the caregivers to care for their ALHIV. This was specifically reported during the interviews conducted with **SW-MP** and **SW-RZ**. The extracts from the interviews are provided in support of this subtheme below:

SW-MP raised lack of the necessary support for social workers to manage the challenges associated with HIV. She made the following remarks:

> *"I think lack of family support because they fail to disclose, they don't disclose that the children they are living with are HIV positive, so it's difficult for them because they failed to tell others or they even can't share their frustration about something since they failed to disclose HIV status to family members or with somebody who's closer to them. So support is very important. Sometimes failure to disclose can be too way, I mean you might find out that it is grandmother, and her daughter passed away because of HIV and she did not tell anyone, so now the burden remains with the grandmother who needs to look after the children without knowing their HIV status. On the other hand, you might find out that the grandmother knows the HIV status and that her daughter passed away because of HIV but failed to tell other family members, maybe within the family, because they fear of judgment and to be stigmatise."*

SW-RZ also mentioned lack of support for primary caregivers to manage the challenges associated with HIV:

"I think lack of support, because every parent wants a healthy child, but to find out that the child is living with HIV, then when the family find out and they start rejecting that child and the primary caregiver. The community still has the perception that if your child has HIV, it means you had too many partners, so nobody wants to associate with you, these leads to primary caregivers blaming themselves. That's what I used to come across when I work with them. Most of the primary caregivers are lonely most of the time. It's one of the challenges that they are faced with because there is no one around them to give them the support and assurance."

SW-MP told the researcher:

"Challenges related to disclosure, is caregivers most of the time do not disclose to the child who is living with HIV or either to the family members, or friends and it becomes difficult to get support because of failure to disclose. Disclosure can lead to failure to adhere to treatment, because the primary caregiver did not disclose it is difficult to get support, for example the caregiver is from Limpopo and left her child with a family member so that family member won't be able to track if the child is taking treatment because they don't know."

What the participants shared in this study regarding disclosure corroborates with a South African study conducted by Lentoor (2017) on the psychosocial challenges associated with caregiving in the context of pediatric HIV, where it was found that primary caregivers tend to be isolated without any family support due to failure to disclose HIV-positive status and the fear of being stigmatised and discriminated against, which consequently impacts negatively on the child's health. Molato, Moloko-Phiri, Koen and Matsipane (2024) also point to the primary caregivers' challenges such as lack of support from social services, family, stigma, and discrimination in their caring roles due to failure to disclose. Furthermore, failure to disclose the HIV positive status of ALHIV by primary caregivers may result in lack of necessary support from families and communities which is needed to manage HIV-related challenges including compliance with treatment (Mafune et al., 2017). Poor adherence to treatment due to lack of support was also found in Yiryou et al.'s (2024) study of the challenges experienced by family caregivers seeking antiretroviral therapy services for children

living with HIV/AIDS in Ghana. This study demonstrated that caregivers of children living with HIV are overwhelmed and need family support, which if not provided, might lead to poor adherence to HIV treatment.

One of the elements of the ecological systems theory is the macrosystem which encompasses broader factors such as cultural beliefs, social norms, customs and values that families have (El Zaatar & Maalouf, 2022; Liao, 2016). In considering primary caregiver difficulties with disclosure from the ecological systems theoretical perspective, it is essential to do so in the context of the cultural beliefs and norms held by communities and societies. Primary caregivers may be reluctant to disclose the HIV status of ALHIV due to fear of stigma and discrimination which is in most instances, fuelled by cultural beliefs, norms and customs that associate HIV with death, immoral behavior or punishment from God or even bewitchment or failure to adhere to cultural prescripts (Asrina, Ikhtiar, Idris, Adam & Alim, 2023; Fauk, Hawke, Mwanri & Ward, 2021).

4.4 SUMMARY OF THE CHAPTER

An overview of the study findings was presented in this chapter. The chapter began with a presentation of the demographic characteristics of all the categories of participants (eight primary caregivers, eight ALHIV and eight social workers) in the study as well as an overview of all eight themes, twenty-two subthemes and four categories that emerged from an analysis of the data. The demographic characteristics were presented in Tables 4.1, 4.2 and 4.3, and they focused on gender, age, ethnic background, educational qualifications, and employment status of all the three categories of the participants. A discussion of these characteristics was presented, and the data was compared and contrasted against findings from the existing literature. The first four themes pertaining to the experiences and challenges associated with caring for an ALHIV were presented in the form of four themes, twelve subthemes and four categories. These themes, subthemes and categories were then discussed in the context of the existing literature and adopted theoretical frameworks.

CHAPTER FIVE

CAREGIVER'S NEEDS AND SUGGESTED SOLUTIONS ASSOCIATED WITH CARING FOR ALHIV

5.1 INTRODUCTION

This chapter is a continuation of presentation on the research findings based on the needs and suggested solutions associated with caring for ALHIV. The chapter is based on one of the objectives of this study which sought to understand the needs of primary caregivers and find ways of best addressing them. The responses shared by the participants in this regard were categorised into themes and subthemes. This chapter will introduce and discuss the remaining four themes and then subthemes that emerged from the data analysis. These themes and subthemes are introduced and supported by extracts from the interviews. Each theme or storyline is then evaluated in the context of the existing literature and theoretical frameworks. A summary of chapter serves as a conclusion.

5.2. CAREGIVER'S NEEDS AND SUGGESTED SOLUTIONS ASSOCIATED WITH CARING FOR ALHIV

One of the research objectives of this study was to identify the needs of primary caregivers of ALHIV. These needs were explored from the perspective of the caregivers themselves, the ALHIV, and social workers. Following data analysis, four themes emerged, namely A *need for material support*; *employment*; *financial support* and *support in HIV management*. These themes are introduced and discussed below.

5.2.1. Theme 5: A need for material support

Primary caregivers of ALHIV often tackle a variety of material needs to effectively support their adolescents and the household as whole. Participants (primary caregivers, ALHIV and social workers) in this study were asked to respond to the questions on what the needs of primary caregivers are in caring for ALHIV and they expressed a variety of material needs. These material needs were further filtered into three subthemes: food and clothing, shelter as well as financial support and they are discussed in detail below.

5.2.1.1. Subtheme 5.1: Need for Food and clothing

The primary caregivers stated that there is a need for healthy and nutritious foods, essential for maintaining the health conditions of their ALHIV and ensuring that they take their medication regularly.

C-MJ who highlighted her dependence on the child's father, indicated that lack of employment contributes to lack of nutritious food at home. This is how she narrated her story:

"What I need is my child to get healthy food daily because I am not working, it is hard to raise a child who is sick without money and only rely on his father."

C-ID admitted to being stressed because of the lack of nutritious food for her ALHIV. She narrated her story in the following manner:

"Just for him to eat the right food, it becomes difficult when you find out that there is a shortage, because you become stressed and start thinking that if she doesn't get the right food she will get worse and sick again."

C-ES added that she would be please if she had the ability to provide healthy food for her ALHIV:

"I will be happy if I can be able to provide for her and give her healthy food so that she can be able to take her medication and be strong."

C-TB was also troubled about not having healthy food to maintain a healthy status for her ALHIV. This is how she explained her story:

"She paused for while (thinking), Ya if I can get groceries (food) so that I can look after her it will help, ya I just need food for her that will help, more especially healthy food because it will help her to remain healthy."

For C-SF the difficulty to provide for basic needs such as clothing for ALHIV was mainly due to lack of financial resources. She explained herself in the following manner*:*

"I will be happy if I can be able to provide for her. Lack of money is also a problem because I am struggling sometimes to get her school uniform or to take her to a private doctor and end up going to the clinic. You know girls like to look beautiful and I can't afford to buy her expensive clothes and I hate to always ask from

family members, I should be able to provide for my children, ya that will be all I need money and working will make a difference in my life and stop begging."

C-VS likewise, struggled to provide nutritious food and clothing, which then causes her ALHIV to become angry. Her remarks were captured in the following manner**:**

"Yes, it is difficult you might find out that he has lot of needs that you are unable to meet like he might need money, healthy food or clothes and you don't have money so he becomes angry at you."

The issue of food also emerged from the interview conducted with one of the ALHIV, **ALHIV-AK** who had this to say:

"Food, because obviously when we are living with this condition, you have to eat healthy, so I think those are the challenges she went through, even now that I do not eat healthy that much, she makes sure that the food I eat has vegetables on them."

This part of the research findings correlates with a Ugandan study conducted by Nasuuna et. al. (2019) on the challenges encountered by caregivers of virally non-suppressed children in an intensive adherence counselling programme which also found that lack of food and infrequent meals resulted in poor adherence to HIV treatment, consequently rendering the primary caregivers unable to provide the necessary care to their children. When these needs are not met, it causes stress and makes it difficult for caregivers to support ALHIV; the body needs food to hold down medicine for proper absorption and for ALHIV to remain healthy.

In a paper addressing services and interventions in Orphans and vulnerable programs for children and ALHIV, Medrano (2023) accentuated that food plays a major role in promoting adherence to HIV treatment and recommended food support programs since most of children and ALHIV are from impoverished households.

Mofokeng and Green (2017) outlines Maslow's hierarchy of needs which indicates that individuals' motivation rests on a hierarchy of needs, of which one of them is physiological needs such as shelter, food, sleep and other basic needs for human survival (Ștefan, Popa & Albu, 2020; Mofokeng & Green, 2017). Onono et al. (2025) in their Kenyan study of the impact of food security improvement on parenting practices and caregiver–adolescent relationships, found that income-generating

intervention may assist in getting food and improve food security within the family and therefore contributing positively to parenting practices and adolescent psychosocial well-being and behaviour. Based on the above literature as supported by the findings of the current study, basic needs of primary caregivers are paramount and failure to meet them might result in stress and other mental health issues, which in turn has the potential to negatively affect the health conditions of the ALHIV.

5.2.1.2. Subtheme 5.2: Need for Shelter

The primary caregivers stressed that providing shelter to their ALHIV is an essential need. A safe and stable housing to accommodate the whole family and provide a private space wherein sensitive issues can be explored, was considered crucial for the wellbeing of the ALHIV.

One of the caregivers who was concerned about shelter issues was **C-VS**. He pointed to the challenges with lack of privacy particularly because since his ALHIV was now old*:*

> *"I want a place to stay so that my children can have their own room and I can have mine, I only follow with department of housing for RDP house. It is difficult not to have a place to stay you know even a toilet we do not have, so at night we have to use a small bathtub, and you know with such an old child it is difficult there is no privacy, it is difficult, and it is stressing me."*

C-SF also mentioned the need for a safe and stable house environment. This is how she narrated her story***:***

> *"I believe I am fit to work that's why I would like to open a day care centre if only I could find a two room house so I can have a place to start, eish right now I live in a shack, I want the kids to have a safe place not in a shack but in a house build with bricks that is secured if I could get that because at this age it's not easy to get a job I rather do something for myself but then I don't have resources*."

C-TB likewise mentioned safe housing big enough to accommodate her family. This is what she said***:***

> *"I wanted assistance, (She paused) eish I need assistance with a place to stay, you know I am staying in a flat with my children and grandchildren, so the place is small. I and my husband once registered for RDP house [free government*

housing] but till today nothing so I went for assistance to get a better place to stay with my children since my husband passed on."

It is clear from the primary caregivers' statements that shelter is crucial to providing a safe, stable and supportive environment for their families and ALHIV. This is a confirmation of the observations made by some scholars that primary caregivers of ALHIV experience unique challenges that extend beyond medical care such as lack of structural resources which create poor living conditions and exacerbate the pressing need for food, clothing and items for school (Mutluri, 2021; Lentoor, 2017; Yarney, Adjei, Asamoah, Bawole & Ahenkan, 2015). Likewise, Mugumba (2019) in her Zimbabwean study of the experiences of children living in HIV/AIDS in child-headed families, found lack of housing and proper shelter, with some of the participants reporting overcrowding, poor ventilated and poor build houses. Mofokeng and Green (2017) added that shelter as one of the physiological needs, plays a major role in providing a proper care for ALHIV since the kind of HIV medication they take might not be exposed to an environment that can negatively affect its effectiveness. Crowded poorly ventilated shelter may jeopardise the effectiveness of antiretroviral treatment (ART) and contribute to the development of opportunistic infections such as TB or pneumonia, leading to the risk of transmission to other members in the household including the very same primary caregivers who cares for ALHIV.

Mofokeng and Green (2017) support what **C-TB** touched on regarding an overcrowded flat where she was staying with her grandchildren including the one living with HIV which causes her some stress. Mugumba (2019) added that health problems are common in overcrowded areas and risk the spread of diseases such as TB. Nonetheless, safe, stable and decent housing is closely linked to successful HIV outcomes and eventually lead to improved quality of life for primary caregivers and ALHIV (Mcinziba, Bock, Hoddinott, Seeley, Bond, Fidler & Viljoen, 2023; Aidala, Wilson, Shubert, Gogolishvili, Globerman, Rueda, Bozack, Caban & Rourke, 2016). Based on literature and the responses from primary caregivers as participants for this study, it is evident that shelter is one of the essential basic needs, which if not met, might cause stress and impaired quality of life for both primary caregivers and ALHIV.

5.2.1.3. *Subtheme 5.3: Need for Financial support*

Financial support is one of the needs that emerged among the material needs voiced by the caregivers themselves. All the caregivers contributed to this subtheme.

In an interview conducted with **C-MJ**, this is what she said regarding financial support**:**

> *Ok, maybe to also have adequate clothes. You know the government is giving us child support grants, but it is not enough for a child who is living with HIV, so if the government can increase the grant to cover extra needs such as clothing, transport to go to the clinic and extra medication that is needed for the child and also healthy food which is expensive.*

C-ID shared similar sentiments, pointing to lack of financial resources as a threat to access healthcare centres:

> "*Yes, transport to go to the clinic, since I am not working and I don't receive social grant, so it's hard on me."*

In another interview with **C-VS**, reported that money is essential to get healthy food the ALHIV:

> *"All I need is money, food, he needs fruits and nice things not only pap, so I will say getting money will help because sometimes he has friends, and he compares himself with his friends who have money because their parents are working, and I am not working. This is stressful for me, but I do not have money and can't afford it."*

C-TB confirmed a need for financial resources to enable her to buy food:

> ***"****Food and money to buy food is the most important, I am working part-time sometimes but the money is not enough to cover all our basic needs".*

Likewise, **C-ES** said this about financial resources:

> *Yes, maybe also assist with adding a grant for children who are sick because this can help with so many clinic visits and healthy food we need to give to these children.*

According to **C-MJ,** when she gets to the clinic she is told about healthy food yet she doesn't have money to afford them*:*

"For me is food and financial support because when we are at the clinic, they use to tell us about healthy food that we need to give to our children to remain healthy."

C-TB said the following about food and financial support**:**

"I think if it was for me, primary caregivers caring for ALHIV need money to look after them and to remain healthy. My granddaughter was fat but now she lost weight because of lack of food sometimes, you know sometimes she doesn't have any nutritious food to eat, ya that is my suggestion."

C-MO felt that social workers should improve the service they render by, among other things, providing food and vouchers, which is an indication of a need for financial resources:

"Yes, in terms of Social Workers I do not have a specific request for them, but they can improve on services they offer to us. You know they need to give food parcels or voucher while you are still waiting for foster care grant because it is process and also it needs money, they need so many documents and meantime how do they expect you to survive so a voucher might assist in the meantime while still in the process of getting the foster care grant and they can stop it after you get the grant. Things are hard so it is difficult to survive without money and looking after children who orphans."

The caregivers' needs for financial resources were also raised by the adolescents when asked what in their views could be the challenges faced by the caregivers. This specifically emerged from the interviews conducted with all adolescents who took part in this study.

ALHIV-AD stated that her primary caregiver needs money and employment to be able to meet her needs and those of other family members*:*

"Since there are some who are still growing and still in school, they can keep sending us food parcels for the young ones who are still in school, when they can. "I think she will need money since she is unemployed but self-employed, she runs a spaza shop which the money is not enough to look after us or even to buy food for all of us."

The need for financial resources also emerged from the interview with **ALHIV-TN** who reported that although her primary caregiver is trying her best to meet their basic needs, she encounters challenges, particularly her inability to afford clothes and shoes***:***

"I mean she tries to get us food or clothes when she has money, she tries shame even though you know these days things are hard, food is expensive, but she tries shame to look after all of us, but sometimes she doesn't have and it frustrates her. I always tell her that it is ok, all we will be well in time. As a girl you always need to look good and sometimes, she can't afford to buy expensive clothes and shoes because she can't afford so fails to meet some of my needs."

On financial resources, this is what **ALHIV-VP** had to say:

"I think she needs to be able to meet some of my needs, you know as girl I have friends who are well off at home their parents can afford to buy them expensive things like cell phones, nice clothes and have enough pocket money and my mom can't afford those things and I want to fit in with my friends. I think she needs money, maybe if she can get a job and be able to assist my stepfather that will make it easier for her to meet all my needs."

ALHIV-AM shared similar sentiments and said their primary caregivers need financial stability to meet basic needs:

"Money, yes money especially that this time she is not working, obviously she is a mother so she has to close that bridge that her kids do not sleep on empty stomachs, you know obviously when we are living with this condition, you have to eat healthy, so I think those are her needs."

For **ALHIV-NM**, financial stability was the crucial thing that her primary caregiver needed. This is how she explained herself:

"I don't want this to come in like in a very weird way, but I feel like she needs a bit of financial stability to be able to take care of me properly. You know because she is capable to looking after me, you know, she knows how to deal with me with my HIV status and to ensure I remain healthy by giving healthy food and giving me money to the clinic."

ALHIV-TM added that financial support from her father and extending her grant [financial assistance provided by South African Government to vulnerable individuals

and families with the aim of improving their living standards] will assist her mother in meeting her basic needs which includes transport money for health care visits. This is how she narrated her story:

> *"I think money and also support from my father. Yes, it is difficult for my mom to raise the children alone while my father is having a nice time and also she has to ensure that I take medication and when I am sick she has to take care of me alone and most of the time she doesn't have money to take me to the doctor. I think social workers can help like I said with extending my grant, this will help my mom to look after me better and I won't struggle when I go to the clinic."*

ALHIV-JP indicated that social workers could help her uncle to get a foster care grant. This is how she expressed herself*:*

> *"I think social workers can help with foster care grant, this will help my uncle to look after me better since I am no longer receiving child support grant."*

Two participants (caregivers) were very specific about the form of financial assistance required, namely social grants.

C-MO explained how she approached social workers for a foster care grant for her ALHIV:

> *The only time I reached out it was before I got the foster care grant, and they also referred me to SASSA [government agency administering social grants] saying there are food parcels but I never got anything from them. I also always followed up but never got anything until I got the foster care grant last year for these children and soon it will be kicking them out soon because the other one is pregnant and the social worker mentioned that the one who is pregnant it will kick her out after giving birth so she can only apply for the child support grant.*

C-ES echoed this:

> *Yes, I asked assistance on getting a grant, I know once we receive the grant, we will no longer have problems. Yes, that is the only need I can think of for now.*

Social workers also made contributions to the significance of financial resources for the caregivers. This emerged during the interviews conducted with SW-MJ; SW-PF; SW-JM; and SW-MP.

SW-MJ pointed to the need for financial support for caregivers:

"I think they need financial support because some are grandmothers, and they do not have money to buy healthy food for the adolescents in their care and also money to take them to the clinic.

Another social worker who alluded to financial issues was **SW-PF**, who had this to say:

"Their needs is money and food you know, this community I am working in is poverty stricken you know people are poor and on the other side the ALHIV has to take medication on an empty stomach the is no food and most of the people in the community are not working and do not have money to look after the needs of their ALHIV and sometimes they do not even have food at home but rely on food parcels."

SW-JM indicated financial support will enable caregivers to buy healthy food:

"Yes, one last need, I think they need financial support because some of them are not working and they need healthy food and basic needs to look after their children who are living with HIV and they do not have money nor working to able to buy such."

SW-AM highlighted the need for financial support alongside other needs such as food parcels and social grants. This is how she narrated the story***:***

"OK you know one of the important needs of our primary caregivers is financial support, working for Department of social development we also work with drop-in centres , whereby you encounter primary caregivers/parents who are not working, not financial stable, and I realised that they need money, employment, some form of grant or even receive food parcels."

As evident from this subtheme, ALHIV, social workers and primary caregivers were of the view that primary caregivers need financial support to address the needs of these adolescents. This subtheme seems to support previous studies such as a South African study of the challenges of caregivers of children who are on ART in the Mutale local municipality of the Limpopo province (Mafune et al., 2017). In Mafune et al. (2017), participants reported experiencing financial burdens that result from transport costs during follow-up visits at healthcare facilities plus insufficient money for food, clothing for the ALHIV and pocket money for lunch boxes during school hours.

Likewise, Ferry, Seeley, Weiss and Simms (2022) recommended financial support as an appropriate intervention to meet the health needs of ALHIV and their primary caregivers, which will in turn improve adolescents' ART adherence outcomes.

Nasuuna et al. (2019) highlighted that multiple financial demands on caregivers leading to an incapacity to provide the level of care they should be giving to their children living with HIV. Katana, Abubakar, Nyongesa, Ssewanyana, Mwangi, Newton and Jemutai (2020) Kenyan study focusing on the economic and mental health burden among primary caregivers of perinatally HIV infected adolescents, also found that the economic burdens for primary caregivers were high, with most expenditure linked to travel costs for clinic visits and medication to combat opportunistic infections and other health-related conditions representing approximately a quarter of their monthly income. This economic burden results in poor quality of life for primary caregivers. In a South African study of the resilience of children living with HIV in the KwaZulu-Natal province, Gomo, Raniga and Motloung (2017) found that social grants make it possible to provide better care for children living with HIV. Equally, Carries et al. (2023) point out the need to support caregivers through access to direct financial relief programmes such as cash transfers or grants for essential needs such as food and housing and any other basic needs. Based on the literature shared above and the findings of the current study, financial support and provision for food parcels is important and has the potential to impact positively on the wellbeing of both the primary caregivers and ALHIV.

Regarding social grants, one of the primary roles of social workers in South Africa is to link their clients to resources such as social grants (Hildebrand, 2017). A South African study on social workers' views on the implementation of legislation guiding service delivery to child-headed households by Mkhavele, De Jager, and Mokwele, (2024) recommended that social workers should assist households that qualify to access social grants. Ecological systems theory supports the notion that one of the roles of social workers is to assist with mobilisation of resources and developing strategies such as access to social grants (Germain & Knight, 2021). A South African study by Sesane and Geyer (2017) focusing on community members' perceptions of the role of social workers in managing HIV and AIDS by enhancing social capital, also highlighted the importance of social workers' in facilitating access to social welfare services such as social grants. In Gomo, Raniga and Motloung's (2017) study of the

resilience among children living with HIV from the perspective of foster parents who receive grants, found that social grants plays a significant role in improving the lives of primary caregivers and children living with HIV.

In addition to material support, the need for employment was also highlighted as an essential need of caregivers.

5.2.2. Theme 6: A need for employment

One of the issues that were raised by the participants (primary caregivers) was the need for employment. They mostly indicted that employment would enable them to meet the needs of ALHIV such as shelter, food, medical care and education.
Among those who contributed to this theme was **C-VS** who had the following to say:

> *"No those* [referring to food and money] *are the most important ones if I had money or was employed, I will be able to provide for him and get a house with bigger space and privacy."*

An interview conducted with **C-MM** also ended up with her mentioning the need for employment. This is how she expressed herself:

> *"For me I need a job to be able to buy food and we can take medication on a full stomach and now I rely on a grant which is not enough to cater for our needs."*

C-SF was concerned about her child's future after matric and indicated that she would be happy if she can get employment or at least become self-employed*:*

> *"I would like to work so I can be able to provide for her, you know after she completes her Grade 12 she has to go to university so as a parent you have to have money to pay for her fees, you can't say you will wait for NSFAS and also asking money from the family because the is no guarantee that they will support us till she gets NSFAS. I believe I am fit to work that's why I would like to open a day care centre. I should be able to provide for my children, yes that will be all I need money, and working will make a difference in my life and I can stop asking for money."*

The findings pertaining to the need for employment among the primary caregivers of ALHIV seem to be common in existing literature. Exavery, Charles, Kuhlik, Barankena, Mubyazi, Kikoyo and Jere (2020) found in their Tanzanian study focusing on food sufficiency and HIV infection among caregivers of OVCs, that primary caregivers are

unable to secure employment because of their involvement in caring for ALHIV, which results in lack of food in the family. Similarly, Maddocks and Chetty (2020) in a South African study focusing on the burden of caring for children living with HIV, found that most primary caregivers were unemployed and survived through social grants or pensions. Some were even surviving on an income of less than R2000 a month, which is less than the minimum salary recommended by the South African department of labour which is estimated at R3440 per month (Maddocks & Chetty, 2020). Another South African study by Lentoor (2017) on the psychosocial challenges associated with caregiving in the context of paediatric HIV in the rural Eastern Cape revealed that majority of the primary caregivers were unemployed which posed a challenge in their caregiving role since they fail to meet some of their basic needs. Based on literature and the responses from participants of the current study, lack of employment by primary caregivers of ALHIV seem to contribute to financial difficulties which consequently lead to failure by the primary caregivers to provide basic needs.

5.2.3. Theme 7: A need for psychosocial support

In addition to being supported to manage HIV and its related challenges, it emerged from all categories of participants in the study that caregivers are also in need of psychosocial support to effectively cope with the challenges associated with HIV and adolescents in general. This theme was further subdivided into three subthemes, namely *a need* for social support networks, counselling and peer support programmes as explained below.

5.2.3.1. Subtheme 7.1: A need for social support networks

Primary caregivers of ALHIV often rely heavily on social support networks such as family members and professionals such as social workers to effectively manage their caregiving responsibilities. According to the participants (ALHIV) their primary caregivers need support from family members and other professionals in order to provide the necessary care. Among the ALHIV who contributed to this subtheme were ALHIV-TM; ALHIV-AD; ALHIV-AK and ALHIV-JP.

ALHIV-TM said that her mother needs support from her father who is absent. This is how she narrated her story*:*

> *"She* [referring to her mother] *needs support from my father who left us long time ago, my dad because doesn't care at all. Yes, she won't be able to do it alone,*

because my father is not there, she gets frustrated sometimes and it is not only my mom's fault that I am HIV so he needs to be involved and stop acting like he doesn't care. You know I heard that my dad is working also but he won't help with anything and sometimes I feel like it is too much for my mom to carry all the burden. If my father can change and be supportive it can help."

ALHIV-AD also felt that primary caregivers need support from social workers. This is what she said to the researcher:

"Yes, she wouldn't be able to do it alone, but she also needs assistance from social workers in case I want counselling then I would go to the social workers and also, we get parcels from Friends for life sometimes which is very helpful."

ALHIV-AK expressed her concern about her mother who is stressed and requires the assistances of family and social service professionals. This is what she told the researcher:

"It is not easy to look after a child with this condition so I think they might need support to deal with stress from professionals such as social workers, nurses and psychologist, you know here they also help her to accompany me to the clinic when she is not available. You know it is stressful to look after a child with HIV so also family support will really help and she doesn't have that."

Lastly, the need for social support networks also emerged during the interview conducted with **ALHIV-JP** who said the following*:*

"My uncle needs support from my family, I mean my grandmother and dad because they don't care at all. Yes, he won't be able to do it alone, because my grandmother and father are not there and on the other side his wife is not supportive. You know my aunt is working also but she won't help with anything and sometimes I feel like it is too much for my uncle to carry all the burden. If my father can change and be supportive it can help."

What emerged from the participants' narratives pointed to the crucial need for social support networks for the benefit of the participants. A South African study conducted in the North West province by Molato, Moloko-Phiri, Koen and Matsipane (2024) focusing on the strategies adopted by the caregivers of AIDS orphans to cope with caregiving-related challenges revealed that the primary caregivers use social

networks such as support from significant others such as family members and life partner and other social networks such as social services. In another study conducted by Kasande et al. (2022), the findings of which corroborated those of the current study, it was recommended that primary caregivers caring for ALHIV should not be left to shoulder the burden of caring for ALHIV on their own, but should be supported by other family members and social networks within the communities in order to strengthen their coping strategy.

5.2.3.2. Subtheme 7.2: A need for counselling

In addition to social support networks required by the caregivers, the participants reported a need for counselling in order to cope with death and the loss of loved ones. They also needed counselling for themselves and their family members to deal with HIV-positive diagnoses of their ALHIV and its related challenges as well as for the latter to better understand their HIV positive statuses.

C-ES expressed a need for support from social workers to cope with loss and a better understanding of HIV since nurses in health facilities are not supportive. This is what she said to the researcher:

> *"Yes I think by assisting with family issues and also coping with loosing a child and on top of it you have to care for a child who is HIV positive and sometimes you don't know that she is HIV positive and sometimes you are scared that you will be infected with HIV and nurses do not have time to explain more about this disease."*

Another participant, **C-ID** felt there was a need for disclosure counselling from social workers. She explained her story in the following manner*:*

> *"My child is not aware that she is taking HIV medication, so I only told her that he is taking treatment for headaches, I am scared to tell him because he will blame me and don't know how to do it. Maybe social workers can give us counselling and help me to tell him because you know now he is growing and maybe he is already having a girlfriend, and he will infect her with HIV."*

C-MJ shared similar sentiments on the importance of disclosure counselling. This is what she said:

> *"By giving counselling and helping us support our children, because there are things that I don't understand about child, he is sort of slow and sometimes I don't*

understand him and why is he so slow and to understand what is wrong with him so that I can support him better and for our family to receive counselling on how to assist such a child."

For **C-MJ**, it is essential that social workers provide counselling because they deal with challenging issues associated with HIV. She explained by saying the following:

"I think social workers can assist us by giving us counselling, you know as a family sometimes it is difficult to deal with this disease and always worried about her that she will get pregnant and bring a child who is also HIV in this world, so giving us counselling and educating us about how to look after ourselves will help us."

An interview conducted with **C-VS** also involved the need for counselling. She specifically expressed the need for counselling to educate her son about the importance of adhering to treatment:

"I think they can help by counselling, and encouraging me and my son, they should be educating him on how to take his treatment properly and to adhere to clinic visits, if he can understand that his life depends on taking his medication because when I talk to him he feels like I am abusing him, please help me and talk to him so that he can take his medication, that will help. Please help me and talk to him."

C-MO also pointed to the importance of counselling and added that adherence counselling should include topics such as teenage pregnancy. This is what she said:

"Yes, they can assist with counselling particularly when these children are not taking their treatment well. so, I think these children also need to be educated on different topics such as teenage pregnancy, how to look after themselves."

ALHIV also made contributions to the subtheme of counselling, with participants such as **ALHIV-AK** mentioning that communicating effectively with their primary caregivers would be helpful. Her contribution was captured as follows:

"There are a lot of things that I would like to ask her but I cannot, because I am scared to see her reaction. I think social workers can help us talk and clear both our chests, that is the thing that I can say is the problem. Yes, my mother is a private person, I think having family counselling between me and my mother will assist. Having one-on-one with a social worker would help."

In another interview, **ALHIV-AM** had this to say:

"Counselling will help, I think social workers can also help us the is a lot I want to ask my aunt but I am scared because she might get angry. my aunt is a private person, and she is always screaming but I understand that she is frustrated, I think a social worker will assist to open up. I want to ask my aunt especially about my mom and my dad whereabouts, ya I want to know more about my mom I miss her so much and my dad I would want to know what happened that made him not to be part of our lives and his whereabouts."

ALHIV-JP also felt that counselling can improve communication between her and her uncle and added that psychosocial support from social workers can assist in dealing with community stigma and getting to understand HIV better. She explained herself in the following manner:

"I think he needs support from social workers, it is difficult for my uncle because I am girl and sometimes it is hard to discuss certain things with him you know women stuff and also, I am teenager I can't discuss relationship issues with him, on the other side this disease that is stressful and sometimes community members talk about us. Eish, when I went to clinic I saw one of our neighbours so I think they gossip about my illness and I think my uncle is not happy about it and sometimes it upset me but I told myself that it is ok I didn't plan to be HIV and I told the social worker from Friends for life about it and she has been supporting and now I don't care about it, it is their business."

ALHIV-AD added that psychosocial support and education about HIV will assist primary caregivers and ALHIV to live with HIV successfully and improve adherence to HIV treatment and dealing with loss. Her utterances were captured as follows:

"I think counselling, I had difficulty dealing with the death of my mother and on top of it with this disease, so my aunt got me social workers to assist me with that."

ALHIV-NM highlighted the importance of social workers in supporting caregivers and ALHIV through adherence counselling. Her remarks were recorded as follows:

"Well, the social workers will help by assisting parents of children with HIV and children to understand they have HIV and to take medication, like they assisted me and to accept my condition and they also helped with moving me from my

father to my sister because there were lots of fights since my step mother was not accepting me and saying that I will infect her children with my HIV, so she was fighting with my father."

Among the social work participants who contributed to the subtheme of counselling for caregivers was **SW-RZ**, who felt that adherence counselling is important to ensure that ALHIV adhere to HIV treatment. She said that support should be given to primary caregivers to cope better with caring for an ALHIV. her remarks were as follows:

"*I think programs on adherence and ensuring that the ALHIV have and are supported to continue taking treatment because they tend to stop taking treatment when they get old because they don't want to be seen by their peers taking medication and some are just tired of taking the treatment from childhood until now so they need support and encouragement. Maybe any form of support needed by primary caregivers, it is difficult to look after an adolescent whether HIV or not they can be difficult, also primary caregivers can be supported on how to cope with raising an adolescent who possible have their own minds and how to deal with stress."*

SW-RZ added as follows:

"Programmes such as Vhutshilo 3 and Kidz Alive. Vhutshilo 3 and Kidz Alive are support groups we provide to children and adolescent living with HIV. So, kidz Alive also assist primary caregivers to disclose to their children/adolescent, and the vhutsilo 3[3] is more focused on empowering adolescents to live better with HIV."

SW-PF said the following regarding adherence counselling*:*

"OK, services such as adherence counselling, providing guidance or even when the is new information about HIV we inform them, you understand. We also help adolescent living with HIV to feel accepted, help with homework support if they have difficulties at schools and we also help with process of disclosure since we are working with clinicians from the clinic and also the clinic refer if they identify psychosocial issues at home. We also assist with disclosure particularly if the ALHIV is not taking their treatment well or no longer coming to the clinic."

[3] By Vhutsilo 3, SW-RZ refers to a structured peer group programme that was tailor made for ALHIV between the ages of 14 to 18 years.

SW-JM had a similar suggestion about adherence counselling and added that social workers should also share current information about HIV and treatment. This is how she explained it:

"Services such as adherence counselling, providing guidance or even when the is new information about HIV we inform them, like now we have a new HIV drug that they need to give their children, so all children need to be switched to the new drug called dolutegravir. Counselling, adolescents social support as a whole because it involves almost everything."

For **SW-ZM** primary caregivers should be provided with psychosocial support any time of the day since it is difficult to care for ALHIV. She highlighted her views as follows:

"For now, I think I've basically touched on things that social workers can do to support the caregivers, but most importantly is being there for the caregivers. When I'm thinking about being there, like also having that relationship with a caregiver in such a way that the caregiver may call or WhatsApp you anytime when they feel like they need your assistant at that particular moment. So I think social worker being open to the caregivers and allowing them to have that person they can rely on because as I've said before, HIV still has stigma, so they may not have someone to talk to within the family, but if they know that they do have someone, if I may say so that they may keep in touch any time. I think that can assist, but it's all what I've mentioned like supporting them psychosocially also physically, they also need to be fit to take care of the adolescent and also be healthy."

SW-MP added that introducing a programme called memory box can assist primary caregivers to deal with grief and loss. Below is her utterances:

"The was a program long time ago called memory box, which was for debriefing and were a person was given a chance to cry but it was only implemented with children who lost their parents not with the primary caregiver who lost their children. The primary caregiver is expected to just continue and also to take care of the child without talking to anyone about their loss. So, I feel that those program where primary caregivers can be able to express their grief and loss will be beneficial to them."

SW-AM referred to the benefits of a social work programme called 'family matters for primary caregivers'. This is how she verbalised it*:*

> *"OK, we provide services such as adherence counselling, we also have programmes such as family matters, it's a programme where primary caregivers can come together and have dialogue, where they can communicate about issues, not only related to HIV, but also substance abuse, where they can also talk about gender-based violence and more."*

Lastly **SW-VM** emphasised the need for general support to deal with stress associated with family dynamics and to assist with disclosure of HIV-positive status. Here remarks were as follows*:*

> *"The conferencing or counselling is also helpful to the guardians to be able to deal with stress of raising an HIV positive child who is always sick, you know release the stress they have, or the challenges that they have, and also be able to guide them to resolve the problems that they have, whether it's the children not going to school or any challenges and psychosocial problems, including extend family issues such as fights you are able to help the guardians. I also think we forget disclosure counselling which is important to deal with a child who lost their parents and now a granny might find it difficult to assist with telling the child they have HIV."*

The suggestions by social work participants to provide psychosocial support to primary caregivers in this study fall within the central roles and responsibilities of social workers working with people affected and infected with HIV as highlighted by HIV testing services guidelines for social service practitioners by the National Department of Social Development (South African Government, 2019). The HTS guidelines for social service practitioners describe the roles and responsibilities for social workers which are, among others, to provide individual and group-based interventions (such as disclosure counselling, adherence counselling, HIV education) and linkage to HIV treatment and care. Shaari, Zakaria, Rajaratnam, Ijon, RRazak, Halim and Waller (2024) also emphasise that social workers should provide services such as counselling, treatment adherence guidance, and addressing coinciding health issues to PLHIV and their families. Therefore, the findings of this study corroborates what was found in a South African research study conducted by Gutura and Khosa (2024) focusing on the roles of social workers and community volunteers in the provision of

services to foster care children living with HIV, which emphasised the importance of social work interventions in supporting disclosure of HIV-positive status to help primary caregivers deal with the emotional turmoil presented by ALHIV.

Maddocks and Chetty (2020) in a South African study focusing on the burden of caring for children living with HIV, concluded that family-centered counselling focusing on both the ALHIV and their primary caregivers is important to improve the wellbeing of the entire family. Correspondingly, Molato et al. (2024) in a South African study of coping mechanisms used by caregivers of orphans living with HIV to highlight that one of the responsibilities of social workers is to conduct thorough assessments in order to offer counselling to primary caregivers of ALHIV. An European study conducted by Bilić Skokandić and Puljak (2022) with the aim of gaining insight on the grief experiences of caregivers who are providing at-home palliative care for their ill spouses, concluded that primary caregivers who are experiencing grief and loss of a loved one will benefit from professional counselling which will enable them to process their grief and manage the emotional challenges of caregiving. This correlates with the findings of the current study in which primary caregivers themselves have emphasised that they need counselling to cope with grief and loss of loved ones. Gill, Ndimbii, Otieno-Masaba, Ouma, Jabuto and Ochanda (2022) conducted a study in Kenya to investigate the challenges and opportunities for optimising care through enhanced adherence counseling for adolescents with suspected HIV treatment failure.

Based on the literature discussed above and the responses from participants in this study, social workers are essential in providing family counselling, including HIV education, adherence counselling to both primary caregivers and ALHIV to encourage ALHIV to never stop taking treatment. They are also instrumental in guiding the integration of drug-taking into daily schedules and therefore contributing to improving both the ALHIV's health and the mental health of the primary caregivers.

Lekganyane and Alpaslan (2019) conducted a study in South Africa, to investigate the suggestions of caregivers caring for PLHIV on how best social workers can support them to manage their challenges. Among their findings was a need for psychosocial support from social workers in the form of counselling and trauma debriefing. Considering the findings of the current study in relation to the psychosocial support for ALHIV and their primary caregivers from a policy perspective, the South African DOH

(2018) recommended that psychosocial support should include emotional support (with disclosure, adherence counselling and HIV treatment literacy; including stigma and discrimination), physical, mental, and spiritual experiences. It should also involve means for addressing the needs of ALHIV and their families as a way of minimising the negative impact of HIV. Casale, Boyes, Pantelic, Toska and Cluver (2019) underscore a need for psychosocial support in improving the psychosocial health of ALHIV and their caregivers and reducing stress. They state that support may include emotional, informational and instrumental assistance (Casale et al., 2019). In a literature review study focusing on caregiving in Sub-Saharan Africa with specific attention on older female caregivers in Nambia, Kalomo, and Besthorn (2018), concluded that there are gaps in current intervention strategies provided to primary caregivers of ALHIV and suggested an urgent need for social work professionals, researchers and relevant stakeholders to develop interventions that will support primary caregivers, reduce their stressful roles and improve their wellbeing. Likewise, Okonji, Mukumbang, Orth, Vickerman-Delport and Van Wyk (2020) pointed to a dearth of psychosocial support interventions to cater for the needs of ALHIV and their primary caregivers and recommended that research should be conducted to develop programmes that address psychosocial support interventions. Based on this part of the findings and literature, the strength-based perspective holds that individuals have innate capabilities and strengths to deal with the challenges in their lives. Social workers thus need to develop respectful and collaborative relationships with primary caregivers and ALHIV to develop appropriate interventions that address their challenges (Pulla, 2017; Kral et al., 2018).

5.2.3.3. Subtheme 7.3: A need for peer support programs

Peer support programmes connect primary caregivers with others who are also caring for ALHIV and have similar challenges. It offers them the opportunity to share experiences and strategies that can assist in reducing feelings of isolation and stress and provide a sense of community and understanding of HIV. This subtheme emerged from the information provided by the participants expressed when answering a question pertaining to the needs of the primary caregivers. Among the participants who contributed to this subtheme were caregivers and social workers.

Among the caregivers, **C-MJ** said the following*:*

"Oh, I remember another support will be for social workers to assist with handling an adolescent it is difficult to care for them."

C-ES also expressed a need for peer support from other parents which will assist her in finding solutions and providing a better care. She reported it as follows*:*

"I think they can help by linking us to parents who have children who are living with HIV, you know sometimes it can be lonely to face these challenges alone. Yes, sometimes it is stressful because you don't know how to deal with them more especially when they grow and start asking questions or start dating."

C-MO was also of the view that support groups can support caregivers to protect their children from acquiring the virus. Her views were as follows:

"I think a support group will also be beneficial to us, you know I joined the support group when I had my first child and it really helped me to protect my other children from getting this virus. I think education will help to prevent problems."

As for social workers, all of them contributed to this subtheme.

SW-JM believed that peer support groups would be beneficial since they share similar challenges. This is what she said in her explanation:

"I think, I'll go back to the group, I feel like a group for primary caregivers can be better because they are facing similar problems. Only a few caregivers disclose to their children, most of them don't disclose. It will be all about them supporting each other with the different challenges they face while raising these children. Some might be going through the same challenge and are able to look for a solution or advice each other on how to deal with it."

SW-RZ was of the view that HIV education will assist primary caregivers and ALHIV to understand the HIV better and live with it successfully:

"Some of them I mentioned earlier and support groups is what they need in order to get knowledge on how to leave with this disease. So, in providing support it is important to work with the family not only the primary caregiver, so that they can give support to the primary caregiver and the ALHIV and to educate them about HIV, because they see it as a monster that comes to destroy."

SW-ZM shared similar sentiments and added that the information should include adherence and disclosure counselling:

"OK, firstly I think most of the fears or the challenges, it's because of a lack of information. I think they need to be educated on disclosure processes, adherence and they need support need support to take care of themselves, if we can have support groups for caregivers in caring for adolescent living with HIV, where they will share their experiences, share their coping strategies. I think it might assist them in coping or in dealing with challenges they experience in caring for adolescent living with HIV. I also think that if they can be supported, even if it's not a support group where they discuss about HIV, if they can have those activities where they sit together, get their minds off."

SW-VM suggested that intervention methods to support primary caregivers such as individual counselling, group interventions and case conferencing should form part of the support mechanisms available to primary caregivers. This is how she shared her perspective:

"Support groups, they can attend support groups. They can have individual sessions in terms of dealing with the family issues, have case conferencing with primary caregivers to discuss the child's progress and challenges. Support groups because with the support groups, they're able to share and help each other, you know, when you're sitting at home alone, you think it's you with all the problems and you think a lot, but only to find that there's people with more problems than you, so when they attend the support groups they learn that others are able to help, advice and support each other."

SW-PF shared the same sentiments in terms of support groups:

"I think support groups specifically for primary caregivers where they will come together with other primary caregivers who are in a similar situation, so that they can see that it is not only them who are facing this challenge, so that they can also be able share among themselves about challenges they face in raising children/adolescents living with HIV and learn from each other about the coping strategies."

SW-MJ said the following:

"I think, I'll go back to the group, I feel like a group for primary caregivers can be better because they are facing similar problems. Only a few caregivers disclose to their children, most of them don't disclose. It will be all about them supporting each other with the different challenges they face while raising these children. Some might be going through the same challenge and are able to look for a solution or advice each other on how to deal with it."

SW-MP indicated that social workers do not have enough support programmes for primary caregivers of ALHIV and this is a concern. She shared her views in the following manner:

"Since we don't have enough programmes for them, I feel we need programs which are more focused on their challenges. Before we go to program for children, social development use to have a program for primary caregivers who are within the caseload of foster care cases, but the program can miss those that are not on the foster care database. So, I feel that we need to have programs that will accommodate all primary caregivers, and they speak about how they feel and the challenges that they're going through in looking after children who are living with HIV". In the support group I think we can also talk about grief, finances, HIV knowledge and they can share any other challenges they think are relevant in the session."

SW-AM had similar views about programmes that cater for primary caregivers of ALHIV. Her story was captured as follows:

"For me there are no programmes directly related to primary caregivers living with ALHIV but it will be good to have those, maybe programs that can support primary caregivers such as support groups."

Peer support programmes for primary caregivers caring for ALHIV can enable them to manage the unique challenges they face in their caring roles and therefore reduce feelings of isolation and stress. The participants' accounts indicate that caregivers would benefit from peer support programmes, particularly for primary caregivers. This part of the findings is supported by a study conducted by Berg, Page and Øgård-Repål (2021) aimed at reviewing the effectiveness of a peer support programme for PLHIV. In this study, it was found that peer-support programmes are effective in improving

ART adherence and viral suppression. It was also found that peer support improves the quality of life and enhances the social support of primary caregivers and their ALHIV. Correspondingly, Toromo, Apondi, Nyandiko, Omollo, Bakari, Aluoch, Kantor, Fortenberry, Wools-Kaloustian and Vreeman, (2022) concluded in a Kenyan study of the challenges around HIV status disclosure of adolescents, that peer programmes can improve communication among primary caregivers and ALHIV, consequently helping them to address issues related to disclosure of the HIV-positive statuses and stigma.

In addition, the findings of this study in terms of the perceptions of social workers, support those from a study conducted by Mannsåker, Vågan, Geirdal and Stenberg (2023) on the health literacy contributions of hospital social workers to parents of acutely and critically ill children. Mutluri (2021) added that group work improves the social functioning of individuals and families. According to Bateganya, Amanyeiwe and Dong (2015), the WHO and the President's Emergency Plan for AIDS Relief (PEPFAR), promoting peer support groups is one of the effective interventions to address the special needs of PLHIV which includes ALHIV and their primary caregivers. Peer support groups enable group members to share experiences and encourage disclosure of HIV-positive status, thereby reducing stigma and discrimination, which eventually leads to improved self-esteem and enhances the coping skills and psychosocial functioning of primary caregivers and ALHIV. skills. This results in improved HIV treatment adherence and retention in HIV care for ALHIV (Mark, Lovich, Walker, Burdock, Ronan, Ameyan & Hatane, 2019; South African Government, 2019; Bateyanya et.al., 2015). Based on the literature and responses from the participants of the current study, it is evident that social workers can play a vital role in facilitating peer group sessions and HIV education by tapping into their capabilities and strengths during group sessions. Social workers can use a strength-based approach to tap into the innate capabilities of primary caregivers since this approach is based on the belief that every person has potential, and it is people's unique strengths and capabilities, not their limitations, that determine their abilities to deal with challenges. In addition, illnesses and struggles may be injurious, but they are sometimes sources of challenge and opportunity (Caiels et al., 2021; Samet, Blokhina, Cheng, Walley, Lioznov, Gnatienko, Quinn, Bridden, Chaisson, Toussova & Gifford, 2019; Kral et. al., 2018).

5.2.4. Theme 8: The current and suggested social work support services for caregivers of ALHIV

One of the questions posed to the participants required them to share their views on current social work support services. The question also required them to share their suggestions on social work support services which they deem essential for supporting the caregivers as they navigate the challenges associated with caring for ALHIV. Their answers to this question resulted in a theme, 'the current and suggested social work support services for caregivers of ALHIV'. This theme was further categorised into subthemes, namely assistance with disclosure of a HIV-positive status, assistance with adherence to treatment, linking caregivers with resources for support and education on HIV management.

5.2.3.1. Subtheme 8.1: Assistance with disclosure of an HIV-positive status

For caregiver category of the participants of this study, supporting them meant assisting them with disclosure of an HIV-positive status. Two caregivers indicated that they had reached out to social workers for assistance with disclosure of HIV positive status.

C-MJ was among those who indicated the significance of assisting caregivers with disclosure. This is what she said:

> *"Yes, they can help with disclosure of HIV positive status to our partners and children for me this happened while she was still small and in hospital where they provided us with counselling and assisted me to tell my partner that I am HIV positive and that he needs to test and later they also helped with my child and now she knows that she is HIV positive."*

For **C-TB**, social workers play a crucial role in supporting the disclosure process of their ALHIV to prevent them from hearing it on the streets. She shared these perspectives in the following manner:

> *"Social workers can help by assisting us with telling our children about how they got HIV, you know they get angry at us if they get the information on the street that they are taking HIV pills."*

Disclosure of an HIV-positive status to a child is a sensitive and complex matter for primary caregivers, triggered by fear of negative consequences such as stigma, the

child's inability to comprehend and deal with the diagnosis, and unintended disclosure to others. According to the South African National DOH (2016), adolescent disclosure is a gradual process through which an adolescent gets to know their HIV-positive status or the status of their caregiver by giving them their age-appropriate information in relation to their illness, leading to full disclosure depending on their cognitive and emotional maturity. Primary caregivers should therefore be supported emotionally and psychologically to make such a disclosure, and social workers play a vital role in that regard (Wariri, Ajani, Raymond, Iliya, Lukman, Okpo & Isaac, 2020; Glaser, 2018; Madiba, 2016). According to Glaser (2018), primary caregivers often prefer social workers or community caregivers to be actively involved during the disclosure process, because they play a vital role in assisting them with decision making on whether or not to disclose an HIV positive status. In the current study, some of the primary caregivers indicated that they accessed services from social workers for assistance with disclosure. This points to the crucial role of social workers in supporting with disclosure.

5.2.3.2. Subtheme 8.2: Support with adherence to HIV treatment and appointment reminders for clinic visits

Treatment adherence support for primary caregivers caring for ALHIV is critical in ensuring effective HIV treatment and the overall wellbeing of both the ALHIV and their caregivers. It was therefore not surprising that participants pointed to the significance of social work support with adherence to HIV treatment and reminders for clinic visits. **C-SF** indicated the supportive role of social worker with adherence to treatment and appointments for clinic visits. This is what she told the researcher:

> *"You know the social workers from Mayibuye [*one of the NPOs] *the one that contacted me to meet you, yeah my mother was using them to assist us. Yes they can continue assisting us by ensuring that we visit the clinic, they come visit us and also remind us on how to take treatment and how the importance of taking these pills on time."*

In another interview, **C-SF** said she reached out to social workers who eventually recruited her into a support group. She explained this by saying the following:

> *"I was referred by the clinic and I also received a call from lady from Mayibuye (gave a name and she is a social auxiliary worker) and I was asked to join a*

group, actually my daughter had to attend certain sessions on Saturdays and get her treatment at the clinic as a student she had to come on Saturdays. Ya that is how we started with Friends for Life.[4]"

C-TB said social workers visit her granddaughter to give adherence counselling. She explained this as follows:

"Yeah assistance I get from them so, most of the time they come visit at home to discuss how my granddaughter is doing and the importance of taking treatment and going to the clinic. Like I said they also mentioned that they will assist with accompanying my granddaughter to the clinic if I am not available and she also said they will provide counselling during school holidays."

In another interview conducted with **C-ID**, this is what she told the researcher about the supportive role of social workers with treatment adherence:

"Yes, social workers can also assist in helping my son to take his pills every day and he can also understand that he will remain healthy if he takes his treatment, education on HIV is important."

C-MJ expressed the supportive role of a social worker when she was frustrated by her daughter who stopped taking medication. She explained this situation in the following manner:

"My daughter once stopped taking her treatment and only to find out that she hides them in under an old car we have at home, only to find out when the car had to be moved to the scrapyard. When I ask her she says she is tired of taking these pills, so telling us the importance of taking them will help lot of parents and teenagers."

On the supportive role of social workers on treatment adherence, **C-TB** had the following to say:

"Yes, I would suggest, they should be educating us on treatment and the importance of taking it always."

For **C-MJ**, social workers can play a big role by educating them on taking treatment correctly. This is how she shared her views:

[4] By Friends for Life, C-DF refers to a Non-profit Organisation rendering services to OVCA&Y including PLHIV

"Yes, education on taking treatment the correct way will help, you know sometimes living with HIV and taking pills everyday can be exhausting and you know how teenagers are, sometimes they don't look after themselves well nor care about the consequences of their actions so they will just stop and don't even tell you."

Treatment adherence for people living with HIV is crucial in ensuring that they live healthy lives while receiving necessary support. It was therefore not surprising that the participants pointed to the significant role of social workers in supporting treatment adherence and reminding them about the clinic appointments. The South African National DOH (2016) on the adherence guidelines on HIV, TB and non-communicable diseases, recommend adherence counselling and treatment literacy as a way to improve adherence to HIV medication. In Tanzania, a study on caregiver roles in adherence of HIV medication among HIV-infected orphans by Gichane, Sullivan, Shayo, Mmbaga, O'Donnell, Cunningham and Dow (2018), found that primary caregivers play a significant role in improving treatment adherence in ALHIV, which suggests that primary caregivers also need to be supported. In this regard, Ferrand, Simms, Dauya, Bandason, Mchugh, Mujuru, Chonzi, Busza, Kranzer, Munyati and Weiss (2017) argue that support from social workers will assist primary caregivers in ensuring that their ALHIV adhere better to HIV treatment. Contrary to the findings of the current study, caregivers who took part in a Ghanaian study conducted by Atanuriba, Apiribu, Laari, Bonsu, Dzomeku, Afaya, Salifu and Amooba (2023) focusing on the perceptions of caregivers of children living with HIV/AIDS on their sources of support reported that social service organisations provide little or no support to them.

5.2.3.3. Subtheme 8.3: Linking caregivers with resources for support

Another subtheme that emerged from the ALHIV in relation to the supportive role of social workers is that they should assist primary caregivers by connecting them to community resources such as income opportunities, grants, clothing including school uniforms and food parcels. This subtheme emerged from the interviews conducted with six ALHIV.

ALHIV-AK said that social workers could assist in connecting them to income-generating opportunities so that the primary caregivers can provide basic needs such as food. She explained herself by saying the following:

"Maybe job opportunities, because I see that it is what we are struggling with, she works hard to make sure that her kids eat before going to sleep as I said, if she finds a job or she does something, then maybe she can be happy."

ALHIV-AD shared the same view in terms of linking caregivers with resources such as job opportunities and said the following:

"I think it can be school or work opportunities, for example I have passed matric, like if one of us is looking for a job and does not have a laptop they can send her somewhere where internet access is granted or assist with applying for jobs or getting jobs."

ALHIV-AM said the following regarding social workers' assistance to caregivers through linking with resources:

"Maybe sort of job opportunities, because I see that it is what we are struggling with, she tries so hard, but you can see that it is difficult if you don't have a permanent job, then maybe she can be happy."

Another participant who pointed to linking the caregivers with resources was **ALHIV-TN**, who said the following*:*

"They can help with donations for food and clothing, those are the things I can think of. So, they shouldn't give us money, rather buy us food and clothes because when they give us money it will be abused."

ALHIV-NM was very brief in her response by making reference to the role of social workers in assisting them with resources such as access to social grants:

"Maybe assist with food and money like grants for them to look after us."

It is clear that social workers play a critical role in connecting primary caregivers of ALHIV to essential resources, including economic resources to enable them to meet their basic needs. This part of the current findings supports the findings from Sesane and Geyer (2017) whose study on the views held by community members on the role of social workers in enhancing social capital in metropolitan areas, recommended the need for social workers to connect the community with financial resources in order to manage the impact of HIV and AIDS. A strength-based perspective ties in with role of social workers in connecting primary caregivers with resources that are available in their communities. This perspective is based on the believe that individuals have

inborn potential and strengths to overcome the challenges. Therefore, individuals are encouraged to establish, leverage and build upon their strengths and capabilities in facing obstacles in collaboration with social workers whereby primary caregivers' needs will be assessed, strengths identified and intervention strategies developed, including identifying and linking primary caregivers with relevant resources (Caiels et al., 2021; Kral, Lambdin, Comfort, Powers, Cheng, Lopez, Murdoch, Neilands, & Lorvick, 2018; Pulla, 2017).

5.2.3.4. Subtheme 8.4: Education on HIV management

What also emerged from the participant interviews was that primary caregivers need to understand how HIV affects the bodies of ALHIV under their care and the importance of antiretroviral therapy. This means providing the necessary knowledge on how ART works to suppress the virus and improve the immune system. From the participants' perspectives, social workers can offer education on HIV and highlight the importance of taking HIV treatment regularly.

C-SF had this to say regarding education on HIV management:

> *"We need education about HIV, I think such information is needed because some parents don't have information and some of them don't even attend the clinic to understand HIV, so they remain at home without information, since I started visiting Friends for life and clinic, I got more information. I now understand everything but the are some parents the group could help."*

ALHIV-JP told the researcher the following regarding education on HIV management:

> *Yes I guess maybe education about HIV, about our medication and how important it is to take HIV medication, or a place where parents can meet and talk about how to look after us better.*

Another participant who contributed to this subtheme was **ALHIV-VP** who added by saying the following:

> *"Maybe our parents can have groups like I normally go to groups at the clinic and be educated about HIV, how to take medication and how to get grants."*

ALHIV-TM felt that her caregivers should understand that she also have needs such as dating and therefore education would in this regard be essential. She narrated this in the following manner:

"I guess maybe education about HIV, she needs to understand that having HIV doesn't mean I can't date, or a place where parents can meet and talk about how to look after us better."

ALHIV-NM felt that social workers should educate caregivers on the best ways for dealing with ALHIV. She verbalised it as follows:

"I think they could educate them further on how to deal with a child who is HIV positive. Well, I mean how to understand us better and see that we are just as normal as any other child even though sometimes it is hard to take medication everyday. Also, education about the virus."

From the participants' accounts, it is evident that they advocate for treatment literacy from social workers as a way to provide support to primary caregivers of ALHIV to ensure that they remain healthy. This part of the findings also emerged from a Zimbabwean study conducted by Bernays, Lariat, Cowan, Senzanje, Willis and Nenguke (2023), where three groups of participants namely ALHIV, primary caregivers and health care workers were measured on their knowledge of treatment to support adherence to HIV treatment for ALHIV. One of the findings from the caregiver cohort was that they had limited knowledge in terms of treatment and therefore treatment literacy was important to ensure adherence to medication and viral suppression. In line with the current study, the SANAC identified severe gaps in HIV literacy, with poor understanding of HIV treatment benefits and viral load testing. Lack of HIV knowledge was found to have negative impacts on progress towards achieving a 95-95-95 strategy[5] for fighting HIV. Consequently, an HIV literacy implementation framework was developed with the aim of scaling up HIV treatment education and incorporating health literacy to achieve the goals of the National Strategic Plan 2023–2028 (SANAC, 2023).

[5] 95-95-95 strategy focusing on ensuring that 95% of people living with HIV know their HIV status, 95% of those diagnosed to be HIV positive receive HIV treatment, and 95% of those on HIV treatment achieve viral suppression.

5.3. SUMMARY OF THE CHAPTER

This chapter presented the second part of the research findings. Whereas the previous chapter focused on the findings based on the first four themes involving the experiences and challenges associated with caring for an ALHIV, this current chapter focused on the remaining four themes involving the caregivers' needs and suggested solutions on how social workers can support primary caregivers in their caring roles, which is key to the development of guidelines. As demonstrated in this chapter, caregiver need essential material support in a form of food and clothing for their ALHIV. They need shelter and financial resources so that they can address the basic needs of their households and those of ALHIV. The need for employment also came out to be at the centre since it is employment that determine financial resources which eventually determine whether the caregiver can afford adequate shelter, food, and clothing. As emerged from the study, psychosocial services in a form of social support networks, counselling, peer support programmes and Education on HIV management. Among the social work support that participants thought caregivers should receive was assistance with disclosure of an HIV-positive diagnosis, adherence to HIV treatment and reminders with appointments.

CHAPTER SIX
SUMMARIES, CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS

6.1. INTRODUCTION

This chapter provides summaries, conclusions, recommendations, and limitations of the study. The approach followed in presenting the summaries is to begin by summarising the research process and the research methods respectively, with each aspect summed up by a conclusion particularly regarding the relevance and usefulness thereof in this study. The research process and the methods will then be followed by summaries and conclusions based on the research findings, with attention being placed on the main themes that emerged from data analysis and the meanings thereof. The recommendations will then be developed based on each of the conclusions regarding the research process and the methods as well as the main study findings. The section on limitations of the study will precede a chapter summary which outlines the key aspects covered presented in this chapter.

6.2. SUMMARIES AND CONCLUSIONS OF THE RESEARCH PROCESS

Part of the research process included planning for this study, which involved consulting literature to set a foundation for the study plan. The research foundation included setting up the general introduction and orientation to the study, as presented in Chapter One. Chapter One laid a foundation for the study and the research topic by providing background information and therefore setting the scene for this study (Thomas, 2017). A background to the phenomenon of ALHIV was presented from a global, African and South African contextual perspective, which indicated that HIV prevalence among adolescent is alarming and that new HIV infections among adolescent is increasing at a fast rate and therefore make HIV infections a growing concern among this cohort (UNICEF, 2023; UNAIDS, 2021). Likewise, the various challenges experienced by ALHIV such as frequent illness, difficulties in disclosing their HIV diagnosis, non-adherence to HIV treatment, battling with stigma and discrimination, were discussed (Zungu et al., 2021; Mapesi, 2020; Kimera et al., 2019). The primary caregivers' responsibilities and challenges such as lack of finances, stigma by association, stress and anxiety that they face when caring for ALHIV were

also presented (Nsibandze, Downing, Poggenpoel & Myburgh, 2020; Mafune, Lebese & Nemathage, 2017; Casale et. al., 2014).

Even though several studies were found to have considered the challenges and needs of primary caregivers of ALHIV in their caring role, a noticeable gap existed in the social work body of knowledge and social work practice particularly regarding the challenges of caregivers caring for ALHIV and availability of support through social work practice. From these noticeable gaps as developed from the introduction and preliminary review of literature particularly in South Africa, the problem statement and the rationale of the study were formulated with the aim of bridging knowledge gap in the social work field. Following the problem statement and rationale for this study, the research goal from which four research questions and objectives were set to focus this research endeavour and structure the process of responding to the research questions, was developed. Although the questions have been addressed in detail in Chapter One (Section 1.3), it is essential to revisit them in this section to determine whether or not they were relevant for the purpose of this study.

The first question sought to understand the experiences, challenges and needs of primary caregivers in relation to caring for ALHIV, from the perspectives of social workers, caregivers and ALHIV. Through this question, the researcher was able to learn that some primary caregivers experience some difficulties when caring for ALHIV, others were found to be doing well without issues. Some of the caregivers indicated that they experience financial burden, stigma associated with caring for ALHIV and lack of proper nutritional and other means to address material needs for ALHIV. ALHIV responded to this question by indicating that the primary caregivers experience financial burden and psychological stress among others. From social workers, it emerged that primary caregivers experience disclosure-related challenges, lack the necessary support and education to manage HIV-related challenges. It also emerged from the social workers that some of these caregivers' experience parenting challenges as well as stigma and discrimination associated with caring for ALHIV. Financially, the caregivers were also burdened and unable to address some of the needs of the ALHIV in their care.

All three categories of participants gave their opinions on what they consider to be the needs of primary caregivers in their caring role. In this regard the three groups had

common responses such as financial support and employment. Moreover, the primary caregivers pointed to their need for food, shelter, and clothing, while ALHIV indicated that primary caregivers need social support networks. For social workers, emotional and psychosocial support were some of the crucial needs of the caregivers.

In view of these lessons, the question was therefore relevant and specific in terms of enabling the researcher to understand the experiences, challenges and needs that the primary caregivers had in caring for ALHIV. Furthermore, it enabled primary caregivers to relate their experiences, challenges and needs in this regard. Based on the answers to this question, the researcher concluded that this question was relevant in relating and understanding the experiences, challenges and needs of the primary caregivers in caring for ALHIV. It also assisted in developing social work intervention guidelines aimed at addressing the challenges faced by the primary caregivers in their caring role.

The second question was aimed at understanding the experiences of ALHIV in relation to being cared for by a primary caregiver.

As revealed by the findings presented in Chapter Four, there were mixed experiences in regard to this question. Some ALHIV reported positive and supportive relationships with their primary caregivers, whilst others reported experiencing lack of support from primary caregivers of whom some were overprotective. A conclusion reached regarding this question is that it was relevant since it enabled the collection of data which assisted the researcher in understanding the experiences of ALHIV with regard to being cared for by the primary caregivers and to provide the necessary data based on the ALHIV which assisted in developing social work intervention guidelines that will best assist ALHIV and their primary caregivers in improving their wellbeing and for social workers to provide the necessary assistance for them.

The third question required the caregivers and ALHIV to share their views on the current and suggested social work support services for assisting the caregivers to manage their difficulties.

From the analysed data, it emerged from the primary caregivers that they reach out to social workers for assistance with disclosure of an HIV-positive status. ALHIV felt that social workers should play a crucial role of linking the caregivers with relevant resources. What was common from both categories of the participants were suggestions for social workers to educate the caregivers on how to raise an ALHIV

such as understanding the needs of an ALHIV and ensuring compliance with their treatment.

Finally, *the fourth question sought to establish the best ways for developing the guidelines for supporting caregivers, ALHIV and social workers based on the findings.* To answer this question, the study findings were further analysed and used to develop the guidelines. Chapter seven of this report presents the full guidelines developed from this study.

6.2.2. Summary and conclusions literature review and theoretical framework

The literature reviewed was of utmost importance since it afforded the researcher with a comprehensive overview of previous and current state of research in relation to the phenomenon under investigation with attention on the global, African and South Africa contexts. The impact of HIV from a socioeconomic and psychosocial perspective was also outlined, with specific attention on ALHIV and their primary caregivers. Literature was also reviewed on available HIV and social work interventions and strategies starting globally and zooming into the South African context. Through the reviewed literature, the researcher was able to identify gaps and functional elements in different interventions and strategies which assisted in developing guidelines for supporting the caregivers, ALHIV and social work practitioners.

The two theories that guided the researcher's understanding of the phenomenon under investigation were introduced in chapter two (see Chapter two, section 2.5) as the strengths-based perspective and ecological systems theory. The strengths-based perspective belief in the inherent potentials and capabilities of individuals and a shift away from focusing on client's deficits to their strengths and resources (Milne & Beadle-Brown, 2021; McCamey, 2015, Hammond, 2010). In view of this approach, it was deemed that the understanding that building on primary caregivers' strengths and resilience with the ultimate purpose of empowering them to overcome challenges and be able to meet their needs, should start by understanding their needs and plight from an approach which appreciates their inborn strengths, talents and competencies.

The ecological systems theory focuses on the interaction and interdependence that occur between people and their social and physical environments (Teater, 2014; Crawford, 2020). Through its consideration of the various sub-systems, the ecological systems theory guided the development of knowledge around the experiences,

challenges and needs of primary caregivers caring for ALHIV from a broader perspective. Based on the two adopted theories, the researcher came to the conclusion that they complemented each other and therefore suitable for this study. They enabled the researcher an opportunity to better understand the experiences, challenges and needs of primary caregivers and their ALHIV from the various systemic contexts of the participants and by outlining some positive issues and strengths associated with caring for ALHIV.

6.3. SUMMARIES AND CONCLUSIONS BASED ON THE RESEARCH METHODOLOGY

Regarding the research methodology, the summary and conclusions will be based on the research approach and the research design applied for this study as well as the study methods used to collect and analyse the data. Lastly, the ethical principles applied for this study will also be revisited with the purpose of ascertaining whether or not they were suitable, relevant, and yielded desired outcomes.

6.3.1. Summary and conclusion of the qualitative research approach

To achieve the goals and objectives of this study and obtain responses from the formulated research questions as stated in Chapter One, the researcher decided to adopt qualitative research approach because it is human centered and allows for people's actions to be studied directly from their own experiences and perspectives (Given, 2015; Rubin & Babbie, 2014). Qualitative research was found to be relevant because it enabled data to be collected directly from the participants and to be described, analysed and interpreted using 'thick description' to further explore their shared experiences and perspectives (Kostova, 2017; Cypress, 2015; Koch, Niesz & McCarthy, 2014). Qualitative research is appropriate when the researcher embarks on a sensitive topic (such as HIV) and especially when very little is known about the investigated phenomenon (Creswell, 2016; Marshall & Rossman, 2016). As indicated in the introduction and general orientation to this study (See Chapter One section 1.2.1), the researcher realised when preliminarily reviewing literature, that there is a gap in the knowledge concerning the experiences, challenges and needs of primary caregivers of ALHIV in their caring role, particularly in social work practice to address the challenges and needs of primary caregivers caring for ALHIV and to offer support through social work practice guidelines. In view of this, the researcher can conclude

that adopting a qualitative research approach for this study was indeed a good fit as it allowed for the exploration and development of an understanding of this phenomenon as experienced and perceived by the participants and focused on individual experiences that occurred in natural settings (i.e. the primary residence, neighbourhood, and workplaces of the participants) (Creswell, 2016; Marshall & Rossman, 2016). In addition, qualitative research was advantageous to investigating the phenomenon since it has not been adequately researched (Nieuwenhuis, 2016; Creswell, 2014).

6.3.2. Summary and conclusion of the research design

Given the researcher's desire to understand the experiences and challenges faced by primary caregivers in caring for ALHIV and how they wish to be supported by social workers, a phenomenological research design which was complemented by explorative, descriptive, and contextual research designs, was deemed suitable design to achieve the set goals and objectives of this study and to answer all the research questions.

Phenomenological research design is considered fitting when the researcher's intention is to explore or to find out how participants experience a phenomenon in their 'live world' (Nieuwenhuis, 2016; Creswell, 2014). In this study the central focus was on the lived experiences of primary caregivers (For example, one of primary caregivers said, *"It is difficult because she is not like other children, she needs extra care, always sick, you need to take her to the clinic. So, you take care of her more than other children and you must ensure that you give her medication all the time and with extra caution so that she can be like other children".* See subtheme 1.1) in caring for ALHIV and the ALHIV on being cared for by the caregiver (For example one of the ALHIV said, *"It's okay, my mom treats me well, she is also on HIV treatment. We always remind each other to take treatment because it is only the 2 of us who take HIV treatment at home."* See subtheme 2.1) and how they translate these into the meanings they attach to them in an effort to interpret the linkages between the scientific world and their everyday life events (Korstjens & Moser, 2017; Bakanay & Çakır, 2016). Therefore, phenomenological research design in this regard, afforded the researcher the opportunity to investigate and understand the lived experiences of the primary caregivers and ALHIV.

Phenomelogical research design was supplemented by explorative research design since the researcher did not bring prior knowledge about the phenomenon into the study but aimed at gaining knowledge or uncover new ideas of the phenomenon under investigation (Swedberg, 2020; Yegidis et.al., 2018). Descriptive research design was also incorporated because its purpose is to describe a phenomenon under investigation in natural state (Fain, 2017; Siedlecki, 2020). The other research design adopted for this study was the contextual design which involves identification of contextual circumstances that exists in the social world of individuals or groups and how it manifests (Moser & Korstjens, 2017; Ritchie et. al., 2014). All these designs were implemented by employing individual semi-structured face-to-face interviews comprising open-ended questions followed by probing questions. The interviews were conducted in the primary residents of the participants and offices where social workers render services to primary caregivers and their ALHIV and as such considered part of the essential contextual information. Moreover, primary caregiver participants were afforded an opportunity to describe their lived experiences, challenges and needs in relation to caring for ALHIV. In addition, the ALHIV were invited to share their lived experiences regarding being cared for by a primary caregiver while social workers described the needs and challenges of primary caregivers and suggestions on how they as social workers working with caregivers and ALHIV, can be supported.

These research designs were therefore found to be instrumental in giving the researcher an opportunity to explore and describe the life-world the participants and in enabling the research questions to be answered, the goal and objectives to be realised.

6.3.3. Study methods

Several strategies or methods implemented in this study were presented in Chapter three (section 3.4) including the methods for data collection, analysis, and research rigor or trustworthiness. As Marshall and Rossman (2016) stated, well-formulated research questions signposts what the study population should be. For this study, such meant that research questions posed at the beginning of the study directed the identification and recruitment of targeted population of this study which were primary caregivers of ALHIV, ALHIV and the social workers. Linked to the study population was the study settings, which were the four municipal areas located in Gauteng province, namely Johannesburg, Ekurhuleni, Sedibeng and Tshwane, from which the

participants were recruited. In view of this, the researcher concluded that the targeted population and the study sites from which they were recruited were suitable for this study. Both the diverse study sites and different participants recruited from these sites provided rich and diverse contextual information around the phenomenon under investigation.

In terms of the data collection methods, individual face-to-face semi-structured interviews were employed. This method afforded the researcher flexibility which enabled a detailed understanding of participants' subjective experiences, perceptions, or accounts of a topic under investigation. It also afforded the participants the opportunity to speak about the topic under investigation freely and authentically. In facilitating face to face semi-structured interviews, the researcher used interview guides tailor-made for each of the three research population groups, namely the primary caregivers, ALHIV and social workers. The questions in this guide were open ended, phrased in a flexible and neutral fashion, and supplemented by follow-up probing questions. As a result of the data collection methods, rich information was collected which comprehensively answered the posed research questions. Based on this, the data collection method was found to be suitable for this study.

As indicated in Chapter Three (Section3.4.3), the researcher decided to adopt Tesch's eight steps of thematic analysis (in Creswell, 2014). These steps assisted her in a systematic and focused way to submerge herself in the huge volume of the collected data. Moreover, they helped her to extract words from the data that display the depth and the breadth of the topic under research. Tesch's analysis method was also able to easily match relevant data set with the posed research questions which then made it easier to describe the phenomenon under investigation. In conclusion, Tesch's data analysis method was found to be a suitable strategy for data analysis.

6.3.4. The Ethical principles

The involvement of human participants in this study required compliance with the ethical principles of obtaining informed consent, upholding confidentiality and anonymity, avoiding harm and managing data. Prior to signing the informed consent participants were informed about the aim of the study and what it meant to participate in the study; the risks and benefits associated with participating and how information will be managed and their identities protected. Due to the sensitive nature of the

research topic, getting informed consent helped the study get participants who were willing to share their lived experiences autonomous. To uphold confidentiality and anonymity pseudonyms were used since they are considered the best method of ensuring anonymity during research (Quick & Hall, 2015). Moreover, the principle of no harm in a research context forms the foundation of all the ethical considerations since it guarantees protection of the study participants, hence this principle was diligently implemented throughout the study by informing all participants about the aim of the study from the inception of the study. In terms of managing data, the participants' identities were protected, and their information was kept in a private space in a locked drawer in the researcher's office at home where they were only accessible to her. All the electronic data was password protected.

In conclusion, the ethical principles upheld for this study enabled authentic interaction between the researcher and the participants. This enables the collection of data from the environment that is characterised by trust, warmth and openness, which then ensured credibility of the data.

6.4. SUMMARIES AND CONCLUSIONS ON THE STUDY FINDINGS

In the following section, summaries and conclusions resulting from the research findings are presented.

6.2.4. Summary and conclusions on the demographic particulars of participants

Among the participants who participated in this study, eight were primary caregivers of ALHIV, eight were ALHIV and eight were social workers. All participants were Black Africans. In all the groups, twenty-one out twenty-four participants were females. In terms of education all primary caregivers never completed Grade 12. Whereas out of eight ALHIV, only 2 managed to complete Grade 12, the rest had grade 11 or less. A detailed presentation of the demographical features of the three groups of participants for this study was provided in Chapter Four (see section 4.2.1, 4.2.2 and 4.2.3).

6.2.5. Summary and conclusions on part one the research findings: the experiences and challenges associated with caring for an ALHIV

The findings of this study were divided into two parts, with part one focusing on the experiences and challenges of primary caregivers in caring for ALHIV and part two focusing on the needs of primary caregivers and the suggested social work interventions for primary caregivers of ALHIV. This section will focus on experiences

and challenges and the next section will focus on the needs and suggestions for social workers. The summaries and conclusions for this section will be based on the four themes that contributed to the first part of the findings.

- **Theme one: Primary caregivers' experiences of caring for ALHIV**

The reflections of the primary caregivers' experiences as participants were clustered into two subthemes which are caregivers' concerns in relation to caring for an ALHIV and coping well with ALHIV. In terms of concerns relating to caring for ALHIV, primary caregivers were worried about regular illnesses of ALHIV and clinic visits that were burdensome on them. Caregivers were also constantly worried about the failure of ALHIV to properly adhere to treatment and therefore running a risk of poor health which may have extreme repercussions. Poor academic performance among ALHIV because of ill-health and cognitive challenges associated with living with HIV were also reported as some of the concerns among the caregivers.

Despite the above-mentioned negative experiences as highlighted by the primary caregivers, the second subtheme emerged indicating that some of these primary caregivers tend to have pleasant experiences in caring for ALHIV. Moreover, they had innate potential and skills to overcome their challenges. They also have positive experiences in caring for ALHIV which corroborates the strength-based perspective (Poteat & Logie, 2022; Caiels et.al., 2021). A conclusion reached in this regard is that, although the primary caregivers are burdened by taking care of ALHIV due to several challenges such as regular illness and poor school performance by ALHIV, they also have positive experiences to report about caring for these adolescents.

- **Theme two: The experiences of ALHIV being cared for by a primary caregiver**

From the responses on the question regarding their experiences on being raised by a primary caregiver, the reflections shared by the adolescents where in this regard, clustered into three subthemes, namely ALHIV enjoy a supportive relationship with the primary caregivers; ALHIV lack the necessary support from primary caregivers and that their caregivers are overprotective.

Although some of the ALHIV reflected positive experiences and that they have a supportive relationship with their primary caregivers, some expressed negative

experiences and lack of support from their primary caregivers, particularly where the primary caregiver is not their biological parent. Some of the ALHIV indicated that they are being unfairly discriminated against and stigmatised based on their HIV diagnoses and misconceptions surrounding HIV with the potential to result in family uproar and other problems that result in less support from their family members (Doat et.al., 2021).

Furthermore, ALHIV were also bothered by their primary caregivers whom they said are overprotective. According to these ALHIV, their caregivers considered them incapable of making decisions and went as far as to prevent them from spending time with their friends, something that resulted in emotional distress on part of these ALHIV.

To conclude, the experiences of ALHIV on being cared for by primary caregivers were generally positive, with the potential to result in good relationship and improvement of ALHIV and primary caregiver's wellbeing. For those who were experiencing negative behaviours such as discrimination and having overprotective primary caregivers, there were risk of negative consequences such as emotional distress which may in turn affect family relationships and ALHIV's health.

- **Theme three: The socioeconomic-related experiences of caregivers caring for ALHIV**

In reflecting on a question requiring participants to share their views on the caregivers' experiences in caring for ALHIV, the responses from all the three groups of participants (ALHIV, primary caregivers and social workers) were clustered into two major themes: the socioeconomic and psychosocial experiences. The socioeconomic experiences were further divided into two subthemes, and they are a subject of the current discussion.

The first subtheme that emerged is financial burden leading to inability to meet the caregivers' basic needs. Participants indicated that primary caregivers lack financial means to address basic needs of ALHIV. They highlighted failure to meet basic needs such as food, clothing, transport money or even money to buy lunch at school. ALHIV added that sometimes their primary caregivers do not have money to take them to clinic when they are sick or to even give them money to buy other necessities. On the other hand, social workers also mentioned that they mostly work with primary caregivers from poor communities and that they experience poverty, which results in

financial burden leading to stress due to their failure to meet some of the basic needs such as nutritious food.

The second subtheme that emerged was that primary caregivers lack the means to provide proper nutritional food to take their medication and for ALHIV to remain healthy. Lack of these means was associated with inadequate or lack of money.

Based on this theme, a conclusion reached is that primary caregivers of ALHIV are mostly from impoverished communities that are characterised by unemployment which then translates into inadequate or lack of finance to meet the needs of ALHIV and their families. These challenges have the potential to negatively hamper the caring roles of caregivers which may in turn affect access to treatment, care, and support by ALHIV.

- **Theme four: The psychosocial experiences of primary caregivers of ALHIV**

In reflecting on the responses from the participants in terms of this theme, the responses were clustered into five subthemes namely (1) perceived psychological stress among the primary caregivers; (2) perceptions that primary caregivers are struggling with disclosure of HIV diagnosis; (3) perceived parenting-related challenges; (4) perceived lack of support for caregivers to effectively manage HIV-related challenges and (5) stigma and discrimination associated with caring for ALHIV.

In terms of perceived psychosocial stress experienced by primary caregivers, participants indicated that primary caregivers experience stress related to the fear that the HIV diagnosis of ALHIV will be known, and they might be discriminated against. They were also stressed by how ALHIV will navigate romantic relationships and early sexual debut because of their HIV diagnosis. Another concern was that ALHIV lack the necessary knowledge around HIV transmissions and therefore risk being reinfected by HIV or infecting others.

Social workers as participants reflected on the struggles that caregivers experience with disclosure of HIV diagnosis of the ALHIV due to fear of how the adolescents will react, and the fear of rejection by ALHIV who may blame them for their HIV diagnosis. Furthermore, other primary caregivers avoided stressing ALHIV with disclosure, they preferred not to even talk about it.

The third subtheme that emerged focused on the perceived parenting-related challenges. Through this subtheme, participants indicated that primary caregivers are stressed by ALHIV's behaviours due to the stage of adolescent which is linked to risky behaviours with the potential to negatively impact on their adherence to HIV medication.

The fourth subtheme as related by the participants was perceived lack of support for caregivers to manage HIV-related challenges. They specifically reported that primary caregivers lack support from family and friends due to their failure to disclose the HIV-positive diagnosis of the ALHIV.

Stigma and discrimination associated with caring for ALHIV was the fifth and last subtheme that emerged under the psychosocial experiences of the primary caregivers. In responding to this subtheme, participants reported that stigma and discrimination perpetuated to caregivers by some members of their families and the communities impacted on ALHIV's access to treatment.

In conclusion, primary caregivers were found to experience emotional distress associated with caring for ALHIV. The stress is caused by several factors such as fear of rejection by ALHIV and stigma from family members and friends, which may subsequently lead to lack of support for the primary caregivers. Moreover, lack of knowledge regarding HIV was also found to result in distress on the part of the primary caregivers. It was also found that the communities and families tend to lack the necessary knowledge around issues of HIV and care and therefore find themselves perpetuating stigma around HIV particularly to caregivers of these ALHIV.

6.2.6. Summaries and conclusions on part two of the findings: the needs and suggested solutions associated with caring for ALHIV

This sub section will focus on the summaries and conclusions related to the needs of primary caregivers in their caring role and suggested solutions. This presentation will specifically focus on the remaining four themes that emerged from the second part of the findings.

- **Theme Five: A need for material support**

In responding to the question pertaining to the needs of and solutions for primary caregivers in their caring role, participants pointed to the need for material support

which was further categorised into three sub themes namely the need for food and clothing, shelter and financial support. In terms of food, participants reported that nutritional food is a necessity for taking medication and for adolescents to adhere to treatment since it is not easy to take medication on an empty stomach. The issue of nutritious food was found significant given the nature of HIV, which among others requires a strong immune system to fight bacteria and maintain a healthy state of life for adolescents. If basic needs such as shelter, food and clothing are not met, individuals lack the necessary motivation to meet other needs such as health which is not regarded as more important compared to food and therefore, they are likely to adhere less to their prescribed HIV treatment (Medrano, 2023; Stefan, Popa & Albu, 2020; Mofokeng & Green, 2017).

In addition, financial support was also reflected upon as one of the caregivers' needs. They emphasised that if the need for financial support is not met, primary caregivers will fail to meet basic needs including transport money to go to the clinics. A lack of financial means by primary caregivers impacts negatively on their wellbeing and that of the ALHIV because they failed to meet some of the basic needs such as nutritious food and sometimes transport money to go for clinic visits. Consequently, ALHIV may fail to adhere to their HIV treatment.

In conclusion, primary caregivers need material support such as financial support, which if met, they would in turn meet other basic needs such as nutritious food and transport money to go to the clinic, of which they are vital for ALHIV to adhere to their HIV treatment and to remain in care. Consequently, if these needs are not met, they may impact negatively on the health and wellbeing of primary caregivers and their ALHIV.

- **Theme Six: A need for employment**

One of the needs highlighted by participants was the need for employment. In looking at the demographics of primary caregivers in Chapter Four (see sub section 4.2.1 table 4.1), five out of the eight interviewed were unemployed and reported to be living on social grants or financial assistance from family members, which might not even be enough to meet their needs. This seems to have posed challenges in their caregiving roles since they fail to meet some of the basic needs of ALHIV.

To sum up this theme, primary caregivers in this study were mostly unemployed hence a need for employment, which correlates with previous studies such as those conducted by Maddocks and Chetty (2020) and Lentoor (2017). Employment is therefore an important need for primary caregivers of ALHIV because unemployment enables them to fail to meet the multiple needs of ALHIV which subsequently lead to mental stress with the risk of negatively affecting the health of ALHIV, due to their potential failure to adhere to HIV treatment or even to their clinic visits.

- **Theme 7: A need for psychosocial support**

Another thing that emerged from data analysis is that caregivers need psychosocial support in order to effectively cope with the challenges associated with HIV and caring for ALHIV in particular, which was then turned into a theme, a need for psychosocial support'. From this theme, the following subthemes emerged: a need for social support networks; a need for counselling and a need for peer support programs

Participants indicated that social workers should link primary caregivers with social networks such as family members and professionals to effectively manage the stress associated with caring for ALHIV. Counselling was also recommended due to its ability to help both the ALHIV and primary caregivers in dealing with the burden of living with HIV and its challenges, managing the disease better and coping with death and loss of loved ones. Lastly it was suggested that support groups for primary caregivers be initiated to enable them to cope better with HIV, to associate with other primary caregivers who are going through the same challenges of caring for ALHIV and to receive education on best ways of managing HIV and caring for ALHIV.

In conclusion, psychosocial support programmes such as counselling, treatment adherence guidance, disclosure counselling to primary caregivers and their families fall squarely within the armpits of social workers working with people affected and infected by HIV (Molato et.al., 2024; South African Government, 2019; National DOH, 2016). This includes the suggestions made by the participants regarding support groups, which have the potential to encourage disclosure of HIV diagnosis, reduce stigma and discrimination, eventually lead to improved self-esteem, enhance primary caregivers and ALHIV's coping skills and their psychosocial functioning (Mutluri 2021; Bateganya et.al., 2015).

- **Theme 8: The current and suggested social work services for caregivers of ALHIV**

From a question regarding the current and suggested social work support services for caregivers of ALHIV, further analysis of data yielded four subthemes: assistance with disclosure of HIV-positive diagnosis, support with adherence to HIV treatment and appointment reminders for clinic, linking caregivers with resources for support as well as education on HIV management.

The participants (particularly primary caregivers) suggested that caregivers should be assisted with disclosure of HIV-positive diagnosis to ALHIV because they were afraid to do it themselves due to fear of negative consequences such as stigma, the ALHIV's inability to comprehend and deal with the diagnosis, and unintended disclosure to others. A suggestion for support in adhering to clinic visits and HIV treatment was strongly highlighted by the participants (primary caregivers) as part of supporting them managing HIV. Furthermore, ALHIV suggested that primary caregivers should be supported in linking them to resources such as income generating opportunities, food parcels, clothing and grants in order to meet their needs and those of ALHIV.

On this note it is concluded that social workers are being consulted by caregivers for various support-related roles. They particularly play a vital role in connecting primary caregivers with resources that are available in their communities such as providing adherence and disclosure counselling and other forms of support to ALHIV and their primary caregivers.

6.5. RECOMMENDATIONS

Based on the literature review, findings, and conclusions made in this study, this section proposes some recommendations for the research process, the research methods and the research findings.

6.5.1. Recommendations based on research methods and the process

Qualitative research approach and phenomenological research design, that was complemented by explorative, descriptive, contextual research and intervention research designs was found to be suitable for this study. Based on this conclusion, the following recommendations are proposed for the research process:

- This research project focused on eight ALHIV, eight social workers and eight caregivers based in the province of Gauteng (City of Johannesburg, Tshwane, Ekurhuleni and Sedibeng) and the sample size was small. It is therefore recommended that future studies include a larger sample to cover other provinces and to incorporate diverse and comprehensive experiences of the participants.
- Based on the conclusions regarding the demographical data of the participants particularly in terms of their gender and race, most of them were black females. Therefore, it is recommended that further studies be conducted to deliberately include other racial and gender groups as well as the economic backgrounds of both the primary caregivers and ALHIV. Such may provide diverse experiences and enrich the existing pool of literature around the subject of ALHIV and their caregivers.
- Participants were recruited from NPOs that were rendering services to primary caregivers of children and the ALHIV. Most of these NPOs were in impoverished communities. This resulted in limited knowledge around communities that are not from poor economic background and the primary caregivers who are not accessing services from the NPOs. It is therefore recommended that future studies be expanded to also include communities that are not from poor economic backgrounds and participants who do not only access services from NPOs.

6.5.2. Recommendations based on the research findings

The recommendations for research findings are directed for social work practice, NGO rendering services to PLHIV and their families, Government departments particularly social development and health, educational institutions for training, and continuous professional development (CPD)

6.5.2.1. Recommendations for the social work practice

Based on the conclusions of the research findings, the following recommendations are proposed:

- Guidelines should be developed by researchers to guide social work interventions for primary caregivers of ALHIV (this part of the recommendation was immediately taken up after this study and it is reported in Chapter Seven of this report).

- Specific programmes for caregivers, ALHIV and social workers working with these client systems should be developed by policy makers and specifically include individual counselling, group work and community work interventions.
- Given the lack of knowledge which even perpetuates HIV-related stigma among community members and the families, advocacy programmes should be designed and developed by policy and programme makers to mobilise resources for social workers working in the HIV field, particularly those based in NPOs that render services to ALHIV and their primary caregivers.
- Most of the participants (primary caregivers) from the study were unemployed and even those that were employed or self-employed faced financial challenges. Therefore, it is recommended that they should be linked to financial support programs and agencies such as SASSA for social grants or any employment opportunities within the community by social work practitioners.

6.5.3. Recommendations for Social work education, training and CPD

Based on the findings of this research the following recommendations are directed towards Social Work education and training including continuous professional development:

- Social work education and training institutions should include a more comprehensive HIV/AIDS curriculum to better equip future social workers and related professionals with the necessary knowledge on HIV/AIDS and related issues.
- HIV is an evolving field. Therefore, it is recommended that CPD training programmes in a form of workshops, seminars and conferences be organised by the SACSSP to educate and update social workers on developments in this field, including the development and improvement of guidelines, policies and programmes so that they can be kept abreast of current issues related to HIV.
- In-service training needs to be provided to social work practitioners on updated guidelines by employers, strategies and interventions related to HIV care and support. This in-service training should also include up-to-date information sessions on medication in HIV treatment and management for ALHIV and their caregivers by experts in the field of HIV

6.6. LIMITATIONS OF THE STUDY

- As much as this study was informative, the sample size was small, comprising only twenty-four participants. A large sample might yield comprehensive data.
- The study was conducted only in South Africa's Gauteng Province due to limited resources. The exclusion of other provinces posed a limitation on information that might have provided contrasting or comprehensive information based on other difference contexts across the country.
- The participants from which data was collected were predominantly females and black in all the three groups. This resulted in a gap in the experiences and challenges from other racial groups such as the white, Indians, coloureds and other genders.
- The areas where participants were recruited were mostly served by NPOs that render services to primary caregivers of children and ALHIV. Most of the communities served by these NPOs were impoverished and this might have posed a limitation on the experiences of communities that are depending on these NPOs (i.e. not from a poor economic background).

6.7. SUMMARY OF THE CHAPTER

The purpose of this chapter was to provide the summaries, conclusions, recommendations, and limitations of this study. It revisited the study introduction and background upon which the study was based and leading to the problem formulation and rationale for the study. Attention was also placed on the literature review and the adopted theoretical frameworks with the aim of summarising their relevance for the study. Then a summary and conclusion of the qualitative research as the approach that guided this study was presented, as well as the research designs and methods adopted. Summary and conclusion of the research findings based on the demographics of the research participants was also outlined in this chapter, followed by the eight themes and subthemes (where applicable) that emerged from the data analysis process. From all the summaries and conclusions, some recommendations based on the research process, social work practice, education and training were drawn. The chapter ended with the limitations of the study. One of the recommendations for social work practice namely, "guidelines should be developed to guide social work interventions for primary caregivers of ALHIV", was immediately actioned by the researcher, and it is presented in the next chapter (Chapter Seven).

CHAPTER SEVEN
THE PROPOSED SOCIAL WORK GUIDELINES FOR SUPPORTING CAREGIVERS CARING FOR ADOLESCENTS LIVING WITH HIV

7.1. INTRODUCTION AND BACKGROUND

The global number of ALHIV for the period 2024 was estimated at 1,7 million, with South Africa accounting for 220, 000, of which 28, 000 were new annual infections. These figures demonstrate that HIV prevalence among adolescents is still alarming and that new infections among this cohort is becoming an increasing cause for concern (UNICEF, 2024; UNICEF, 2023; UNAIDS, 2021). Further compounding these figures, are the challenges of frequent illnesses, difficulties in disclosing HIV diagnosis, non-adherence to HIV treatment, stigma and discrimination as well as financial difficulties faced by caregivers (Nsibandze, Downing, Poggenpoel & Myburgh, 2020; Zungu et al., 2021; Mapesi, 2020; Kimera et. al, 2019; Mafune, Lebese & Nemathage, 2017).

The findings on which the proposed guidelines are based, and supported by the existing literature, confirm some of the challenges faced by the ALHIV and their caregivers, prompting the researcher to consider the need to guide social workers on the best ways for supporting caregivers and ALHIV. The guidelines presented in this chapter were informed by the findings of this study with the specific aim of guiding social work practitioners working with these categories of clients to effectively support them in managing their challenges.

7.2. PROBLEMATISATION

The alarming prevalence of ALHIV and the challenges that they and their caregivers have to contend with, as revealed in existing literature and the findings of this study, necessitates interventions through programmes, policies, legislation and guidelines. Despite South Africa's commitment to ending HIV among adolescents and some evidential success in the prevention of HIV transmission, there are still challenges on follow-up treatment, with stigma and discrimination hampering disclosure due to fear of rejection, isolation and bullying (Aidsfonds, 2023). Existing evidence also demonstrates that children (including adolescents) and their caregivers lack the necessary knowledge about HIV transmission, treatment and disclosure. It is therefore

essential to support caregivers with tools (such as guidelines and programmes) to, among other skills, assist them with disclosure of HIV diagnoses (Aidsfonds, 2023). Researchers such as Kidman and Heymann (2016) and Katana et al. (2020) confirm the lack of intervention guidelines for primary caregivers and inclusive programmes to enable the active involvement of primary caregivers of ALHIV and therefore recommended that such programmes be developed and strengthened.

Zooming into the South African context, the government in response to HIV, developed the NSP which serves as a roadmap to guide the country's overall response to HIV, TB and STIs. This plan (NSP) incorporates lessons learned and enables adaptation to changing circumstances over a period of five years. Although the NSP incorporated social work interventions and appraised the social drivers of HIV, it specifically fell short on how to support primary caregivers of ALHIV (DOH, 2017). The decisions made by primary caregivers affect the health statuses of ALHIV (Atanuriba et.al., 2021). Yet, in South Africa there is a noticeable gap in social work guidelines to address the challenges and needs of primary caregivers, and this poses a risk to treatment adherence among ALHIV.

7.3. THE RATIONALE FOR GUIDELINES TO SUPPORT CAREGIVERS AND ALHIV FROM A SOCIAL WORK PERSPECTIVE

These guidelines are based on the suggestions made by primary caregivers, ALHIV and social workers on how best social workers can support ALHIV and their primary caregivers in their caring roles. The proposed guidelines are aimed at guiding the coordination of social work interventions for supporting ALHIV and their primary caregivers to be able to cope better with the challenges associated with caring for ALHIV, therefore reduces stress and improve health of both ALHIV and their primary caregivers. In addition, address the identified gap in the body of knowledge and social work practice. They are aligned with South Africa's commitment to ending HIV infections among children and adolescents as indicated in the fifth generation of the National Strategic Plan (SANAC, 2023), which is also in line with the Global Alliance to end AIDS in children by the year 2030. Furthermore, they align with the Global Alliance commitment to addressing HIV-related stigma and discrimination in order to ensure that PLHIV have access to services and support (SANAC, 2023).

7.4. METHODOLOGICAL BASIS OF THESE GUIDELINES

The development of these guidelines was based on the design and development model (D&D) proposed by Rothman and Thomas (1994). Rothman and Thomas (1994), propose the following five steps in the design process for interventions:

7.4.1. Problem analysis and project planning

Problem analysis and project planning entails selecting and studying a specific problem and establishing a specific goal for the purpose of developing an intervention.

7.4.2. Information gathering and synthesis

The main focus of information gathering and synthesis is on conducting an exhaustive literature review which includes review of existing programmes or interventions to avoid replication.

7.4.3. Design intervention

Focuses mainly on the actual designing of the intervention, which for the purposes of this study, are the guidelines.

7.4.4. Early development and pilot testing

Refers to the pilot testing of the intervention (guidelines for this study).

7.4.5. Evaluation and advanced development

Refers to the assessment and the intervention (guidelines) and its outcomes.

7.4.6. Dissemination

Involves dissemination of the research findings plus the produced intervention (guidelines).

In this study financial and time constraints did not allow the process to be followed to the end as suggested above. The pilot testing, experimental evaluation and advanced development stages could not be part of the process. The research process was rather contextualised in the following manner:

(a) Problem analysis and project planning
(b) Information gathering and synthesis
(c) Designing the guidelines and early development
(d) Dissemination

A presentation on how each of the above was implemented is outlined below:

In phase one, the focus was on **problem analysis and project planning**. This stage involved a literature review which revealed a noticeable gap in South Africa in social work guidelines for supporting caregivers and ALHIV in managing their challenges. A plan was then developed outlining, among others, the project aims and objectives, methodology, project phases, time frames and outputs. Primary caregivers caring for ALHIV, ALHIV and social workers were identified as the target population for data collection purposes. This plan was subjected to a relevant institutional review committee through the University of South Africa's College of Human Sciences Research Ethics Committee.

Phase two of this process entailed **collecting data through interviews.** Individual semi-structured face-to-face interviews were conducted with primary caregivers, ALHIV and social workers to among other objectives, invite their suggestions on how best social workers can support the caregivers and ALHIV in question. The collected data was then analysed, and key components and themes were identified for incorporation into the guidelines.

Phase three was the final stage. It entailed developing a first draft of the guidelines. This draft was based on the collected data as well as a review of the relevant literature around the challenges of caregivers, social workers and ALHIV. The draft in question is the current chapter.

7.5. PURPOSE AND OBJECTIVES OF THE GUIDELINES

7.5.1. Purpose of the guidelines

The proposed guidelines aim to support social work practitioners in providing the necessary psychosocial support to ALHIV and their primary caregivers.

7.5.2. Objectives of the guidelines

Specific objectives to be attained through the guidelines:

(a) To outline the policy and legislative context of HIV support for ALHIV and their caregivers.
(b) To guide the implementation of social work programmes that support ALHIV and their primary caregivers.

(c) To guide the social work intervention processes for the purpose of supporting ALHIV and their caregivers.

7.6. THEORETICAL FRAMEWORK THAT UNDERPINS GUIDELINES

These guidelines adopted the strengths-based perspective and the ecological systems theory as theoretical frameworks. A strengths-based perspective focuses on identifying and mobilising the resources, knowledge, wisdom, and assets inherent in every person and their environments (Pulla, 2017). It focuses on the resources and strengths of clients/users rather than their deficits resulting from being infected or affected by HIV. Moreover, it encourages collaboration between the client requesting services (ALHIV and their primary caregivers) and those rendering such services (social workers). The ecological systems theory focuses on the interactions and interpersonal relationships crosscutting multi-dimensional and multifaceted levels, differentiated as the microsystem (The immediate environment such as the family, inclusive of ALHIV as members thereof, and the work environments, school and socioeconomic circumstances of primary caregivers); the mesosystem (The challenges faced by Primary caregivers and ALHIV such as frequent illness, failure to take medication regularly, feeling stigmatised and disclosure challenges); the exosystem (The availability or lack of and access to resources such as employment, health care and social services) and lastly the macrosystem (The broader spectrum of culture to which the primary caregivers or the ALHIV subscribe, which shapes the needs and challenges they face).

7.7. VALUES AND PRINCIPLES FOR GUIDELINES

The guidelines are based on the following values and principles:

7.7.1. Respect

Respect for human rights, dignity and welfare of the ALHIV, their caregivers, their significant others and all other people affected by HIV.

7.7.2. Human rights and social justice

Promotion of social justice for ALHIV, their caregivers and all other people in relation to care and support for PLHIV and their significant others.

7.7.3. Non-judgementalism

Unconditional acceptance of ALHIV, their caregivers and all other affected people with the sole purpose of supporting them.

7.7.4. Integrity

Being consistent, trustworthy, acting with honesty and upholding professional values for the benefit of ALHIV, their caregivers and all other people in relation to care and support for PLHIV and their significant others.

7.7.5. Service delivery

Striving to provide optimum and professional social work services to ALHIV, their caregivers and all other affected people to the best of one's competent capacity.

7.7.6. Person-centeredness

Promote the interests of each individual ALHIV, their caregivers and all other people in relation to care, support and related activities.

7.7.7. Confidentiality

Uphold confidentiality of ALHIV, their caregivers and all other people in relation to ALHIV care, support and related activities.

7.8. SITUATIONAL ANALYSIS

In South Africa, an estimated 7.8 million people were living with HIV in 2022, and a total of 90 000 reportedly died from AIDS-related conditions (HSRC, 2023; UNAIDS, 2023). South Africa has the world's largest treatment programme, with reports between 2022 and 2023 estimating that that 5.7 million of the 7.8 million (75%) PLHIV were taking HIV treatment, and 91% of them were 15 years and older (HSRC, 2023; UNAIDS, 2022). Whereas HIV incidences remain high among adolescents and youth, access to HIV treatment differs considerably by age. As a result, the present treatment efforts are not reducing the rates of infection and morbidity among children and adolescents in South Africa. In addition, the South African HIV epidemic is worsened by social, structural and economic barriers faced by children as well as ALHIV and their families.

7.9. LEGAL AND POLICY FRAMEWORK FOR GUIDELINES

The proposed guidelines are developed within the relevant legal and policy provisions of South Africa. Among the legal provisions central to the guidelines, are the

Constitution of the Republic of South Africa Act 108 of 1996; the National Health Act (Act No 61 of 2003), the Social Services professions Act 110 of 1978; the promotion of Equality and Prevention of Unfair Discrimination Act (Act No 52 of 2002); and the Protection of Personal Information Act (Act No. 13 of 2014). Regarding policies, the guidelines are based on the National Development Plan, the National Strategic Plan for HIV, TB and STIs 2023-2028 (NSP); the Guideline for Social Service Practitioners: Enabling Access to HIV Testing Services for children, adolescents and youth; Adherence Guidelines for HIV, TB and Non-Communicable Diseases; and the Disclosure Guidelines for Children and Adolescents in the context of HIV, TB and non-communicable diseases. These policies and legislations are clearly not exhaustive; there are many others applicable to guide the development and implementation of these guidelines.

7.9.1. Constitution of the Republic of South Africa (Act No. 108 of 1996).

The Constitution is the supreme law of the Republic of South Africa. South Africa has an outstanding Constitution with a progressive Bill of Rights protecting the rights of everyone in South Africa and acknowledges the democratic values of human dignity, freedom and equality. Therefore, all other legislative frameworks are guided by the Constitution. It guides the legal foundation in South Africa and sets out the right of every person to be equal before the law and to be protected by the law. Chapter 2 focuses on fundamental human rights including the right of children to basic nutrition, shelter, healthcare and social services. As defined by Section 1 of the children's Act 38 of 2005, adolescents fall in the category of children.

7.9.2. The National Health Act (Act No 61 of 2003)

The National Health Act (NHA) No 61 of 2003) of South Africa focuses on the establishment of an integrated health system that addresses health issues (such as HIV/AIDS), by ensuring access to healthcare services including HIV testing, treatment and care. The Act advances a rights-based approach to dealing with HIV/AIDS, including respect for confidentiality of health information and HIV status by forbidding unlawful disclosure of HIV without consent from the relevant parties (primary caregiver and ALHIV). This means that a right-based approach adopted by the NHA aims to combat stigma and discrimination against vulnerable groups such as ALHIV and their primary caregivers.

7.9.3. Social Service Professions Act (Act No. 110 of 1978)

The Social Service Professions Act defines the parameters of the social service professions in South Africa by regulating the practice of social workers to ensure compliance with professional standards, the protection of all people and the integrity of the social service profession. Moreover, the Act ensures that ethical principles such as respect, human rights, social justice and non-judgementalism are adhered to, which are central to the proposed guidelines, particularly since they deal with the sensitive topic of HIV and adolescents. Social work practitioners are required to contribute to combating stigma and discrimination and supporting the most vulnerable population groups such as ALHIV. Lastly the Act promotes continuous professional development among social service practitioners to ensure that they remain informed on current developments in the field through guidelines, regulations and strategies related to PLHIV, including ALHIV and their families (primary caregivers).

7.9.4. The Children's Act (Act No. 38 of 2005)

Amongst the objectives of the Children's Act is to give effect to the rights contained in the Constitution and to set out principles concerning the care and protection of children. Part three of the Act specifically provides for protective measures relating to the health of children including provisions for consenting to medical treatment and surgical operations, HIV testing, counselling before and after HIV testing and confidentiality of information concerning their HIV/AIDS status. It is therefore essential for professionals such as social workers working with adolescents and children living with HIV to ensure that the best interests of the children and adolescents are upheld in all interventions. The guidelines specifically seek to ensure that when working with ALHIV and their caregivers, social workers promote the best interests of these adolescents.

7.9.5. Promotion of Equality and Prevention of Unfair Discrimination Act (Act No 52 of 2000)

The Promotion of Equality and Prevention of Unfair Discrimination Act aims to promote equity and address discrimination based on race, gender, disability and unfair discrimination against individuals on the basis of their HIV/AIDS-positive statuses. In addition, the Act outlines actions regarded as unfair discrimination and provides remedies for those who have been unfairly discriminated against. This aligns well with

these guidelines, since ALHIV and their primary caregivers often experience discrimination and stigma which social work practitioners have a professional duty to combat.

7.9.6. Protection of Personal Information Act – POPIA (Act No. 13 of 2014).

The Protection of Personal Information Act (POPIA) seeks to ensure that the personal information of individuals is collected, processed, and stored in a lawful manner. It also aims to promote the right to privacy of individuals' personal information and to ensure that it is protected by both public and private bodies. This Act is therefore central to ensuring that social work practitioners collect and process information concerning ALHIV and their caregivers in compliance with the provisions of POPIA. This includes ensuring that the information is not collected without their consent as required by Section 11 and that it is stored properly in compliance with the provisions of Section 14.

The next section focuses on policies that specifically address ALHIV and their primary caregivers and the management and retention of ALHIV in care including psychosocial support needed for disclosure and adherence to ART treatment.

7.9.7. The National Strategic Plan for HIV, TB and STIs 2023-2028 (NSP)

The NSP serves as a roadmap to guide South Africa's responses to HIV, TB and STIs. It is therefore the primary national policy on HIV/AIDS and related issues in South Africa. Any intervention designed to respond to issues of HIV should be aligned to the NSP. The approach adopted by the NSP is multisectoral people- and communities-centered, aiming to reduce the socio-economic barriers and increase access to prevention and treatment services for HIV, TB and STIs. Therefore, the NSP requires social service practitioners such as social workers to ensure that when planning, implementing or evaluating interventions for HIV, they should do so by placing the interests of people such as ALHIV and their caregivers as well as their communities, at the centre while also promoting collaboration with other professionals or stakeholders.

7.9.8. Guidelines for Social Service Practitioners: Enabling Access to HIV Testing Services for children, adolescents and youth

The purpose of these guidelines is to guide social service practitioners to identify individuals and families at risk of HIV infection early and to provide PLHIV with psychosocial support interventions. Moreover, the Guidelines for Social Service Practitioners highlight the roles and responsibilities for social services practitioners which, among others, aim to provide individual and group-based interventions. Therefore, the guidelines for social service practitioners will also be central to the proposed ones, specifically in guiding social workers on how best to respond to ALHIV and their family members who may be at risk of HIV infection.

7.9.9. Adherence guidelines for HIV, Tuberculosis (TB), and Non-Communicable Diseases (NCDs)

The purpose of the adherence guidelines for HIV, TB and non-communicable diseases (Adherence Guidelines) is to provide a standardised framework for healthcare workers (including social work practitioners) on how to educate, provide adherence counselling and support to people taking medication for HIV, TB and non-communicable diseases, with the aim of linking them to care, retention to treatment and adherence to medication. They provide standardised education on HIV, treatment for ALHIV and their primary caregivers, it is necessary to understand the illness and the importance of adhering to treatment. ALHIV who are struggling with adherence to HIV treatment are provided with in-depth support and counselling to address any challenges they may be facing with the potential to hamper their adherence. Lastly, it guides the process for children and adolescents in disclosure counselling to help and support ALHIV and their primary caregivers in understanding the importance of disclosure. These Adherence Guidelines will undoubtedly reinforce the proposed guidelines to support caregivers and ALHIV.

7.9.10. Disclosure Guidelines for Children and Adolescents in the context of HIV, TB, and non-communicable diseases

The main purpose of the Disclosure Guidelines for Children and Adolescents in the Context of HIV, TB and Non-Communicable Diseases (hereinafter the Disclosure Guidelines) is to empower and equip all stakeholders involved by providing a framework and model to support health care professionals in rendering services to

primary caregivers and their children or ALHIV. Providing support and guidance to address the specific needs of primary caregivers and family members relating to disclosure, increase case findings of children and adolescents living with HIV or who are diagnosed but have not been disclosed to. Supporting disclosure of HIV diagnoses is part of the duties of social workers who are working with ALHIV, which is why the disclosure guidelines will also form part of the policy provisions guiding the proposed guidelines.

7.10. THE SCOPE OF PRACTICE IN SOCIAL WORK CONTEXT

Social work practice incorporates a wide range of areas, including mental health, disability, child protection, family support, schools, domestic violence, addiction and health which include working in the field of HIV. These areas of practice intersect and enable social workers to address the intricacies of human needs across various settings and populations (National Association of Social Workers, 2024). In addition, social work practice involves a variety of intervention methods such as case work, group work and community work.

7.10.1. The general guidelines for social work interventions process

Social work intervention is defined as an action taken jointly by the client and the social worker with the purpose of bringing change in the client's life (Segal, Gerdes & Steiner, 2016). The process starts when a social worker engages with a client, conducts an assessment of the client's circumstances, identifies challenges and strengths, develops an action plan, implements and evaluates the plan, and terminates the process (Kirst-Ashman,2017). Social work interventions are applied through multiple levels namely, the micro level (which involves one-on-one interventions with individuals or families), the mezzo level (interventions with groups) and the macro level (interventions with communities and organisations) (Ebue, Uche & Agha, 2017). It is generally the issues that social workers deal with at each level that determines whether or not to move on to the next level. For example, a social worker supporting an individual ALHIV (the micro level) might find issues that involve her family and friends and therefore move further from the micro level to the mezzo, which may be a circle of the ALHIV's friends or classmates. At the mezzo level, she may find other issues requiring intervention at the macro level and therefore decide to conduct advocacy or similar programmes across the broader community.

The South African DSD in partnership with its Non-profit Organisations developed a framework for Social Welfare Services to inform how a comprehensive, integrated, rights-based, well-resourced, and quality developmental social welfare service must be implemented (DSD, 2013). Table 7.1, as adapted from the Framework for Social Welfare Services, gives an overview of the nature of social welfare services, the levels of intervention, the beneficiaries of social welfare services and the strategic focal areas of service delivery. The prevention of HIV/AIDS as well as the care and support of PLHIV as some of the strategic focal areas for service delivery, though specific reference to primary caregivers caring for PLHIV is not pertinently made. In a nutshell, the proposed guidelines should consider the provisions of this framework.

Table 7.1: Integrated framework for social welfare services

Nature of the social welfare services to be offered	Levels of intervention	Beneficiaries of social welfare service	Strategic focus areas of service delivery
• Promotion, prevention and interventions • Social assistance (food parcels) and relief (referrals for social grants, education, food parcels). • Protection and statutory • Social support • Therapeutic, restorative, and rehabilitative support • Continuous care • Economic development (i.e. financial literacy programmes)	• HIV Prevention • Early intervention for ALHIV and families who tested HIV positive • Statutory intervention (consent for testing and disclosure) • Reconstruction and aftercare (disclosure and HIV education for family members). including primary caregivers.	• PLHIV including children and ALHIV • Primary caregivers of ALHIV • Families of PLHIV	• Poverty alleviation • Social integration and cohesion • Family preservation • Care and protection of PLHIV • Prevention, treatment, care, and support for ALHIV and their primary caregivers • Support for mental and social health/wellness of ALHIV and their primary caregivers • Victim empowerment against stigma and discrimination

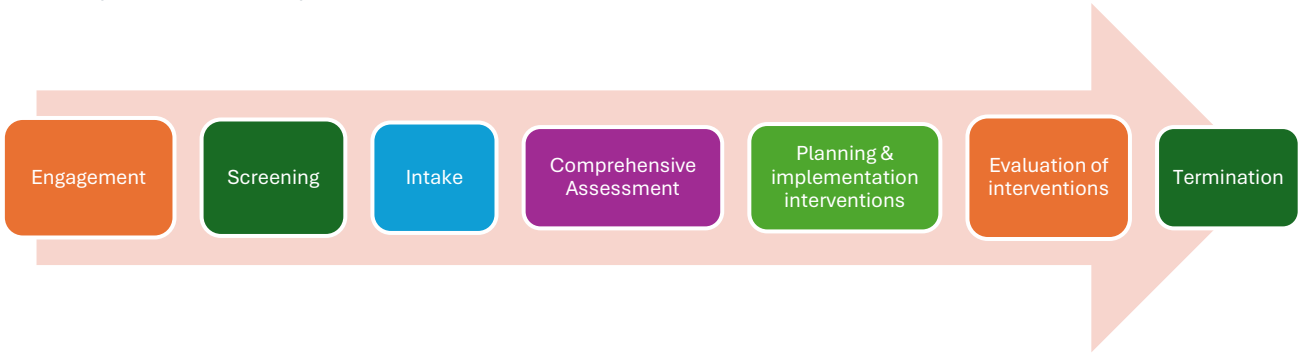
Adapted from: The Framework for Social Welfare Services (DSD, 2013).

In implementing the framework for social welfare services and providing services to primary caregivers and ALHIV, social workers utilise traditional intervention methods namely casework and group work. Specific guidelines following these methods are outlined below.

7.10.2. Specific guidelines for casework intervention

Social casework is a method employed by social workers to understand individual client-specific problems, needs and life circumstances based on one-on-one relationship (Irshad Rahman, 2021; Fjeldheim, Levin & Engebretsen, 2015). The social worker engages with clients or family through one-on-one (either face-to-face or virtual) interactions and provide counselling, support and guidance or link them with relevant resources to facilitate change in their lives. In implementing case work as an intervention method, the social worker may follow seven steps as shown in Figure 7.1 below:

Figure 4: A depiction of seven steps of social casework intervention



The steps are unpacked in detail below:

7.10.2.1. Engagement

The point of engagement is the initial stage where ALHIV, caregivers and/or their families meet with social workers for the first time to access a variety of services (DSD, 2013). It is the point where a positive and trusting relationship is established between a social worker and a client, through skills and techniques such as active listening and rapport building.

Based on the findings of this study, the guideline proposes certain activities to be undertaken by a social worker during the engagement stage of the casework intervention process with ALHIV and their caregivers, as follows:

(a) Create a conducive environment for primary caregivers and ALHIV by conveying a non-judgmental attitude, warmth, respect, unconditional positive regard and empathy, since HIV is a sensitive topic which is associated with discrimination and stigma.
(b) Emphasise the importance of collaboration between the social worker and the primary caregiver and ALHIV or family for them to feel a sense of ownership of the process which will in turn empower them to take charge of their lives.
(c) Begin the screening process of the challenges they experience and assess their needs.

To provide quality service at the engagement stage, the social work practitioner should have sound knowledge of the service delivery system, HIV programmes and psychosocial interventions, policies and legislation guiding social welfare service delivery. Some of these policies and legislations and other guidelines are outlined in section 7.8 above. Once she has engaged with the clients, the social worker will proceed to the screening stage.

7.10.2.2. Screening

Screening is a process that enables a social worker to understand the challenges and needs of her clients (primary caregivers and/or ALHIV) and their families. Once the needs and challenges are identified and understood, the social worker will consider the kind of services or programmes that will be required through which the issues presented by these primary caregivers can be addressed.

Screening takes place through an interview (which can either be face-to-face or virtually through platforms such as Microsoft teams or other equivalent means), with either the primary caregiver and the ALHIV, or with the primary caregiver alone or ALHIV or member(s) of their family. During screening, the social worker should assess if the challenges presented can be dealt with through individual counselling, family therapy or group intervention within the organisation or if it needs to be referred for further interventions. To fully understand the clients' presenting issues and determine the necessary intervention, social workers should consider the following:

(a) Allow both ALHIV and caregivers to freely express themselves.

(b) Evaluate the information shared by both ALHIV and caregiver to determine if they meet the eligibility criteria for the specific service provided within the organisation.
(c) In cases where a referral is necessary, the client will immediately be referred for further intervention. Where it is not required, the process will proceed to the intake level.

7.10.2.3. Intake

Intake is a process of collecting personal information of a client or family (in the context of these guidelines, it will be the primary caregiver and/or ALHIV or their family members) by a social worker on their initial request for services. The social worker collects the client's background, current situation and needs to determine the kind of support they might need and their eligibility for the services from within the organisation.

A process of intake is conducted after an agreement between the social worker and the client is reached, and informed consent is sought from the primary caregiver and ALHIV.

During the intake stage with ALHIV and their caregivers, the social worker may undertake the following activities:

(a) Collect intake forms where the social worker gives demographic information and presents issues/challenges, relevant history and contact information of the client and/or the family. The collection and processing of this information should always be done legally in compliance with POPIA, the Children's Act (see section 7.8.3 and 7.8.6 of this chapter) or any other legislation, based on the client's consent within the conditions of the POPIA.
(b) For the purpose of intervening in issues of ALHIV and the caregivers, essential information to be recorded on an intake form may be things such as presenting problems, personal details of caregiver and ALHIV and recommendations (See Appendix 7 for an example of an intake form specifically for social workers involved in issues of ALHIV and the caregivers).
(c) Based on the information during the intake process, the social worker determines if the client and/or family will be provided with services from within the organisation or if she should be referred for external services. Should she

decide that the intervention be in-house, a comprehensive assessment should be conducted as outlined below. Should she decide to refer the client to other organisations for further intervention, a referral form may be conducted specifying the following:

i. Presenting problem
ii. Reason for referral
iii. Demographic information of the primary caregiver and ALHIV without disclosing HIV status.

In cases where a decision is made to continue with an intervention within the organisation, the process should then move from the intake stage to comprehensive assessment stage as outlined below:

7.10.2.4. Comprehensive Assessment

Assessment is a process through which the social worker analyses the collected information to determine pressing issues, needs and strengths of the client and or family to develop a suitable intervention plan (Segal et al., 2016). The DSD (2013) recommends a developmental approach to assessment as a way to focus on the risk and resilience factors for the client (primary caregiver and ALHIV) and/or family. The process of assessment reduces stress while exploring the clients and/or family's strengths abilities to resolve difficulties using their own skills and knowledge so that they are not disempowered by the helping process.

In conducting a comprehensive assessment for the purpose of supporting ALHIV and the caregivers, social workers may consider undertaking the following activities:

(a) Using a risk assessment tool to guide the assessment process. The tool should include the primary caregiver, children or adolescent living with HIV and any other family member cared for by or staying with the primary caregiver. A suggested tool is provided as an attachment in Appendix 7.
(b) Focusing on the needs, challenges and resources of the primary caregiver and ALHIV or family.
(c) Developing an Intervention plan to determine the form of intervention which will either be case work, focusing on the individual client including family therapy; group work intervention; both casework and group work interventions; or intervention at community level through community work.

(d) Where necessary referring the client and/or family to other required services as per identified needs.
(e) In some instances, facilitating connection to relevant resources such as support groups and other services in line with the assessed needs.

Once assessment is conducted, the intervention should be planned and implemented. This is where a decision is made on whether or not to use casework, group work or community work intervention.

7.10.2.5. Planning and implementation of interventions

Planning involves developing a strategy to achieve what was identified as a need during the assessment phase. A social worker should at this stage coordinate collaboration between herself and the primary caregivers, ALHIV and/or family to create specific steps to address the identified need through the chosen intervention. At this stage, social workers should be mindful of the following aspects of planning as proposed by Kirst-Ashman (2017):

(a) They should not dictate or impose the intervention plan on the client or family but ensure collaboration.
(b) Collaboration between the social worker and client/or family should involve prioritising the identified needs so that most critical ones are addressed first.
(c) Although collaboration is essential, the social worker should take the lead in assisting the client or family to identify alternative interventions.
(d) The social worker should assist the ALHIV and primary caregivers to evaluate the advantages and disadvantages of each course of action decided upon and make a decision about whether or not they are relevant and effective.
(e) The social worker, ALHIV and their primary caregivers should develop goals that both seek to accomplish through the intervention(s).
(f) The actions and goals of the chosen intervention should guide the contract that details the goals, time frames and responsibilities of each party involved in the process (an example of a contract is attached as Appendix 9).

Implementation is a process where the social worker and clients and/or family translate their plans into actions to achieve the goal of the chosen intervention. This step is implemented based on the plans and a contract. It is a joint process between social worker, primary caregivers, ALHIV and/or family.

Based on the findings of the study that gave rise to the proposed guidelines, primary caregivers might present with the following challenges and needs:

(a) Lack of financial means to address basic needs such as food, clothing, shelter or even transport money for health facility visits.
(b) Stigma and discrimination associated with caring for ALHIV.
(c) Psychological stress due to different HIV-related challenges and parenting-related challenges.
(d) They might therefore need assistance with the following:
    i. financial support, such as linking them to financial aid or employment opportunities
    ii. disclosure counselling
    iii. adherence counselling
    iv. to be linked to psychosocial or socioeconomic support networks.

In implementing the interventions with primary caregivers and ALHIV, the focus should always be on supporting them to cope with an HIV positive status, exploring options to build psychosocial wellbeing by facilitating disclosure, offering adherence counselling and linking them to HIV care and management were necessary. The key considerations below are essential for implementation purposes.

A. Measures for improving adherence and retention in care

(a) Establish trusting relationships with the primary caregiver and the ALHIV.
(b) Provide ongoing counselling focusing on issues of dealing with HIV diagnosis, stigma, discrimination and barriers to disclosure of HIV-positive status by primary caregivers.
(c) Provide individual and joint sessions between the primary caregiver and ALHIV to deal with any other parental or HIV-related challenges that they might encounter.
(d) Explore and identify the challenges that might impact on adherence, jointly with the primary caregiver and/or ALHIV and identify solutions to ensure continuous adherence to ART treatment.
(e) Provide HIV treatment literacy on how to take ART.
(f) Facilitate access to health facilities for treatment.

(g) Ensure continuous follow up by primary caregivers and ALHIV with health facilities.

B. Material and nutritional support

Material and nutritional support for primary caregivers and their ALHIV are crucial in ensuring the full benefits of adherence to ART treatment. If during consultations it emerges that the family fails to meet material and nutritional needs, the social worker should facilitate connection and access. The following key considerations may be essential in this regard:

(a) Social grants: Social workers should facilitate access and link primary caregivers who qualify for social grants with SASSA. Furthermore, they may where necessary, also assist in facilitating access to necessary documents such as identity documents and birth certificates through the Department of Home Affairs.

(b) Food support programme: Families that are eligible for a food support programme must be linked and assisted to access vouchers, food parcels, and daily meals where available at community-based centres of the DSD and other organisations.

(c) Financial support programmes: Social workers should also facilitate and link primary caregivers to programmes that facilitate financial literacy or support.

C. Disclosure counselling and support

Disclosure refers to the process whereby a child or adolescent gets to know about their own or their caregiver's HIV positive status. It is a gradual process of giving age-appropriate information regarding the illness of the child, adolescent or caregiver, which starts from partial disclosure to full disclosure when the child or adolescent has the cognitive and emotional maturity to process such information (DOH, 2016).

In providing disclosure counselling and support, social workers need to take into consideration that disclosure is a process, be aware of factors that might contribute to non-disclosure or poor disclosure from primary caregivers as well as the advantages and disadvantages of disclosure. Additionally, they should consider the levels of disclosure (non-disclosure, partial and full disclosure) based on age-appropriate information and the child or adolescent's level or maturity. In addressing the challenges

or barriers to disclosure, the best interest of the child as provided by the children's Act should be considered. The following key considerations are essential:

(a) The need to be guided by appropriate legislation, guidelines, frameworks, principles, and professional code of ethics, including the rights of children and the importance of getting consent prior to the disclosure process.
(b) The disclosure process should be client-centered, or family-centered and move at a pace, timing and intensity that is suitable for the primary caregivers and ALHIV.
(c) Follow-up visits by a social worker are crucial to support and monitor the adolescent's emotional response and understanding of the illness.
(d) The disclosure process should be age-appropriate and guided by the outcome of the specific assessment of the child or adolescent's cognitive abilities.
(e) In certain circumstances, disclosure should be done in a multidisciplinary team with appropriate stakeholders based on the best interests of the child or adolescent.
(f) Sensitivity to cultural beliefs and practices is essential at this stage and social workers should respect such wherever they prevail.

Once an intervention is planned and implemented, it should be evaluated.

7.10.2.6. Evaluation of interventions

Evaluation is a process undertaken by the social worker together with the primary caregivers, ALHIV, family or group to determine and assess the effectiveness of a given intervention in achieving the goals of the client, family or group as well as the goals of the social worker. In doing so, social workers need to have the necessary skills to effectively evaluate service provision and to identify unmet needs and service gaps (Zastrow, 2017). Evaluation will determine termination of services. The following key considerations are essential:

(a) When working with children and ALHIV, the social worker needs to be cautious in closing the case. He or she should rather continue to monitor and reassess the child or adolescent at different developmental stages to ensure they remain healthy and adherent to ART treatment.
(b) The social worker should collaborate with the ALHIV and primary caregivers to evaluate the effectiveness of an intervention.

7.10.2.7. Termination

Termination is the last step, also called disengagement. It is the stage where the social worker together with the client, family or group terminates the helping process that was established at the onset of the intervention (Sekudu, 2015). The framework for social welfare services recommends that termination be a process agreed upon by both social worker and clients. This process should only happen when the ALHIV and/or primary caregivers' needs are met, and when they have been empowered and therefore self-reliant (DSD, 2013). Termination may also happen when the needs are not met, but the social worker wishes to refer the client for service continuation by other professionals. When a decision to terminate a service is made, the following aspects must be considered:

(a) Termination must be properly planned and agreed upon.
(b) Clients should be prepared for termination. Preparing clients for termination will minimise the risk of having them being overwhelmed by losing a relationship which they established and maintained with a social worker for some time.
(c) Where termination is made because the intervention goals are met, clients should be encouraged to return if they still need assistance or even just to update the social worker on progress in their lives.
(d) Where termination is due to referral, the following may be considered:
    i. The client should be party to a referral decision and where possible even decide on where to be referred to (i.e. a specific organisation/ professional).
    ii. A receiving professional/organisation should be prepared and provided with exact details of the requested intervention.
    iii. Referral should be done on a referral form (see Appendix 11) detailing the client's personal information, background and details of a presenting problem as well as details of the social worker referring to the case.
    iv. Once a referral is made, a follow-up should be made preferably on the day the client is expected to report at such an organisation.

Sometimes a client is referred within the same organisation for another intervention such as group work, which is the next part of the discussion.

7.10.3. Specific guidelines on group work with caregivers and ALHIV

Group work is a social work method involving individuals who are helped to enhance their functioning through a group work programme by a social worker who, among other things, guides their interactions through planned activities in line with their needs to develop coping skills for better management of their challenges (Rahman, 2021). Social work practice with groups is founded on the principle that people are enhanced by interpersonal experiences that are motivated towards collectively defined goals and satisfying peer relationships (Chukwu, Chukwu, and Nwadike, 2017).

For the proposed guidelines, group work will focus on structured sessions where primary caregivers and ALHIV come together to share their experiences, gain support, educate each other about the disease, manage stigma, improve coping mechanisms and advocate for their needs in a supportive and non-judgmental environment with the aim of improving their quality of life by fostering connections and shared understanding. According to Anthony (2020) the process of group work intervention should unfold as outlined below.:

7.10.3.1. Establish the purpose of the group work

The social work practitioner should begin by identifying and planning the purpose of the group, of which for these guidelines will be a multi-purpose group as per the needs of the clients. Based on the issues raised by the caregivers, ALHIV and social workers in a study that gave rise to these guidelines, proposed that groups should provide support and education to ALHIV and the caregivers to be able to effectively cope with the challenges associated with HIV. The suggested purpose for these groups could be the following:

(a) For caregivers, the purpose could be to serve as a platform for informational (including effective parenting) and psychosocial support (emotional support to cope with HIV-related stress) to the caregivers so that they can have a good relationship with ALHIV and effectively manage the challenges associated with HIV and its related challenges.

(b) For ALHIV the group purpose could be to serve as a platform where ALHIV can realise their behavioural problems (risky behaviours), and relationship issues and receive the necessary support (including information sharing and adherence support) and guidance from both their peers and the group leader.

7.10.3.2. Planning of the group work process

Planning is necessary for a successful group. Planning encompasses articulating a group's purpose, assessing potential group members, recruiting the members, developing group activities and preparing the environment for group work. It is also crucial to develop an action plan for achieving the objectives of the group and to ensure that such plans take into account the background of the participants and the available time to facilitate the group. The purpose, structure, time frame and size of the group are crucial for effective functioning of the group and should be part of the plan (Poulin, Matis & Witt 2018; Toseland & Rivas, 2022).

7.10.3.3. Recruitment of group members

Social workers can recruit primary caregivers and ALHIV who meet the inclusion criteria from their caseloads, the organisation they work for or other organisations in the community (Toseland & Rivas, 2022). In recruiting potential members, social workers should consider primary caregivers and ALHIV who have given consent to be part of the group. For ALHIV, the caregivers should further provide the necessary assent indicating no objections to joining and participating in the group. Once potential members are identified, they should be recruited, screened and selected for inclusion on condition that they meet the required criteria. The inclusion criteria should guide the recruitment of both caregivers and ALHIV.

For ALHIV, recruitment and enrolment may only happen if they:

(a) are aware of their HIV diagnosis
(b) have given written consent to join the group and their parents have given the necessary assent to support their enrolment, and
(c) are aged between 15 and 20 years[6].

In the case of caregivers, the criteria may be as follows.

Caregivers who:

(a) are living with or caring for an ALHIV

[6] The age criteria is guided by existing literature which indicates that ALHIV in South Africa have poor adherence to ART and find it difficult to navigate through physiological, social, and behavioural challenges at a time when risk-taking and vulnerability to mental health problems are common when dealing with their HIV-positive diagnoses (Mahlasera, 2020; Brittain et.al., 2018; Winskell et.al., 2016).

(b) are aware of the type of group they are joining (caregivers of adolescent living with HIV), and
(c) have given written consent to join the group.

7.10.3.4. Screening and selection of group members

In screening potential members, social workers should conduct assessments similar to the one outlined in case work (see section 7.9.1.1.). However, in group work they should ensure that all the potential members (primary caregivers and ALHIV) are screened individually to determine if they are eligible. The social worker should also ensure that primary caregivers and ALHIV are matched with the most suitable groups based on their needs and preferences (research findings on which the guidelines are based, point to a need for peer support programmes and HIV education). It is also recommended that such a group should be closed with no more than 15 participants due to the sensitivity of the topic. The following key considerations are essential in guiding social workers when screening and selecting the ALHIV and parents:

(a) *Ability to interact and communicate with other people*. Members who are for whatever reason, unable to communicate and interact with others may not benefit from the group and therefore risk rendering the group unable to achieve its objectives. Care should also be exercised to avoid unfairly discriminating against members who may benefit and contribute to the aims of the group.
(b) *Demographic similarities and differences*. The demographic similarities and differences may either enhance or inhibit the group functionality. For example, having one member with extremely different cultural practices in a group where the majority members have similar practices might either risk marginalisation of such a member or enrich the group's functionality and therefore benefit him/her greatly. Selection should therefore be made wisely balancing potential marginalisation against the objectives of the group and his/ her interests as well as the interests of other members.
(c) It is crucial to also select caregivers who are aware of the type of group they are joining and who have given consent, since sensitive issues might be discussed (e.g. HIV status of the children/adolescent).
(d) In terms of ALHIV, selection should only be directed to those who have been disclosed to (meaning ALHIV who know that they are HIV positive) in order to avoid accidental disclosure which might harm the ALHIV.

7.10.3.5. Listing and mobilising required resources

It is crucial to list the resources needed for the group, which may be a venue, materials such as old newspapers, chart papers, pencils, manpower (e.g. co-facilitator) and more. A major resource for a group with primary caregivers and ALHIV is private space to facilitate the group, due to the sensitivity of HIV as well as the fear of stigma and discrimination. Social workers need to be certain that the space mobilised is suitable for achieving the group goals and meeting the needs of the members.

7.10.3.6. Conducting group sessions and recording the process

Once the goal has been clearly formulated, potential members identified and screened and resources mobilised, the group process can be implemented in the form of group sessions. Table 7.2 below outlines ten suggested sessions for groups of caregivers and ALHIV respectively. The group process must be properly recorded in a prescribed manner in the form of reports for professional accountability purposes, organisational audits and to plan effectively for future sessions (an example of a group process report is attached as Appendix 10).

7.10.3.7. Reflection and evaluation

Social workers should help primary caregivers and ALHIV reflect on the outcome of the sessions. Feedback given by the participants and observations made by the facilitators can be used to evaluate the effectiveness of the techniques used during each session and to assist in planning improvement strategies. Reflections and evaluations should be done at the end of each session in writing through questions formulated by the social worker or can be done in the form of verbal feedback particularly for participants who are unable to read and write.

Table 7.2 below focuses on the group sessions for primary caregivers and ALHIV which includes a joint session. The themes covered in each session are guided by suggestions from primary caregivers, ALHIV and social workers who participated in a study which led to the development of these guidelines. Lessons were also drawn from the findings based on the needs of primary caregivers as reported by both the social workers, ALHIV and caregivers. They also influenced the themes covered in each session.

Table 7.2 The group sessions for primary caregivers and ALHIV

SESSIONS FOR CAREGIVERS' GROUPS	SESSIONS FOR ALHIV'S GROUPS
• **Session one: Introduction and orientation** Members get to know each other. The group purpose structure, procedure and ground rules are established. Sensitivity of HIV and assurance of confidentiality is maintained, and a trusting relationship is established with utmost respect to all group members.	• **Session one: My Homies** Members are introduced to the group as their new home and a safe space where they can freely express themselves without being judged or blamed in any way. They are also afforded a space to get to know each other; the purpose, structure, procedure and ground rules are established, including opening and closing traditions.
• **Session two: Stress management** Here the focus is on the causes of stress, signs of stress and the strategies for coping with stigma, problem-solving, and communication. A trusting relationship is still maintained with members experiencing respect from both other members and the social worker as a group leader.	• **Session two: Choose smart, make better decisions** The focus is on making good decisions which include discussion on values and thoughts about difficult choices and disclosure. YouTube or other videos may be used for modeling decision-making among adolescents. Visual materials such as chats can be used for presentations.
• **Session three: HIV education and adherence (treatment literacy)** Basic education is provided on HIV including issues related to the mode of HIV transmission and how to prevent it as well as the following: signs and symptoms of HIV, CD4, immune system, viral load and how HIV is	• **Session three: How HIV works** Helping ALHIV understand what it means to be HIV positive and what happens inside their bodies, including education on viral load and CD4 count. Here the aim is to empower the ALHIV on the basics of HIV to enable them to understand the importance of responsible decision-making to take care of themselves and others. In this

managed. The focus is on supporting primary caregivers and ALHIV to understand medication, treatment regimens, set up daily medication routines and understand when to seek medical attention for medication side effects. In this session a health care professional could be invited to give more information about the clinical components HIV and HIV medication	session a health care professional could be invited to give more information about the clinical components HIV, CD4, viral load and HIV medication
Session four: Disclosure: The session will focus on the importance, advantages and disadvantages of disclosure, different levels of disclosure and the challenges and barriers of disclosure. Caution is exercised in view of the sensitivity of the topic. Caregivers who are struggling with disclosure are supported throughout the process.	**Session four: Shame, dealing with stigma and discrimination** The focus is on ALHIV to understand stigma and discrimination and best ways for managing it. The session also enables ALHIV to learn about aggressive and assertive behaviours and the benefits and drawbacks thereof.
Session five: Dealing with stigma and discrimination: With caution still exercised to the sensitivity of the topic, the focus is now on the impact of stigma and discrimination as well as coping strategies and ways to reduce stigma and discrimination.	**Session five: Coping with being HIV positive and understanding loss** The session focuses on understanding medication and dealing with being HIV positive. Here ALHIV will be empowered on accepting their uniqueness (with care exercised not to encourage self-isolation/self-stigmatisation) due to the level of care required by their condition.

Session six: Financial support and literacy The focus here is on equipping and supporting primary caregivers with knowledge to effectively manage their resources, build a safety net, grow their own food, increase overall food security and enhance nutrition.	**Session six: What's love got to do with it? Having healthy relationships** The focus is on navigating relationships by learning about healthy and unhealthy relationships and exploring choices and learning negotiation skills. Videos and role plays may be used to explore techniques and skills for negotiation relationships.
Session seven: Positive parenting Session seven focuses on improving parenting confidence in primary caregivers to enable ALHIV to speak freely about their fears and concerns and encourage primary caregivers' commitment to support the health and wellbeing of ALHIV.	**Session seven: Safe with one or none: Staying safe in sexual relationships** The session focuses on sexual risky behaviours and how to stay safe. ALHIV are enabled to explore their individual strengths and weaknesses in relationships and to use their strengths to build and maintain safe sexual relationships and avoid unsafe ones.
Session eight: Effective communication This session focuses on equipping primary caregivers with skills to communicate with ALHIV about sexual health-related decision- making prior to facilitating a joint session.	**Session eight: Know your methods: Avoid the risks of teen pregnancy** The theme of teenage pregnancy is addressed with attention on the negative consequences for both males and females. Discussion on different contraceptive methods, risk and how to avoid teenage pregnancy are central to this session.
Session nine: a joint session of ALHIV and caregivers focusing on communication skills	

The session will focus on creating a safe space to discuss sensitive topics related to the health of ALHIV, strategies for active listening and addressing potential challenges associated with the relationship between the ALHIV and primary caregivers**.** During this session, members are also prepared for termination.	
Session ten: Evaluation and termination This session reflects on the caregivers' experiences of the group and celebrates successes. It also prepares caregivers to cope better outside the group. Room is left for caregivers who might wish to return for further support or guidance.	**Session ten: A real buddy: Getting support from our friends.** This session enables ALHIV to reflect on their experiences and to celebrate successes. It also re-emphasizes the significance of adherence and the strengthening of buddy support for ART adherence.

7.10.4. Guidelines on community development to caregiver and ALHIV support

Community intervention is a process through which social workers focus on meeting community needs, identifying problems and finding resources relevant to the identified needs and planning and executing programme activities (Irshad Rahman, 2021; Chukwu, Chukwu, & Nwadike, 2017). Through community work, the social worker focuses on broader wellbeing of communities rather than on individuals or specific groups. Some of the presenting issues brought to the attention of social worker by ALHIV and their caregivers may be broader than case work and group work interventions and therefore require community work methods. For example, the stigma and discrimination associated with caring for ALHIV as reported by social workers in the study on which these guidelines are based, was identified as a community issue. In implementing community work processes, the social work practitioner may follow the process below as outlined by Swanepoel and DeBeer (2016):

Figure 5: A depiction of community work process



The steps are explained below:

7.10.4.1. Step1: Contact making

This stage is normally guided by what transpired either during the individual intervention or the group intervention where a pattern of issues that involve the entire community such as severe stigmatisation of ALHIV and their caregivers was identified. In such instances, a social worker might want to address it through community education in the form of anti-stigmatisation advocacy programmes across the wider community. She will then begin the process by making initial contacts with key members of the community who are also the so-called gatekeepers (i.e. ward councillors, traditional leaders, religious leaders, and others). The purpose here is mainly to establish relationships with them and to get to know the community. The following key considerations are essential for social workers during this stage:

(a) Attend community meetings to understand issues that emanate from the community in relation to HIV, ALHIV and the caregivers.
(b) Visit healthcare centres to observe any issues and activities concerning HIV, ALHIV and caregivers.
(c) Address meetings on issues concerning HIV, ALHIV and caregivers.
(d) Participate in community forums such as local radio stations.
(e) Establish relationships with community gatekeepers.

7.10.4.2. Step 2: Need identification

Although needs have been identified through initial methods such as case work or group work, it has to be properly verified that it is indeed a community-related issue or a need during the second stage which Swanepoel and De beer (2016) call the need identification stage. Here the needs (i.e. to end stigmatisation and enhance social cohesion) are verified and resources available for assisting in addressing such needs, are identified. To verify an identified need, social workers must consider the following essentials:

(a) Conduct focus group discussions
(b) Conduct surveys
(c) Facilitate community dialogues.

7.10.4.3. Step 3: Planning

This step entails developing goals, objectives and strategies to address the needs identified. In this context, the overall aim may be to build social cohesion by dispelling misconceptions around HIV and PLHIV in the community. From this aim, objectives such as the following may be set:

(a) Conducting educational awareness programmes in the community on HIV/ADS, stigma and discrimination.
(b) Identifying resources required for the implementation of the activities.
(c) Identifying key stakeholders to support the project.
(d) Involving community members in the planning process through workshops, meetings, or forums.

7.10.4.4. Step 4: Implementation

Implementation involves the acting on what was planned based on the identified needs of the community. It involves organising and coordinating community events (e.g. campaigns, community dialogues and more), providing services, advocating for change, or working with other community stakeholders to meet the identified needs. The following are key considerations that social workers may consider in the implementation of the plan:

(a) Building and organising community engagement by facilitating community dialogues about HIV-related issues and raising awareness on stigma and discrimination of PLHIV and their families.
(b) Organising and participating in health awareness days such as World AIDS Day.
(c) Engaging the community in the implementation and monitoring of the project.
(d) Ensuring monitoring and documentation of the progress and outcomes of the intervention.
(e) Regularly communicating with community members and other stakeholders involved by providing updates, feedback, and support.

(f) Shaping policy by advocating for the rights of PLHIV and those affected and participating in and influencing policy making that will benefit the wellbeing of primary caregivers and PLHIV including ALHIV.

7.10.4.5. Step 5: Evaluation and termination

This is the last step of community intervention, and it involves the evaluation of the process and results of the community project to sustain or maintain change and terminate if needs are met. The following are key considerations that social workers may consider for evaluation and termination of a community intervention:

(a) Involving the community members and stakeholders in the evaluation process.
(b) Gathering ongoing feedback on the interventions from the community and stakeholders to assess if goals and objectives were met.
(c) Conducting surveys, case studies, feedback sessions with community members
(d) If feedback indicates that the project is not successful, engaging with the community to replan and implement revised plan.
(e) If feedback indicates that the project was successful and needs were met, then the community work intervention will be terminated. Moreover, the social work practitioner should ensure smooth transition and sustainability of the achieved goals by collaborating with the community and creating a sustainability plan, ensuring responsibility is transferred to the community members and lastly ensuring ongoing support if any issues emerge.

7.11. CHAPTER SUMMARY

This chapter presented the proposed guidelines for supporting caregivers and ALHIV. It specifically addressed the situational analysis of the state of HIV epidemic in South Africa, followed by legislative and policy frameworks for guiding social work practitioners when implementing the guidelines. The South African Constitution, various pieces of legislations such as POPIA and some policies were highlighted as available instruments to support the implementation

of the proposed guidelines. The social work intervention process and the framework for social welfare services were discussed with levels to be followed for implementation of the framework. Lastly, specific attention was given to social intervention methods such as case work, group work and community work, with a proposed outline of the process to be followed for each of these methods.

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APPENDIX 1: ETHICAL CLEARENCE CERTIFICATE

UNISA

COLLEGE OF HUMAN SCIENCES RESEARCH ETHICS REVIEW COMMITTEE

19 March 2024

NHREC Registration # :
Rec-240816-052
CREC Reference # :
31368018_CREC_CHS_2024

Dear Ms Jeaneth Linki Matsimbi

Decision:
Ethics Approval from 19 March 2024 to 19 March 2025

Researcher(s): Name: Ms. J. L. Matsimbi
Contact details: 31368018@mylife.unisa.ac.za
Supervisor(s): Name: Dr. M. R. Lekganyane
Contact details: lekgamr@unisa.ac.za

Title: A multi-perspective review of the experiences, challenges and needs of primary caregivers caring for adolescents living with HIV: Social work practice interventions to support caregivers.
Degree Purpose: PhD

Thank you for the application for research ethics clearance by the Unisa College of Human Science Ethics Committee. Ethics approval is granted for one year.

The ***high-risk application*** *was reviewed by* College of Human Sciences Research Ethics Committee, in compliance with the Unisa Policy on Research Ethics and the Standard Operating Procedure on Research Ethics Risk Assessment.

The proposed research may now commence with the provisions that:

1. The researcher(s) will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.
2. Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study should be communicated in writing to the College Ethics Review Committee.
3. The researcher(s) will conduct the study according to the methods and procedures set out in the approved application.

University of South Africa
Preller Street, Muckleneuk Ridge, City of Tshwane
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APPENDIX 2: PERMISSION LETTER TO CONDUCT RESEARCH AT FRIENDS FOR LIFE

Research title: *A multi-perspective review of the experiences, challenges and needs of primary caregivers caring for adolescents living with HIV: social work practice interventions to support caregivers.*

Researcher: Jeaneth Matsimbi

Request for permission to conduct research at Friends for life

Date: 01 May 2023

Ms Lulama Nomgca- Sulupha

Chief Executive Officer

85-11th Road,

Kew,

2090

Telephone number: 011 440 7766

Email address: lulama@friendsforlife.org.za

Dear Ms Sulupha

I, Jeaneth Matsimbi am doing research with Dr MR Lekganyane, in the Department of Social Work at the University of South Africa, towards the Degree of Doctor of Social Work.

We hereby approach you with the request to ask permission to conduct a research project in your organisation. It would also be appreciated sincerely if I could be assisted with the recruitment and engagement of potential participants who meet the inclusion criteria, by making the research known and setting up contact lines with the researcher.

The study is entitled: *A multi-perspective review of the experiences, challenges and needs of primary caregivers caring for adolescents living with HIV: social work practice interventions to support caregivers*.

The aim of the study is to:

- Develop an in-depth understanding of the experiences, challenges and needs of primary caregivers in relation to caring for ALHIV.
- Develop an in-depth understanding of the challenges and needs of primary caregivers caring for ALHIV as perceived by the ALHIV and the social workers rendering services to them.
- Request suggestions from caregivers caring for ALHIV, the ALHIV and social workers rendering service to them on how social workers can support caregivers caring for ALHIV
- Proffer suggestions for social practice interventions in supporting caregivers caring for ALHIV.

We are seeking permission to conduct this research at your organisation as you are rendering services to adolescent living with HIV and their primary caregivers.

The study will entail the following:

- It will focus on collecting information about the experiences, challenges and needs of primary caregivers caring for adolescents living with HIV and also on what social work practice interventions needs to support these primary caregivers.
- Information will be collected from three groups of participants, namely primary caregivers, adolescents living with HIV and social workers rendering assistance to them.
- Participants will be requested to participate in face-to-face interviews with the researcher. They will be requested to respond to a set of biographical and data collection questions related to the topic. The interview will take about 60 minutes at a venue and time convenient to participants.
- Participation is voluntary and participants are free to withdraw at any time without giving a reason. They will receive a copy of the information sheet and be asked to sign a written consent form if they decide to participate in the study.

- Participants names will be kept anonymous, data collected will not be linked to any participants and will be kept confidentially. Hard copies of the collected data will be kept in locked cupboard.
- Participants will not receive any incentives or compensation for participating in the research study and they will not incur any costs to participate in the research study.
- The information gathered through this research project will inform the suggestions for social work practice interventions by social workers in supporting caregivers caring for ALHIV.

The benefits of the study

the nature of the experiences, challenges and needs for support in relation to their caregiving role of the caregivers caring for ALHIV, would become known through this research. This in turn will inform social work services benefitting the caregivers and ALHIV. Moreover, through this research, the gap in the body of social work knowledge related to this topic would be addressed.

Potential risks

As this is sensitive topic that may even be regarded as a “stigma-related topic”, the researcher is aware of the fact that speaking about aspects related to the topic may be difficult and even bring up strong emotions for the primary caregivers and the ALHIV. To minimise the negative consequences of participating in this research, the researcher will:

- Remain attentive to participants’ levels of comfort and discomfort. If the researcher becomes aware that participating in this research project evokes strong emotional responses from a participant, she will stop the interview and allow the participant to regain his or her composure.
- In the case of speaking about the topic remaining too distressing for a participant, the interview will be terminated, the participant debriefed and arrangements made for the participant to go for counselling with a social worker contracted for this purpose.
- In the event of any abuse and/or neglect becoming apparent, in executing her legal duty as social worker to intervene, the researcher will withdraw

the participant from the research and arrange for social work intervention that may be required.

Feedback procedure will entail:

- The findings of this study will be submitted to the University of South Africa in the form of a thesis for the fulfilment of an academic qualification.
- Feedback about the findings will be disseminated in a form of a research report which will be made available to you.
- The findings of this study will also be shared in journal articles and/or conference proceedings.

Your permission for me to undertake this research at your institution will be highly appreciated.

Yours sincerely



Jeaneth Matsimbi

Principal Investigator

APPENDIX 3: RESPONSE LETTER



85-11th Road, Kew 2090, Gauteng, South Africa
Tel: +2711440-2762 Fax: +2711440-9002 Email: info@friendsforlife.co.za
P.O Box 2336, Houghton 2041, Gauteng, South Africa

Date: 05 May 2023

APPENDIX 3: PERMISSION GRANTED TO CONDUCT RESEARCH AT FRIENDS FOR LIFE.

Research title: *A multi-perspective review of the experiences, challenges and needs of primary caregivers caring for adolescents living with HIV: social work practice interventions to support caregivers.*

Dear Principal Investigator

Mrs. Jeaneth Matsimbi

Trust you are well.

Friends for Life hereby grant you permission to conduct your research on A *multi-perspective review of the experiences, challenges and needs of primary caregivers caring for adolescents living with HIV: social work practice interventions to support caregivers.*

You are welcome to conduct your research within our organisation. We also acknowledge that the research will assist us as the organisation, as fundraising marketing strategy to donors.

FFL will appreciate to receive the outcome of the research.

APPENDIX 4: REQUEST TO PARTICIPATE IN A STUDY (PRIMARY CAREGIVERS)

Research title: *A multi-perspective review of the experiences, challenges and needs of primary caregivers caring for adolescents living with HIV: social work practice interventions to support caregivers*

Researcher: Jeaneth Matsimbi

Ethics clearance reference number: 31368018_CREC_CHS_2024

Date: March 2024

Title: A multi-perspective review of the experiences, challenges and needs of primary caregivers caring for adolescents living with HIV: social work practice interventions to support caregivers

Dear Prospective Participant

My name is Jeaneth Matsimbi and I am doing research with Dr MR Lekganyane, in the Department of Social Work at the University of South Africa, towards the Degree of Doctor of Social Work. We are inviting you to participate in my study entitled *A multi-perspective review of the experiences, challenges and needs of primary caregivers caring for adolescents living with HIV: social work practice interventions to support caregivers*

WHAT IS THE PURPOSE OF THE STUDY?

This study is expected to collect important information that could assist with the following:

- Developing an in-depth understanding of the experiences, challenges and needs of primary caregivers in relation to caring for adolescents living with HIV (ALHIV).
- Developing an in-depth understanding of the challenges and needs of primary caregivers caring for ALHIV as perceived by the ALHIV and the social workers rendering services to them.
- Requesting suggestions from caregivers caring for ALHIV, the ALHIV and social workers rendering service to them on how social workers can support caregivers caring for ALHIV

- Formulating suggestions for social work practice interventions in supporting caregivers caring for ALHIV.

WHY AM I BEING INVITED TO PARTICIPATE?

This type of research study has not been conducted in South-Africa before, and there is a need for this research in the field of social work. Therefore, I am inviting you to participate in the research to enable me to empower social workers to support caregivers caring for adolescents living with HIV.

WHAT IS THE NATURE OF MY PARTICIPATION IN THIS STUDY?

You will be requested to participate in an interview with me. The interview will last about 60 minutes, and it will take place at a venue and a time convenient to you. You will be requested to respond to the following biographical and topical questions:

Section A: Biographical/demographic information

1. What is your age?
2. Which gender do you associate yourself with?
3. What is your ethnicity?
4. What is your current employment status?
5. What is your highest educational qualification?
6. How are you related to the ALHIV in your care?
7. When did you find out that the adolescent in your care is HIV-positive?
8. How long have you been living with an ALHIV?

SECTION B: Topical questions

1. Tell me how it is to stay and care for an ALHIV?
2. What challenges do you experience in relation to caring for ALHIV?
3. What are your needs in relation to caring for ALHIV?
4. Have you reached out social workers for assistance in relation to caring for the ALHIV in your care? If so, what kind of assistance did you request?
5. What suggestion do you have on how social workers can support primary caregivers caring for ALHIV?

CAN I WITHDRAW FROM THIS STUDY EVEN AFTER HAVING AGREED TO PARTICIPATE?

Participation is voluntary and there is no penalty or loss of benefit for non-participation. You are under no obligation to consent to participation. If you do decide to take part, you will be given an information sheet to read through and sign a written consent form. You are free to withdraw at any time and without giving a reason. You will receive a copy of the information sheet if you decide to participate in the study.

WHAT ARE THE POTENTIAL BENEFITS OF TAKING PART IN THIS STUDY?

The experiences, challenges and needs for support of participants (the caregivers caring for ALHIV), in relation to their caregiving role would become known through this research. This in turn will inform social work services benefitting the primary caregivers and ALHIV. In addition, through this research, the gap in the body of social work knowledge related to this topic would be addressed.

ARE THERE ANY NEGATIVE CONSEQUENCES FOR ME IF I PARTICIPATE IN THE RESEARCH PROJECT?

As this is a sensitive topic that may even be seen as a “stigma-related topic”, the researcher is aware of the fact that speaking about aspects related to the topic may be difficult and even bring up strong emotions for primary caregivers and the ALHIV. To minimise the negative consequences of participating in this research, the researcher will focus on the following:

- Remaining attentive to participants’ levels of comfort or discomfort. If the researcher becomes aware that participating in this research project evokes strong emotional responses for a participant, she will stop the interview and allow the participant to regain his or her composure.
- If speaking about the topic remains too distressing for a participant, the interview will be terminated, the participant debriefed and arrangements made for the participant to go for counselling with a social worker contracted for this purpose.

- In the event of any abuse and/or neglect becoming apparent in executing her legal duty as social worker to intervene, the researcher will withdraw the participant from the research and arrange for social work intervention that may be required.

WILL THE INFORMATION THAT I CONVEY TO THE RESEARCHER AND MY IDENTITY BE KEPT CONFIDENTIAL?

Your name will not be recorded anywhere and no one will be able to connect you to the answers you give. Your contribution will be listed under a pseudonym and if necessary you will be referred to in this way in the data, any publications, or any other research reporting methods such as conference proceedings.

Apart from the researcher, only her research supervisors and an independent coder will have access to the data and these individuals will undertake to treat the information confidentially by *signing a confidentiality agreement.* Your answers recorded under your pseudonym, may be reviewed by the individuals mentioned above. Nobody else will have access to the data without your permission.

Apart from being captured in my thesis to be handed in at the University, the data received anonymously from you, may be used for other purposes, such as in a research report, journal articles and/or conference proceedings. Your privacy will be protected in any publication of the information, such as a report of the study that may be submitted for publication. Individual participants will not be identifiable in such a report.

HOW WILL THE RESEARCHER(S) PROTECT THE SECURITY OF DATA?

Hard copies of your answers will be stored by the researcher for a minimum period of five years in a locked cupboard at her home office for future research or academic purposes; and electronic information will be stored on a password protected computer. Future use of the stored data will be subject to a further research ethics review and approval if applicable. After five years, hard copies with data will be shredded and electronic copies will be permanently deleted from the hard-drive of the computer through the use of a relevant software programme.

WILL I RECEIVE PAYMENT OR ANY INCENTIVES FOR PARTICIPATING IN THIS STUDY?

You will not receive any incentives or compensation for participating in the research study. You will also not have to incur any costs to participate in the research study. I will visit you to conduct the interviews.

HAS THE STUDY RECEIVED ETHICAL APPROVAL?

This study has received written approval from the College Research Ethics Committee of the College of Human Sciences at Unisa. A copy of the approval letter can be obtained from the researcher if you so wish.

HOW WILL I BE INFORMED OF THE FINDINGS/RESULTS OF THE RESEARCH?

If you would like to be informed of the final research findings, please contact the researcher Jeaneth Matsimbi. Should you require any further information or want to contact the researcher about any aspect of this study, please contact Jeaneth Matsimbi at 0834523846 or email: matsimbij@gmail.com. Should you have concerns about the way in which the research has been conducted, you may contact Dr MR Lekganyane at lekganmr@unisa.ac.za, or telephone number 012 429 2906. You may contact the research ethics chairperson of the College Research Ethics Committee, Prof KB Khan at Khankb@unisa.ac.za or telephone number 012 429 6549 if you have any ethical concerns.

Thank you for taking time to read this information sheet. I look forward to your participation in this study.

Thank you



Jeaneth Matsimbi

APPENDIX 4: REQUEST TO PARTICIPATE IN THE STUDY (ADOLESCENTS LIVING WITH HIV)

Research title: *A multi-perspective review of the experiences, challenges and needs of primary caregivers caring for adolescents living with HIV: social work practice interventions to support caregivers*

Researcher: Jeaneth Matsimbi

Ethics clearance reference number: 31368018_CREC_CHS_2024

Date: March 2024

Title: A multi-perspective review of the experiences, challenges and needs of primary caregivers caring for adolescents living with HIV: social work practice interventions to support caregivers

Dear Prospective Participant

My name is Jeaneth Matsimbi am doing research with Dr MR Lekganyane, Professor and Senior Lecturer, in the Department of Social Work at the University of South Africa towards the Degree of Doctor of Social Work. We are inviting you to participate in my study entitled *A multi-perspective review of the experiences, challenges and needs of primary caregivers caring for adolescents living with HIV: social work practice interventions to support caregivers*

WHAT IS THE PURPOSE OF THE STUDY?

This study is expected to collect important information that could assist with Developing an in-depth understanding of the experiences, challenges and needs of primary caregivers in relation to caring for adolescents living with HIV (ALHIV).

- Developing an in-depth understanding of the challenges and needs of primary caregivers caring for ALHIV as perceived by the ALHIV and the social workers rendering services to them.

- Requesting suggestions from caregivers caring for ALHIV, the ALHIV and social workers rendering service to them on how social workers can support caregivers caring for ALHIV
- Formulating suggestions for social work practice interventions in supporting caregivers caring for ALHIV.

WHY AM I BEING INVITED TO PARTICIPATE?

This type of research study has not been conducted in South-Africa before, and there is a need for this research in the field of social work. Therefore, I am inviting you to participate in the research to enable me to empower social workers to support caregivers caring for adolescents living with HIV.

WHAT IS THE NATURE OF MY PARTICIPATION IN THIS STUDY?

You will be requested to participate in an interview with me. The interview will last about 60 minutes, and it will take place at a venue and a time convenient to you. You will be requested to respond to the following biographical and topical questions:

Section A: Biographical Information

1. What is your age?
2. Which gender do you associate yourself with?
3. What is your ethnicity?
4. What is your highest educational qualification?
5. How long have you been living with HIV?
6. How are you related to your primary caregiver?

Section B: Topical Questions

1. Tell me about your experience in living with your primary caregiver.
2. What do you perceive to be the challenges experienced by your primary caregiver in caring for you?
3. What do you perceive to be the needs of your primary caregiver in caring for you
4. How can primary caregivers caring for ALHIV be supported by social workers in terms of their caregiving role?

CAN I WITHDRAW FROM THIS STUDY EVEN AFTER HAVING AGREED TO PARTICIPATE?

Participation is voluntary and there is no penalty or loss of benefit for non-participation. Participants are under no obligation to consent to participation. If you do decide to take part, you will be given an information sheet to read through and sign a written consent form. You are free to withdraw at any time and without giving a reason. You will receive a copy of the information sheet if you participate in the study.

WHAT ARE THE POTENTIAL BENEFITS OF TAKING PART IN THIS STUDY?

The experiences, challenges and needs for support of the caregivers caring for ALHIV, in relation to their caregiving role would become known through this research. This in turn will inform social work services benefitting the primary caregivers and ALHIV. Through this research, the gap in the body of social work knowledge related to this topic would be addressed.

ARE THERE ANY NEGATIVE CONSEQUENCES FOR ME IF I PARTICIPATE IN THE RESEARCH PROJECT?

As this is a sensitive topic that may even be seen as a “stigma-related topic”, the researcher is aware of the fact that speaking about aspects related to the topic may be difficult and even bring up strong emotions for the primary caregivers and the ALHIV. To minimise the negative consequences of participating in this research, the researcher will

- Remaining attentive to participants’ levels of comfort or discomfort. If the researcher becomes aware that participating in this research project evokes strong emotional responses for a participant, she will stop the interview and allow the participant to regain his or her composure.
- If speaking about the topic remains too distressing for a participant, the interview will be terminated, the participant debriefed and arrange made for the participant to go for counselling with a social worker contracted for this purpose.

- In the event of any abuse and/or neglect becoming apparent, in executing her legal duty as social worker to intervene, the researcher will withdraw the participant from the research and arrange for social work intervention that may be required.

WILL THE INFORMATION THAT I CONVEY TO THE RESEARCHER AND MY IDENTITY BE KEPT CONFIDENTIAL?

Your name will not be recorded anywhere and no one will be able to connect you to the answers you give. Your contribution will be listed under a pseudonym and you will be referred to in this way in the data, any publication, or any other research reporting methods such as conference proceedings.

Apart from the researcher only her research supervisors and an independent coder will have access to the data and these individuals will undertake to treat the information confidential by *signing a confidentiality agreement.* Your answers recorded under your pseudonym, may be reviewed by the individuals mentioned above. Nobody else will have access to the data unless with your permission.

Apart from being captured in my thesis to be handed in at the University, The data received anonymously from you, may be used for other purposes, such as in a research report, journal articles and conference proceedings. Your privacy will be protected in any publication of the information, such as a report of the study that may be submitted for publication, but individual participants will not be identifiable in such a report.

HOW WILL THE RESEARCHER(S) PROTECT THE SECURITY OF DATA?

Hard copies of your answers will be stored by the researcher for a minimum period of five years in a locked cupboard at her home office for future research or academic purposes; and electronic information will be stored on a password protected computer. Future use of the stored data will be subject to a further research ethics review and approval if applicable. After five years, hard copies will be shredded and electronic copies will be

permanently deleted from the hard drive of the computer through the use of a relevant software programme.

WILL I RECEIVE PAYMENT OR ANY INCENTIVES FOR PARTICIPATING IN THIS STUDY?

You will not receive any incentives or compensation for participating in the research study. You will not have to incur any costs to participate in the research study. I will visit you to conduct the interviews.

HAS THE STUDY RECEIVED ETHICS APPROVAL?

This study has received written approval from the College Research Ethics Committee of the College of Human Sciences at Unisa. A copy of the approval letter can be obtained from the researcher if you so wish.

HOW WILL I BE INFORMED OF THE FINDINGS/RESULTS OF THE RESEARCH?

If you would like to be informed of the final research findings, please contact the researcher Jeaneth Matsimbi. Should you require any further information or want to contact the researcher about any aspect of this study, please contact Jeaneth Matsimbi at 0834523846 or email: matsimbij@gmail.com.

Should you have concerns about the way in which the research has been conducted, you may contact Dr MR Lekganyane at lekganmr@unisa.ac.za, or telephone no 012 429 2906. Contact the research ethics chairperson of the College Research Ethics Committee, Prof KB Khan at Khankb@unisa.ac.za or telephone no 012 429 6549 if you have any ethical concerns.

Thank you for taking time to read this information sheet. I look forward to your participation in this study.

Thanks you



Jeaneth Matsimbi

APPENDIX 4: REQUEST TO PARTICIPATE IN THE STUDY (SOCIAL WORKERS)

Research title: *A multi-perspective review of the experiences, challenges and needs of primary caregivers caring for adolescents living with HIV: social work practice interventions to support caregivers*

Researcher: Jeaneth Matsimbi

Ethics clearance reference number: 31368018_CREC_CHS_2024

Date: March 2024

Title: A multi-perspective review of the experiences, challenges and needs of primary caregivers caring for adolescents living with HIV: social work practice interventions to support caregivers

Dear Prospective Participant

My name is Jeaneth Matsimbi am doing research with Dr MR Lekganyane, in the Department of Social Work at the University of South Africa towards the Degree of Doctor of Social Work. We are inviting you to participate in my study entitled *A multi-perspective review of the experiences, challenges and needs of primary caregivers caring for adolescents living with HIV: social work practice interventions to support caregivers*

WHAT IS THE PURPOSE OF THE STUDY?

This study is expected to collect important information that could assist with the following:

- Developing an in-depth understanding of the experiences, challenges and needs of primary caregivers in relation to caring for adolescents living with HIV (ALHIV).
- Developing an in-depth understanding of the challenges and needs of primary caregivers caring for ALHIV as perceived by the ALHIV and the social workers rendering services to them.
- Requesting suggestions from caregivers caring for ALHIV, the ALHIV and social workers rendering service to them on how social workers can support caregivers caring for ALHIV

- Formulating suggestions for social work practice interventions in supporting caregivers caring for ALHIV.

WHY AM I BEING INVITED TO PARTICIPATE?

This type of research study has not been conducted in South-Africa before, and there is a need for this research in the field of social work. Therefore, I am inviting you to participate in the research to enable me to empower social workers to support caregivers caring for adolescents living with HIV.

WHAT IS THE NATURE OF MY PARTICIPATION IN THIS STUDY?

You will be requested to participate in an interview with me. The interview will last about 60 minutes, and it will take place at a venue and a time convenient to you. You will be requested to respond to the following biographical and topical questions:

Section A: Biographical Information

1. What is your age?
2. What is your ethnicity?
3. Which gender do you associate yourself with?
4. What is your highest educational qualification in Social Work?
5. How long have you practicing as a social worker?
6. How long have you been providing social work services to ALHIV and their primary caregivers?

Section B: Topical Questions

1. What do you perceive to be the challenges experienced by caregivers in relation to caring for ALHIV?
2. What do you perceive to be the needs of primary caregivers in relation to caring for ALHIV?
3. What social work services do you specifically provide to primary caregivers caring for ALHIV?
4. What kinds of social work services do primary caregivers caring for ALHIV reach out to your organization for?
5. What suggestions do you have on how social workers can support caregivers in terms of caring for ALHIV?

CAN I WITHDRAW FROM THIS STUDY EVEN AFTER HAVING AGREED TO PARTICIPATE?

Participation is voluntary and there is no penalty or loss of benefit for non-participation. You are under no obligation to consent to participation. If you do decide to take part, you will be given an information sheet to read through and sign a written consent form. You are free to withdraw at any time and without giving a reason. You will receive a copy of the information sheet if you participate in the study.

WHAT ARE THE POTENTIAL BENEFITS OF TAKING PART IN THIS STUDY?

The Participants' experiences, challenges and needs for support of participants (the caregivers caring for ALHIV), in relation to their caregiving role would become known through this research. This in turn will inform social work services benefitting the primary caregivers and ALHIV. Through this research, the gap in the body of knowledge related to this topic would be addressed.

ARE THERE ANY NEGATIVE CONSEQUENCES FOR ME IF I PARTICIPATE IN THE RESEARCH PROJECT?

As this is a sensitive topic that may even be seen as a "stigma-related topic", the researcher is aware of the fact that speaking about aspects related to the topic may be difficult and even bring up strong emotions for the primary caregivers and the ALHIV. To minimise the negative consequences of participating in this research, the researcher will focus on the following:

- Remain attentive to participants levels of comfort or discomfort. If the researcher becomes aware that participating in this research project evokes strong emotional responses for a participant, she will stop the interview and allow the participant to regain his or her composure.
- If speaking about the topic remains too distressing for a participant, the interview will be terminated, the participant debriefed and arrangements made for the participant to go for counselling with a social worker contracted for this purpose.
- In the event of any abuse and/neglect becoming apparent, in executing her legal duty as social worker to intervene, the researcher will withdraw the participant from the research and arrange for social work intervention that may be required.

WILL THE INFORMATION THAT I CONVEY TO THE RESEARCHER AND MY IDENTITY BE KEPT CONFIDENTIAL?

Your name will not be recorded anywhere and no one will be able to connect you to the answers you give. Your answers will be listed under a pseudonym and if necessary you will be referred to in this way in the data, any publication, or any other research reporting methods such as conference proceedings. Apart from the researcher, the research supervisors and independent coder will have access to the data and these individuals will undertake to treat the information confidential by *signing a confidentiality agreement.* Your answers recorded under your pseudonym, may be reviewed by the individuals mentioned above. Nobody else will have access to the data unless with your permission.

Apart from being captured in my thesis to be handed in at the University, the data received anonymously from you, may be used for other purposes, such as in a research report, journal articles and conference proceedings. Your privacy will be protected in any publication of the information, such as a report of the study that may be submitted for publication. Individual participants will not be identifiable in such a report.

HOW WILL THE RESEARCHER(S) PROTECT THE SECURITY OF DATA?

Hard copies of your answers will be stored by the researcher for a minimum period of five years in a locked cupboard at her home office for future research or academic purposes; and electronic information will be stored on a password protected computer. Future use of the stored data will be subject to further research ethics review and approval if applicable. After five years hard copies will be shredded and electronic copies will be permanently deleted from the hard drive of the computer through the use of a relevant software programme.

WILL I RECEIVE PAYMENT OR ANY INCENTIVES FOR PARTICIPATING IN THIS STUDY?

You will not receive any incentives or compensation for participating in the research study. You will not have to incur any costs to participate in the research study. I will visit you to conduct the interviews.

HAS THE STUDY RECEIVED ETHICS APPROVAL

This study has received written approval from the College Research Ethics Committee of the College of Human Sciences at Unisa. A copy of the approval letter can be obtained from the researcher if you wish.

HOW WILL I BE INFORMED OF THE FINDINGS/RESULTS OF THE RESEARCH?

If you would like to be informed of the final research findings, please contact the researcher Jeaneth Matsimbi. Should you require any further information or want to contact the researcher about any aspect of this study, please contact Jeaneth Matsimbi at 0834523846 or email: matsimbij@gmail.com.

Should you have concerns about the way in which the research has been conducted, you may contact Prof AH Alpaslan at alpasah@unisa.ac.za or telephone number 012 429 6739 or alternatively Dr MR Lekganyane at lekganmr@unisa.ac.za, or telephone number 012 429 2906. Contact the research ethics chairperson of the College Research Ethics Committee, Prof KB Khan at Khankb@unisa.ac.za or telephone number 012 429 6549 if you have any ethical concerns.

Thank you for taking time to read this information sheet. I look forward to your participating in this study.

Thank you



Jeaneth Matsimbi

APPENDIX 5: CONSENT FORM

CONSENT TO PARTICIPATE IN THIS STUDY

Research title: *A multi-perspective review of the experiences, challenges and needs of primary caregivers caring for adolescents living with HIV: social work practice interventions to support caregivers*

Researcher: Jeaneth Matsimbi

I, _____ (participant name), confirm that the person asking my consent to take part in this research has informed me about the nature, procedure, potential benefits and anticipated inconvenience of participation.

I have read the information sheet (or had it explained to me) and I understand the aim and procedures of the study as explained in the information sheet.

I have had sufficient opportunity to ask questions about it and am prepared to participate in the study.

I understand that my participation is voluntary and that I am free to withdraw at any time without any penalty.

I am aware that the findings of this study will be processed into a research report, journal publications and/or conference proceedings, but that my participation will be kept confidential unless otherwise specified.

I agree to the recording of the interview to be conducted with me.

\I have received a signed copy of the informed consent agreement.

Participant Name & Surname (Please print)		Date:
Participant Signature:		
Researcher's Name & Surname (Please Print		Date
Researcher's Signature		

APPENDIX 6: INTERVIEW-GUIDE - PRIMARY CAREGIVERS OF ALHIV

Section A: Biographical/demographic information

1. What is your age?
2. Which gender do you associate yourself with?
3. What is your ethnicity?
4. What is your current employment status?
5. What is your highest educational qualification?
6. How are you related to the ALHIV in your care?
7. When did you find out that the adolescent in your care is HIV-positive?
8. How long have you been living with an ALHIV?

Section B: Topical questions

1. Tell me how it is to stay and care for an ALHIV?
2. What challenges do you experience in relation to caring for ALHIV?
3. What are your needs in relation to caring for ALHIV?
4. Have you reached out social workers for assistance in relation to caring for the ALHIV in your care? If so, what kind of assistance did you request?
5. What suggestion do you have on how social workers can support primary caregivers caring for ALHIV?

APPENDIX 6: INTERVIEW-GUIDE - ADOLESCENTS LIVING WITH HIV

Section A: Biographical Information

1. What is your age?
2. Which gender do you associate yourself with?
3. What is your ethnicity?
4. What is your highest educational qualification?
5. How long have you been living with HIV?
6. How are you related to your primary caregiver?

Section B: Topical Questions

1. Tell me about your experience in living with your primary caregiver.
2. What do you perceive to be the challenges experienced by your primary caregiver in caring for you?
3. What do you perceive to be the needs of your primary caregiver in caring for you
4. How can primary caregivers caring for ALHIV be supported by social workers in terms of their caregiving role?

APPENDIX 6: INTERVIEW-GUIDE - SOCIAL WORKERS PROVIDING SERVICES TO ALHIV AND THEIR PRIMARY CAREGIVERS

Section A: Biographical Information

1. What is your age?
2. What is your ethnicity?
3. Which gender do you associate yourself with?
4. What is your highest educational qualification in Social Work?
5. How long are you practicing as a social worker?
6. How long have you been providing social work services to ALHIV and their primary caregivers?

Section B: Topical Questions

1. What do you perceive to be the challenges experienced by caregivers in relation to caring for ALHIV?
2. What do you perceive to be the needs of primary caregivers in relation to caring for ALHIV?
3. What social work services do you specifically provide to primary caregivers caring for ALHIV?
4. What kinds of social work services do primary caregivers caring for ALHIV reach out to your organization for?
5. What suggestions do you have on how social workers can support caregivers in terms of caring for ALHIV?

APPENDIX 7: INTAKE FORM

CONFIDENTIAL

Briefly explain at the start of the interview Your name, title, mandate of the organisation and the purpose of the interview, as well as the client's rights in the process including participation, confidentiality and their right to services and information, dignity and respect. Note that in some cases there may be multiple clients in one case		**Intake Ref Number**
Primary Client Surname	**Primary Client First name**	**Primary Client ID Number / Date of Birth**
If client is a child, add details of caregiver(s) below		
Caregiver Surname	**Caregiver First name**	**Caregiver ID Number / Date of Birth**
Presenting problem(s) and expectations of the client *Ask the client to explain their main concerns, expectations and coping skills applied*		
Preliminary / Initial Assessment by the social worker *Provide your professional opinion of the matter that is presented to you*		

Primary Problem Code (see CW 06)		**Other Problem Codes**	
Risk Level (see CW 07)	☐ Emergency 24 hours – 48 hours	☐ High 1 week	☐ Mild 3 weeks

APPENDIX 8: RISK ASSESSMENT FORM

HIV Risk Assessment Form

District		Risk Assessment completed by: (Full Name)	
Organisation		Date	
Service Point		Job Title	
Parent's/Legal Guardian/ Caregiver Full Name		Parent's/Legal Guardian Contact Details	
Child's Full Name		Child's Contact Details	
Child's ID Number		Child's Date of Birth	

PART 1: HIV SCREENING			
Has the child previously been tested for HIV?		Yes	No
UNKNOWN	**If UNKNOWN:** Continue to PART 2, Risk Indicator questions.		
NO	If **NO**: Continue to PART 2 Risk Indicator questions		
YES	If **YES**, please determine whether the test results were:		
	POSITIVE		
	NEGATIVE		
	UNKNOWN		
	If POSITIVE: Ensure that the child is enrolled in a treatment and care programme and support them with adherence and retention.		
	If NEGATIVE: First determine when the test was conducted – if more than 6 months ago and child is over 13 years of age: Proceed to risk assessment questions		
	If WITHIN PAST 6 MONTHS: HIV test not needed. ***(as per HTS Policy)*** **STOP screening and refer to social and behaviour change programme.** If possible confirm documentation of the test results.		

PART 2: RISK INDICATORS		
Circumstantial Indicators (Parental/Family)	Yes	No
Are either of the child's biological parents reported to be HIV positive		
Are one or both of his/her parents deceased due to a known AIDS related illness?		
Does the child have one or more siblings that are deceased? Siblings of the child are deceased *(ask probing questions on the cause of the death, especially if the cause is HIV, TB)*		
Does any member of the household have concerns about addictive substances?		
Has there been incidents of domestic violence in the family?		
If YES to any of the above the CHILD IS AT RISK of HIV and supportive referral for TESTING IS ADVISED (referral to local hospital, clinic or health funded NPO)		

Health Indicators		Yes	No
Has the child been sick for more than three weeks at a time?	Including ANY of the following: • Fever, a cough, shortness of breath, rapid shallow breathing • Runny stomach – continues for 3 – 5 days and happens often e.g., every month • Ear infection (pus (yellow substance) leaking from ear, may have been leaking for a long time and is not responding to treatment or stops when on treatment only to restart again • Skin problems (itchy, spotty skin) • Thrush (rash in the child's mount)		
Is the child small and/or underweight for his/her age?	If available - review the child's road to health card. Does the child not gain weight even if they are receiving regular nutritional meals?		
Has the child been diagnosed with TB?	Check road to health card if available		
Has the child been admitted to hospital in the past six months?	Check road to health card if available		
If YES to any of the above the CHILD IS AT RISK of HIV and supportive referral for TESTING IS ADVISED (referral to local hospital, clinic or health funded NPO)			
Behavioral Indicators			
FOR YOUNGER CHILD		Yes	No
Do you know if the child has been sexually abused?			
Do you suspect that the child may have been exposed to sexual violence? Child has been exposed to sexual abuse (There is a suspicion that the child may have been abused/or it has been reported to you or the police or a social worker) *Please note that all suspicion of abuse **MUST** be reported to a social worker*			
ADOLESCENT/YOUTH INTERVIEW		Yes	No
Do you have an intimate partner?			
Are you sexually active?			
Have you ever engaged in sexual activities with anyone other than your intimate partner?			
Have you been sexually and/or physically abused*? (There is a suspicion that the adolescent may have been, abused/or it has been reported to you or the police or a social worker)*			
Have you been drunk or high on substance and had sex? Adolescent is abusing alcohol or drugs and engaged in sexual activity.			
If YES to any of the above the CHILD IS AT RISK of HIV and supportive referral for TESTING IS ADVISED (referral to local hospital, clinic or health funded NPO)			

PART 3: ASSESSMENT RESULT AND ACTION	
Date of assessment:	
Test Required	
Routine testing every six months required	
Test Not Required	
Child Referred for HIV Testing (indicate where OVCAY is referred to)	
Date for Follow- up:	
Confirmation of testing received:	
Ensure that all Referrals are Entered on the Referral Log and the Referral is noted on the individual child's file	
Social Service Practitioners Comments: Action required: 1. 2.	

APPENDIX 9: SOCIAL WORK INTERVENTION CONTRACT

(For Primary Caregivers and Adolescent Living with HIV)

Organisation Name		**Social worker's names**	
Caregiver (parent/guardian) details		**ALHIV details**	
Name & Surname		Name & Surname	
Age		Age	
DOB/ID no.		DOB/ID no.	

1. PURPOSE OF THE CONTRACT

This contract is established to guide the collaborative intervention process involving the adolescent living with HIV, their primary caregiver(s), and the social worker. The contract aims to support the adolescent's physical and emotional well-being, promote medical adherence, strengthen family relationships, and empower the caregiver(s) in their supportive role.

2. IDENTIFIED ISSUES / NEEDS

1.
2.
3.
5.
6.
7.

3. GOALS OF INTERVENTION

PLAN OF ACTION			
Overall goal. *Briefly describe the overall goal of the intervention. The goal should describe the result or change in the life of the primary caregiver/ALHIV that is agreed with the client that the plan aims to achieve. Goal should also include when it is estimated to achieve this goal.*			
Views of the client(s). *Briefly describe the views of the client(s) to address the issues identified in the assessment, including if relevant how their views or wishes changed during the process, and/or if their wishes differ from the action plan below, explain the reasons for this.*			
Issues to be addressed:	**Planned intervention to be taken**	**Due date for intervention**	**Respon sibility** *(may include case*

List key issues or problems identified in the assessment below			*manager, other SSP, other service provider and/or client(s)*
Due Date for Evaluation:			

4. RESPONSIBILITIES OF THE ADOLESCENT

The adolescent agrees to:
1.
2.
3.
4.
5.
6.
7.

5. RESPONSIBILITIES OF THE PRIMARY CAREGIVER(S)

The caregiver(s) agree to:
1.
2.
3.
4.
5.
6.
7.

6. RESPONSIBILITIES OF THE SOCIAL WORKER

The social worker agrees to:
1.
2.
3.
4.
5.
6.
7.

7. CONFIDENTIALITY

All shared information will remain confidential unless disclosure is required by law (e.g., harm to self or others, abuse). The adolescent's HIV status will be handled with strict confidentiality, respecting the adolescent's and caregiver's rights and privacy.

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8. TERMINATION

This contract may be concluded:

- When the intervention goals are met successfully.
- By mutual agreement of the adolescent, caregiver, and social worker.
- If the client family withdraws or disengages from services.

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9. AGREEMENT AND COMMITMENT

We, the undersigned, agree to actively participate in this intervention process and work together toward the best interest of the adolescent.

Name & surname of ALHIV		**Signature**		**Date**	
Name & surname of Primary caregiver		**Signature**		**Date**	
Name & surname of Social worker		**Signature**		**Date**	
Name & surname of Supervisor		**Signature**		**Date**	

APPENDIX 10: GROUP WORK PLANNING AND REPORTING

Facilitator name and surname		**Date of the session**	
Type of a group (Open or closed group)		**Number of participants**	
Target group (who is the participants)		**Topic of the session**	
Duration of session		**Curricula used**	

Section A: Planning (this section is completed before conducting the group session)

Aim of the group *(what do you want to achieve)*	
Brief description of group activities and the resources needed	
Activity	**Resources needed**

Section B: Report (this section is completed after the group session was conducted)

Comment on the group process – discuss the major highlights/challenges		
Comment on the learning material and the knowledge and experience of participants		
Action points (any tasks or actions to be done after the group session)		
What needs to be done?	**Who needs to do it?**	**By when should it be done?**

Compiled by:		**Date:**	**Signature**
	Designation:		
Approved by:		**Date:**	**Signature**
	Designation: Supervisor/Manager		

Please note: attach an attendance register

APPENDIX 11: REFERRAL FORM

REFERRING ORGANISATION DETAILS:

Date Referred		**Organisation Name**		**Client Household Reg. or File Nr or Registration Number/Unique ID**	
Contact Number		**Physical Address**			
Referred by			**Designation**		

RECEIVING SERVICE PROVIDER DETAILS:

Service provider Name			
Contact Number		**Physical address**	
Attention		**Designation**	
Service(s) Required:	◯HIV test ◯Adherence ◯CD4 Test ◯PrEP ◯VMMC ◯eMTCT ◯Mental Health ◯PEP ◯STI's ◯TB ◯Nutrition ◯SRHS ◯Child Care ◯Psychosocial Support ◯I ACT Adult Support ◯I ACT Adolescent Support ◯Grant Support ◯Legal Support ◯Food Support ◯Drug related SAPS services ◯Medical services ◯Citizenship documentation ◯Forensic medical exam ◯Psychological services ◯ Career/Educational services ◯ Shelter Other (specify below in Presenting Problem)		

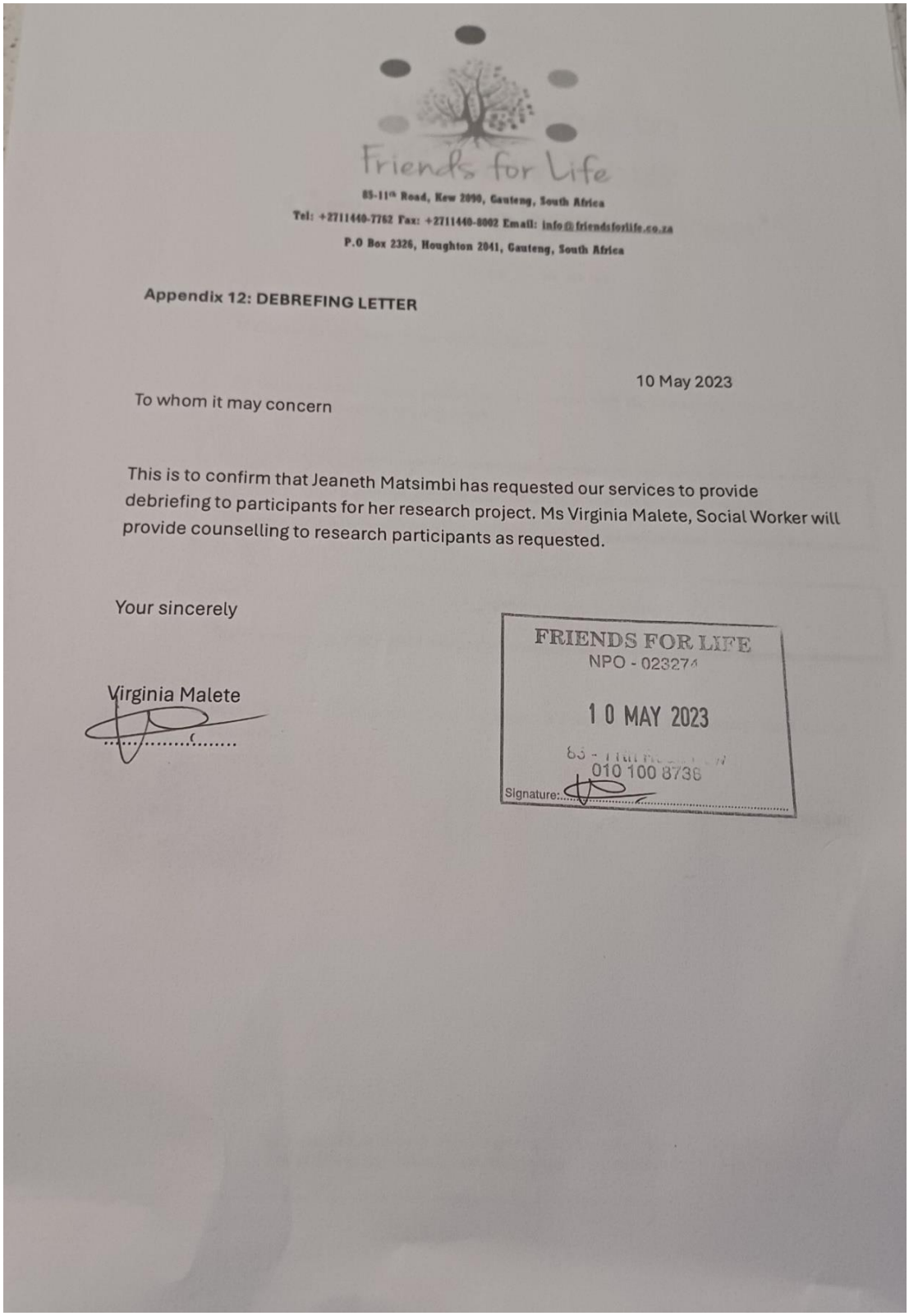
DETAILS OF CLIENT:

Name						**Surname**		
Gender	**Male**		**Female**		**Age**		**Date of birth**	
Contact Number			**Physical address**					
Guardian Details *(if different from those of child)*	**Name & Surname**		**Telephone no**		**Physical address**		**Relationship with the child**	

PRESENTING PROBLEM *(Please write detailed observation. You may use another page or the back of this page if space is insufficient):*

Signature of referrer:		**Signature of Supervisor:**	
Date:		**Date:**	

APPENDIX 12: DEBRIEFING LETTER



Friends for Life

85-11th Road, Kew 2090, Gauteng, South Africa
Tel: +2711440-7762 Fax: +2711440-8002 Email: info@friendsforlife.co.za
P.O Box 2326, Houghton 2041, Gauteng, South Africa

Appendix 12: DEBREFING LETTER

10 May 2023

To whom it may concern

This is to confirm that Jeaneth Matsimbi has requested our services to provide debriefing to participants for her research project. Ms Virginia Malete, Social Worker will provide counselling to research participants as requested.

Your sincerely

Virginia Malete

FRIENDS FOR LIFE
NPO - 023271
10 MAY 2023
010 100 8736
Signature: