CONTRIBUTION OF CARETAKERS TO THE LOW SELF-ESTEEM OFADOLESCENTSLIVING WITH HIV/AIDS IN KALUNGU DISTRICT.

CASE STUDY: LUKAYA HEALTHCARE CENTRE.

A dissertation presented to

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Master of Mental Health Counselling Psychology

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July 2025

DECLARATION

UGANDA MARTYRS UNIVERSITY

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Master's Dissertation

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DISSERTATION FINAL DRAFT SUBMISSION FOR MARKING

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Date: 7th July 2025.

APPROVAL

This is to certify that Zalwango Rebecca (2022-M372-20873) did her study (Contribution of Caretakers to The Low Self-Esteem of Adolescents Living with HIV/AIDS in Kalungu District) under my supervision and guidance whose report is now here presented for examination with my approval.

Signature: ____________________

Name: __Lubyayi Francis Desales____

___7th July 2025______

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Incomparable appreciation goes to the Almighty God for the mercy, wisdom and unreserved provision from the time I started the journey of upgrading to this academic stratum, especially for enabling me to complete this research.

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DEDICATION

This dissertation is dedicated to my husband for being understanding and for encouraging me not to give up whenever I felt like not continuing. I also dedicate this piece of work to my children Kitiibwa Bernice and Mwesigwa Kemuel for being patient with me when I didn’t have time for them as a mother, because I had to complete this thesis in the designated time.

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LIST OF ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
ALHIV	Adolescents living with HIV/AIDS
ARV	Anti-retroviral
ART	Anti-retroviral Therapy
CBO	Community Based Organization
CLHIV	Children Living with HIV
HIV	Human Immunodeficiency Syndrome
NGO	Non-governmental organization
OVC	Orphaned and Vulnerable Children
WHO	World Health Organization
PLHIV	People Living with HIV/AIDS
SSA	Sub-Saharan Africa
LHCC	Lukaya Healthcare Center

ABSTRACT

This study was intended to analyze the contribution of caretakers to the low self-esteem of adolescents living with HIV/AIDS. Self-esteem is a person's complete sense of their worth. It is how much someone likes, respects and values themselves.

Research shows that the existence of low self-esteem is high among Adolescents Living with HIV (ALHIV), compared to their HIV negative peers, which is evidenced through the feeling of unworthiness about one's HIV status which prevents them from living a full and enjoyable life. Scholars have attributed this to factors like rejection, loss of social identity and non-disclosure. The contribution of the caretakers to the low self-esteem of ALHIV has been overlooked and is silent in the literature. This study therefore sought to address this gap, found in the literature, by assessing the contribution of the caretakers to the low self-esteem of ALHIV.

A qualitative single case study design was used to collect and analyze data using interview guides. The research was driven by three objectives; To assess the caretakers' knowledge on HIV/AIDS and its impact on the self-esteem among ALHIV, To determine the caretakers' attitude towards the ALHIV, and To establish the challenges caretakers face while taking care of ALHIV in Kalungu district; a case of Lukaya Healthcare Centre.

Lukaya town council was selected because it is one of the hot spots for HIV/AIDS in greater Masaka region, while Lukaya Healthcare Centre is the biggest ART Clinic in the district.

The study found out that most ALHIV have a low self-esteem, according to the scores from the Adolescent Self-Esteem Questionnaire Tool, and caretakers play a big role and have contributed greatly to the low self-esteem of these ALHIV because they have spent most of their time with them while growing up, nurturing them and talking into their lives.

The study further found out that the caretaker' lack of knowledge on the basics of HIV/AIDS, their negative attitude towards the ALHIV and the challenges they face as caretakers while taking care of the ALHIV are some of the things that have caused the caretakers to make this great contribution of to the low self-esteem of adolescents living with HIV (ALHIV).

In order to boost the self-esteem of ALHIV, both ALHIV and caretakers should be sensitized on what self-esteem is, the public in general should be taught the meaning of HIV/AIDS, caretakers should be cautioned on their attitude and should be supported to with income generating activities.

CHAPTER ONE

GENERAL INTRODUCTION

1.1 Introduction

Self-esteem is a person’s complete sense of their worth. It’s a feeling about oneself, encircling beliefs, emotions and experiences. It is generally how much someone likes, respects and values themselves. Wright (2015) also explains self-esteem as an individual’s global evaluation of liking him or herself. He further states that self-esteem is a calculation of one’s strengths minus weaknesses and more of an overall feeling of affection.

The only way social scientists have for measuring self-esteem is through self-reports, and yet people’s feelings of self-esteem are bound to change as they go through their daily lives depending on all sorts of experiences. Many studies have indicated that self-esteem tends to decline early in adolescents but then slowly increase by mid and late adolescence (Ellis, Hoski and Ratnasingam 2018).

Studies have found that one third to one half of adolescents struggle with low self-esteem especially in early adolescent, which is temporary but can lead to various problems including mental illness (Harter 1990). He further states that this low self-esteem is influenced by peer relationships, past experience, societal expectations and criticisms, and family dynamics which include guardian/caretakers and sibling attitude.

On the other hand, Human Immunodeficiency Virus (HIV) infection poses one of the greatest challenges and most serious public health threat globally. The density of this infection is rooted in the complicated interactions between the social, cultural, and biomedical aspects of the disease. The accessibility of a wide array of effective HIV prevention tools and methods, care and treatment, and interventions from different organizations like the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) has not completely stopped PLHIV from dying. However, these interventions have succeeded in reducing on the mortality rate by a certain percentage. UNAIDS (2023) estimated that in 2022, around 630,000 people died from AIDS-related illnesses worldwide, compared to 2 million people in 2004 and 1.3 million in 2010.

The UNAIDS (2023) factsheet states 39 million people globally were living with HIV as of 2022; of which 1.3 million people were new infections. 37.5 million were adults (15 years or older) while 1.5 million were children (0–14 years). At the end of December 2022, 29.8 million PLHIV (76%) were accessing antiretroviral therapy, with only 57% CLHIV having access to care and treatment. Meaning, 43% of the CLHIV do not have access to treatment, or the caretakers are not willing to take on the extra burden of engaging into the essential part of chronic care management.

Certain regions of the globe especially on the African continent are excessively affected by HIV. For instance, in 2022, there were 20.8 million people with HIV in eastern and southern Africa, 4.8 million in western and central Africa, 6.5 million in Asia and the Pacific, and 2.3 million in Western and Central Europe and North America (UNAIDS, 2023).

According to Uganda Media Centre (2020), in Uganda, the prevalence of HIV among adults of reproductive age 15 to 49 years was 5.5 percent (7.1 percent among women and 3.8 percent among men). The magnitude of the epidemic varied considerably across the 11 geographic regions from the lowest being 2.1 percent in North East (Karamoja) region followed by 2.8 percent in West-Nile region; 4.2 percent in Mid-Eastern region; 4.2 percent in North East (Teso) region; 4.5 percent East Central (or Busoga region); 5.5 percent in Mid-Western region; 6.0 percent in central - Kampala; 6.2 percent in Central 2 (Greater Mubende, Luwero and Mukono) region; 6.3 percent in South Western region; 7.6 percent in Mid North region; and 8.1 percent in Central 1 region (greater Masaka, where Kalungu District is located). However, among the children aged 0-14 the magnitude is 0.5% which corresponds to approximately 95,000 children living with HIV in Uganda.

HIV rates are reported to be increasing in sub-Saharan Africa (SSA) despite the many efforts to counter its increase (Lubinga et al. 2016). One consequence of this is that the epidemic is estimated to have orphaned 18 million children under the age of 18 in sub-Saharan Africa, highlighting the dramatic impact of this epidemic for children. Lubinga et al. (2016) further state that Orphaned and Vulnerable Children (OVC) make up over 52 million of the SSA population. Where the HIV epidemic has contributed significantly to the number of OVCs that are now recorded in the statistics. This leaves guardians for these children with a bigger responsibility of raising and nurturing them.

1.2 Background of the Study

The HIV/AIDS epidemic devastating consequences have saturated and reshaped the social, cultural and economic fabric of family lives, rendering children in Uganda and SSA at large destitute and vulnerable. With the latest advances in medical research and the rollout of ARVs in Africa, there is hope that like in countries such as the UK and the USA, HIV will no longer mean a death sentence but rather that infected children will be able to live longer and healthier lives to manage the psychosocial effects of the disease and its consequences, as they undergo their course of life long treatment (Lee & Boyle, 2021).

According to UNICEF Innoceti Research Centre (2006), HIV/AIDS epidemic cuts childhood short. Children are pulled out of school to care for dying parents or to earn money for a living. Many become helpless when their parents die. By the time these children become adolescents, the powerful combination of shame and fear surrounding HIV and AIDS feeds a culture of silence that fuels stigma and inflicts further damage to them. Hungry and lonely, they grieve silently in constant fear that they might be next or that their secret might be told.

HIV/AIDS compromises children's rights to survival, education and health care. The epidemic further jeopardizes children's right to protection from discrimination and abuse and sexual exploitation, including child trafficking and child labour. The situation robs children, adolescents in particular of their rights to grow up in a family environment and to develop to their fullest potential at a very tender age (Jinga et al, 2019). Sometimes they end up in child-headed homes, or with distant relatives in extended families where they are not fully loved or wanted, and yet it is the caregivers in these families that are to take responsibility to care for them, especially ensuring adherence on ART for ALHIV.

Adolescence and early adulthood are a time of learning and growth (Backes and Bonnie 2019). This is also the life stage when most mental health disorders emerge, alongside vast physical, emotional, and social changes. While peer relationships become increasingly important in adolescence, caregivers remain a key potential source of support for adolescent's health and wellbeing. Adolescent-caregiver relationships are an important dimension of family functioning and can affect adolescent mental health. HIV/AIDS orphan-hood on the other hand exposes children to vulnerabilities that are beyond the coping capacity of caregivers; such as, loss of shelter (protection), non-enrollment in school and drop-out, poor health, malnutrition, abuse, and above all threats that are harmful due to stigmatization (Jinga et al, 2019).

Furthermore, Vreeman, McCoy and Lee (2017) state that adolescents living with HIV (ALHIV) often are at a heightened risk of mental health challenges compared to their peers. Poor mental health may reduce adolescent adherence to anti-retroviral treatment, retention in care, and increased risk behaviors, negatively affecting life trajectories and survival.

The growing population of ALHIV poses another health challenge for physicians, mental health professionals and other health care, social and behavioral practitioners who are not prepared on how to deal with paediatric HIV (Britto et al. 2016). ALHIV experience challenges in their social context that are different from their caregivers or parents. Therefore, as these adolescents and young people grow up, their specific life experiences ought to be considered differently from a public health perspective.

In addition to the social challenges, CLHIV and ALHIV must manage ongoing engagement with chronic care management, HIV-related stigma, and lifelong uptake of ART among other things (Toska et al. 2017). The process of HIV management requires the collaboration of different role players in the health care system and beyond. Moreover, the effective collaboration among different stakeholders and key role players in paediatric HIV is significant in improving the lives of CLHIV beyond HIV management.

Amzel et al. (2017) suggests that feedback and approval seeking from peers is a phenomenon that contributes to changes in the establishment of a sense of self among adolescents. In the existing literature, the concept of 'self' has gained wider research attention but the implications of self-esteem, self-efficacy and self-concept is yet to be determined. Until now, self-esteem remains a primary component of social maturity and mental health. It is a construct used to describe individuals' evaluation of worthiness and totalities of qualities or attributes.

Self-esteem is the concept of how human beings value and perceive themselves. This is based on the opinions and beliefs about oneself. Some scholars describe it as self-confidence or self-concept. Smith and Mackie (2007) define self-esteem as what we think about the self; which can be positive or negative evaluations. One’s self-esteem affects a number of factors in the day to day life, for example the value one attaches to him/herself, decision making ability, recognition and acceptance of one’s strengths and weaknesses, ability to try new/difficult things, forgiving oneself and moving on without self-blame, creating time for oneself, believing that you are good

Research from different scholars like Ayemong et al. (2020), Kalomo et al. (2021) and UNICEF (2016) shows that the occurrence of low self-esteem is high among Adolescents Living with HIV (ALHIV), compared to their peers who are HIV free. Worries about the future, health, body image and disclosure are common and having unanswered questions about them, lowers the adolescents’ self-esteem. Feeling guilty and unworthy about one’s HIV status can stop them from taking an active role in society and prevents them from living a full and enjoyable life. The media stories, both positive and negative, are a constant reminder to the ALHIV that they are now ‘different’ in some way.

The contribution of the caretakers to the self-esteem of adolescents in general (high or low) is available in the literature, however, when it comes to discussing the low self-esteem of ALHIV, other factors like stigma/discrimination non-disclosure, loss of societal identification and peer influence are considered, according to scholars like Mathew and Manjula (2021); Ke et al. (2020); and Orth and Van-Wyk (2022). The caretaker's contribution to the low self-esteem of ALHIV has been overlooked and is silent in the literature.

1.3 Statement of the Problem

Research shows that the existence of low self-esteem is high among Adolescents Living with HIV (ALHIV), compared to their peers who are free from HIV. This is evidenced through factors like un-forgiveness, feeling guilty and unworthy about one's HIV status which can stop them from taking an active role in society and prevents them from living a full and enjoyable life.

Scholars have attributed this to factors like rejection, loss of social identity, physical and social consequences of HIV and non-disclosure. The contribution of the caretakers to the low self-esteem of ALHIV has been overlooked and is silent in the literature. The care burden experienced by persons on whom ALHIV depend for support has been overlooked, yet most of them have not embraced it positively. This study therefore sought to address this gap, found in the literature, by assessing the contribution of the caretakers to the low self-esteem of ALHIV.

The bearing of low self-esteem found in adolescents living with HIV/AIDS, necessitates immediate attention and intervention by different stake holders; and until the contributing factors or causes are established, this will remain a dream. This is because it affects the adolescents' adherence to treatment, affects positive living, which leads to poor quality of life and poor decision making, leading to a dull future.

1.4 Research Objectives

1.4.1 General Objective

The purpose of this study was to assess the contribution of caretakers to the low self-esteem of adolescents living with HIV/AIDS, a case of Lukaya Healthcare Centre in Kalungu District.

1.4.2 Specific Objectives

The study was guided by the following objectives:

1. To assess the caretakers' knowledge on HIV/AIDS and its impact on the self-esteem among ALHIV in Lukaya Healthcare Centre in Kalungu District.

2. To determine the caretakers' attitude towards the ALHIV in Lukaya Healthcare Centre in Kalungu District.

3. To establish the challenges caretakers face while taking care of ALHIV in Lukaya Healthcare Centre in Kalungu District.

1.5 Research Questions

The study was guided by the following research questions:

1. How does the caretakers' knowledge on HIV/AIDS impact the self-esteem of the ALHIV in Lukaya Healthcare Centre in Kalungu District?

2. What is the caretakers' attitude towards ALHIV in Lukaya Healthcare Centre in Kalungu District?

3. What challenges do caretakers face while taking care of ALHIV in Lukaya Healthcare Centre in Kalungu District?

1.6 Scope of the Study

1.6.1 Content Scope

The study aimed at establishing the contribution of the caretakers to the low self-esteem of adolescents living with HIV/AIDS, a case of Lukaya Healthcare Centre in Kalungu District. It assessed the caretakers’ knowledge on HIV/AIDS and its impact on the self-esteem among ALHIV, it determined the caretakers’ attitude towards the ALHIV, and also established the challenges caretakers face while taking care of ALHIV in Lukaya Healthcare Centre in Kalungu District.

1.6.2 Geographical Scope

The study was carried out in Lukaya Healthcare Centre in Kalungu District in Central Uganda. Lukaya town council was selected because it is one of the hot spots for HIV/AIDS in greater Masaka (Mayanja, 2021). It has many fishing sites which comprise of fisher folks, it has many Commercial sex workers and long distance truck drivers rest in this area. Lukaya Healthcare Centre is the biggest ART Clinic in the district with over 3900 patients. It is located along Kampala-Masaka road and is owned by AHF-Uganda Cares which is one of the largest providers of free HIV services in the country.

1.6.3 Time Scope

The study reflected a period of four (4) years from 2019-2022. This study period intentionally includes the year 2020 when Covid-19 pandemic sent the children back home (out of school) to stay with the caretakers for a longer period of time. Post Covid-19 pandemic, a number of initiatives have been put forward to curb HIV epidemic, yet the caregivers are still left with challenges of caring for the ALHIV. Thus this period helped in generating comprehensive data which will be used when analyzing the information to help bring the insight on the contribution of caretakers to the self-esteem of adolescents living with HIV/AIDS.

1.7 Significance of the Study

The study deserved high priority because its findings will enable health workers and counselors in gathering information to be applied in the management tasks like allocation of resources, proper planning/implementation of activities because they would be in position to know the reasons for the low self-esteem of the adolescents.

The findings of this study give an insight to the challenges faced by adolescents affected or infected with HIV/AIDS and their caretakers, which enables counselors and health workers of the adolescents to learn how to manage or deal with them.

There are also public health benefits to knowing and understanding the lives of these adolescents and young people and their guardians as they navigate HIV as a chronic illness.

1.8 Justification for the Study

HIV continues to unequally affect adolescents, particularly girls, with a higher prevalence compared to the general population. Lubinga et al. (2016) state that Orphaned and Vulnerable Children (OVC) make up over 52 million of the SSA population where the HIV pandemic has contributed significantly to the number of OVCs that are now recorded in the statistics. The reason for this is that HIV positive children are transitioning into adolescents and adulthood. This leaves guardians for these children with a bigger responsibility of raising and nurturing them.

A report made by Elizabeth Glaser Pediatric AIDS Foundation (2025) clearly states that the HIV pandemic could be reignited if the challenges faced by ALHIV are not addressed. The report explains the urgency to intervene and support these young people is needed in order to maintain the progress that has been achieved and ensure they all have the opportunity to live long, productive lives. This is because HIV/AIDS cuts childhood short by making many children and adolescents become helpless when their parents die. By the time these children become adolescents, the powerful combination of shame and fear surrounding HIV and AIDS feeds a culture of silence that fuels stigma and inflicts further damage to them (UNICEF Innocenti Research Centre 2006).

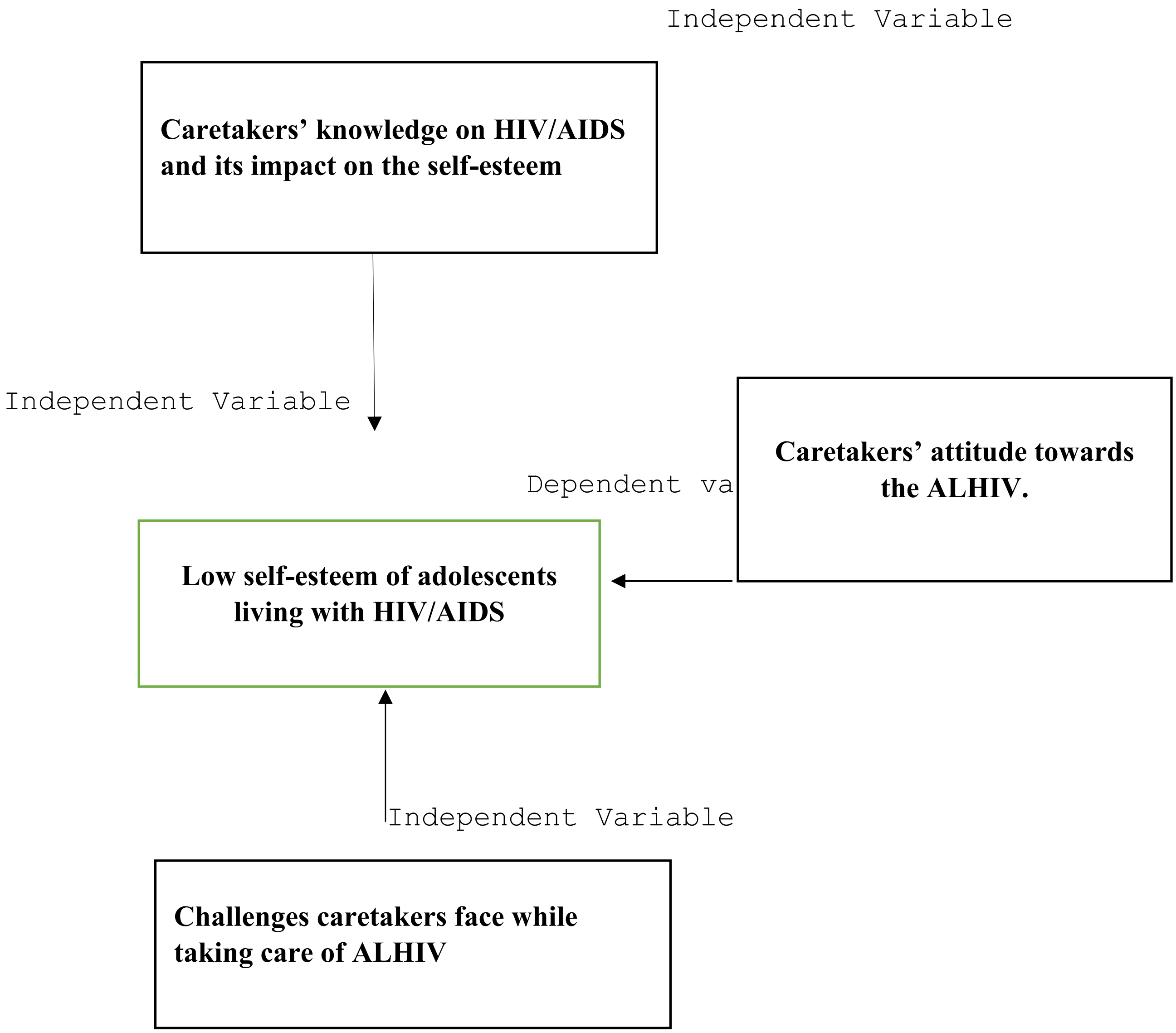
Research from different scholars like Ayemong et al. (2020), Kalomo et al. (2021) and UNICEF (2016) shows that the occurrence of low self-esteem is high among Adolescents Living with HIV (ALHIV), compared to their peers who are HIV free. This is augmented by concerns about the future, health, body image and disclosure are common and having unanswered questions about them. Feeling guilty and unworthy about one’s HIV status can stop them from taking an active role in society and prevents them from living a full and enjoyable life and in the long run impacts negatively on their self-esteem.

The contribution of the caretakers to the self-esteem of adolescents in general (HIV positive and negative) is available in the literature, however, when it comes to discussing the low self-esteem of ALHIV, other factors like stigma/discrimination, rejection, non-disclosure, loss of societal identification and peer influence are considered, according to scholars like Mathew and Manjula (2021); Ke et al. (2020); and Orth and Van-Wyk (2022). The caretaker’s contribution to the low self-esteem of ALHIV has been overlooked and is silent in the literature.

The care burden experienced by persons on whom ALHIV depend for support has been overlooked, yet most of them have not embraced it positively. This study therefore seeks to address this gap, found in the literature, by assessing the contribution of the caretakers to the low self-esteem of ALHIV. The presence of low self-esteem found in adolescents living with HIV/AIDS, necessitates immediate attention and intervention because it affects adherence to treatment and distorts positive living which leads to poor quality of life, poor decision making and loss of hope for the future. Until the contributing factors or causes are established, interventions by different stakeholders will be futile.

1.9 Conceptual Framework

A conceptual framework illustrates the expected relationship between variables and how they come together to draw coherent conclusions (Swaen 2024). Below is the conceptual frame work showing the relationship between the dependent and independent variables.



1.9.1 Conceptual Review

The study sought to analyze the significance of the caretakers on the low self-esteem of ALHIV. Research shows that the existence of low self-esteem is high among Adolescents Living with HIV (ALHIV), compared to their peers who are free from HIV. The reason for this has been attributed to other factors like depression and non-disclosure. The contribution of the caretakers to the low self-esteem of ALHIV has been overlooked and is silent in the literature, yet the care burden these caretakers face is evident. This takes us to the review of literature under the objectives of the study.

1.9.2 Extraneous Variables

Extraneous variables are factors outside of the independent variables and are not being investigated, but can possibly unintentionally influence the dependent variable and results of the study (McLeod 2023). The researcher has to make sure that the independent variable has an effect on the dependent variable; hence all the other variables that could affect the dependent variable must be controlled to ensure validity of the research findings.

Types of extraneous variables include, but are not limited to participant variables, situational variables, demand characteristics, methodological variables and experimenter effects. The researcher in this study identified 4 extraneous variables namely:-

1. Gender and level of education of participants

There was a possibility of gender influencing responses where by male caretakers may not be directly involved in the affairs of the ALHIV because of their busy schedule. On the other hand, the level of education of the participants, both the caretakers and adolescents had a possibility of influencing the findings.

2. HIV sero-status of the caretakers

The HIV status of caretakers could impact their attitude towards the research and hence have an influence on the kind of answers given.

3. Experimenter effects

This can come about when inadvertent actions or prejudices by the researcher could influence the study outcome

4. Time of day

This is a situational variable which has potential to influence participants’ alertness and ability to fully interact during the interview.

The researcher plans to control these extraneous variables through standardization and randomization.

1.10 Definition of Key Terms

1.10.1 Self-Esteem

Ellis, Hoski and Ratnasingam (2018) define self-esteem as the extent to which an individual views themselves in a positive light, reflecting the value they place on themselves. Wright (2015) also explains self-esteem as an individual’s global evaluation of liking him or herself. This means self-respect towards one’s own self-worth and abilities. There are 3 types:- High, Low and Inflated self-esteem.

1.10.2 HIV/AIDS

The Human Immunodeficiency Virus (HIV) is a retrovirus that attacks cells that help the body fight infections and diseases. If left untreated, HIV can lead to a disease called Acquired

Immunodeficiency Syndrome (AIDS) due to low body immunity (WHO 2024).

1.10.3 Caretakers

Colton et.al. (2012) define caretakers in this context as individuals, usually distant family members as individuals who provide daily care and support to children and adolescents living with HIV/AIDS to help them manage the complexities of living with the virus including medication management, emotional support and overall wellbeing.

1.10.4 Knowledge

According to oxford dictionary, knowledge refers to facts, information and skills acquired through experience or education. Elbadawi and Mirghani (2014) define knowledge in the context of HIV as accurate information about the virus, its transmission, prevention and treatment.

1.10.5 Attitude

Attitude is a learned, relatively enduring predisposition to respond favorably or unfavorably to a person, object, or situation. Cherry (2024) defines attitude as the way we negatively or positively respond to something or someone influenced by how we evaluate them.

1.10.6 Challenges

A challenge is something that needs great mental or physical effort in order to be done successfully and therefore tests a person's ability. Challenges are obstacles or difficulties that require individuals to mobilize personal and social resources to overcome them (Giddings 2023).

1.11 Conclusion

In conclusion therefore, this chapter has presented the general introduction, background of the Study, statement of the Problem, research Objectives and research questions. The chapter went ahead to explain the scope of the Study, breaking it down to the content, geographical and time scope. The significance and justification of the study have also been highlighted in this study, followed by the conceptual Framework and the definition of Key Terms.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter is a review that critiques, evaluates and clarifies the literature related to the low self-esteem of ALHIV and the contributing factors; the area of study stated in the topic. A literature review surveys books scholarly articles and other sources relevant to a particular area of research through providing a descriptive critical evaluation of these works in relation to the research problem being investigated (Arlene, 2014). Without literature review, there is neither interpretation of the existing knowledge, nor the identification of the gaps in this knowledge; which makes the research project irrelevant because it is the identified silences that the research seeks to address.

The reasons for reviewing literature include, but are not limited to: getting to know what has already been written about the topic, placing each work in the context of its contribution in understanding the research problem being studied, identifying the gap in the existing knowledge, to acknowledge who the key contributors in this knowledge are, the major debates, arguments assumptions and to relate the seemingly contradicting information from previous studies and to identify silences in them.

This chapter therefore discussed the reviewed existing literature informing the different objectives that the researcher drew from the identified problem of the research. The chapter consists of literature reviewed under these themes/objectives: the caretakers' knowledge on HIV/AIDS and its impact on the self-esteem among ALHIV, the caretakers' attitude towards the ALHIV, and the challenges caretakers face while taking care of ALHIV. The chapter finally gives a summary of the identified knowledge gaps of the reviewed literature

2.2 Reviewing of the literature under the different objectives

2.2.1 Caretakers' knowledge on HIV/AIDS and its impacts on the self-esteem of ALHIV

Studies have shown that majority of the caretakers especially those who are not biological parents could not think of HIV as an illness for the children and adolescents, because they thought their children were young and not sexually active; few of them think of Mother To Child Transmission (MTCT). It is usually after these children have got very sick and tested HIV positive after treating all other suspected diseases in vain (Kasande et al. 2022). They further state that even for the mothers living with HIV do not think of HIV as the illness disturbing their children much as they are in and out of hospital, which in the long run make these children look malnourished or have stunted growth and they end up looking different from their peers.

Because of the vulnerability of the chronic illness faced by the ALHIV, caretakers who lack knowledge on how to handle the challenges that come with raising these adolescents fail to raise them in a socially acceptable manner as they feel these adolescents already have enough burden and should be left to live their life as they wish. However, Bernays (2023) shows how this impacts the self-esteem and the lives of the ALHIV in general when she says that globally, adolescents still suffer relatively poor treatment and social outcomes – not because of lack of access to treatment, but the circumstances around them and their upbringing. She further states that the impact of poor treatment outcomes usually has a negative impact how the adolescents view themselves and determine their self-worth.

More to that, since most of the ALHIV grow up in extended families after being orphaned or abandoned, most parents admit and show fear that they are unable to take care of these children because they lack knowledge and expertise to offer the necessary emotional and psychological support (UNICEF, 2016). This is because of the fact that these children are bereaving the absence of their parents and the HIV sero-status itself. The report further states that a critical feature of a child's social and emotional development is the opportunity to form attachments with a significant caregiver who is warm, sensitive and responsive; lack of these components can have a negative impact on a child's sense of self-esteem and self-worth. It can challenge a child's sense of hope about their future, their life, and relationship opportunities.

Agyemang et al. (2020) explains this clearly when they state that in SSA, specifically Ghana, the occurrence of low self-esteem and depression among adolescents is highly pronounced among the ALHIV. The reason they give for this is that there is need for a professional (mental health practitioner) touch so as to help this vulnerable group, which the caretakers cannot offer because they lack the technical know-how. Whereas these scholars think that professional mental health workers are the only ones who can help the ALHIV, in my opinion, I think it would be prudent if the caretakers are taught and empowered how to handle these situations and more, since they interact with the adolescents more often than the health workers.

Vranda & Mothi, (2013) have a similar observation to that of Agyemang et al. (2020) about the high prevalence of low self-esteem of ALHIV as compared to their peers, and the reason for this, according to them is due to the stigma and discrimination as a result of unpleasant treatment and isolation given to them by their peers as well as their extended family members/caregivers.

In a qualitative study conducted in West Africa by Atanuriba et al. (2021), it is the lack of knowledge that a child born with HIV can live a normal healthy life that makes caretakers perpetrate stigma by reacting badly to their children’s HIV-positive status with fear, shame, guilt and even suicidal ideation. They end up abusing and discriminating the ALHIV, which in the long run impact on their self-esteem as they grow up.

On the other hand, Biadgilign et al. (2011) slightly differ from the previous scholars when they state that in Ethiopia, majority of the caretakers of ALHIV are knowledgeable about HIV, much as they still have some myths and misconceptions, like thinking that HIV/AIDS can be cured with Adherence to ART. McHenry et al. (2016) confirm this when they state that in the communities of Kenya, negative beliefs and misinformation about HIV/AIDS are still common and this instilled caretakers’ lives with fear, particularly about physical, emotional, or social isolation resulting from HIV/AIDS stigma. They further state that these feelings of fear and stigma, coupled with misconceptions negatively impact adherence to treatment, disclosure of HIV status, mental health and self-perception and self-esteem.

Kimera et al. (2021) comes in with a new concept of looking at caretakers in the perspective of both parents and school staff because school going ALHIV spend most of their time in schools, as some are in boarding sections. In the study they carried out in Western Uganda, they posited that schools need to develop a strong knowledge base about HIV/AIDS and support needs of ALHIV and collaborate extensively with external stakeholders so as to build the knowledge gap that the staff members have. This lack of knowledge and insight from the school staff has greatly impacted on the mental health and self-esteem of the ALHIV to the extent that parents and students proposed that teachers should desist from using known and suspected ALHIV as examples in class while talking about HIV/AIDS. They further requested for instituting punitive measures for those who stigmatize and discriminate ALHIVs.

When talking about the knowledge of caretakers of ALHIV in Kabale district, Wadunde et al. (n.d.) state that inadequate caregiver knowledge of HIV/AIDS in one of the major reasons for poor adherence on ART. More to that, in the study conducted in Kampala and Hoima districts, Nasuuna et al. (2019) confirms this when they state that this inadequate knowledge by caretakers is due to failure of these caretakers to attend the counselling sessions and general health educations at the facilities. As the caretakers do not know how to help the ALHIV adhere to their treatment, the ALHIV are not taking their medicines well due to loss of hope and finding no reason for living, which obviously impacts on their wellbeing and self-esteem, yet this impact does not come out well in the literature.

According to Ministry of Health (2010), most caretakers in the community lack HIV knowledge even about the basics like urgently testing and treating children born to HIV positive mothers. Whereas some do not even know where to find these paediatric services, sadly others still think that children infected with HIV will die early. When such children who did not get proper treatment in their early childhood days become adolescents, they develop resentment both for themselves and for the people around them due to the negligence and poor ART adherence fuelled by their caretakers. But even with such information in the literature, caretakers of ALHIV are not featuring anywhere when it comes to accounting for their low self-esteem.

Nyamaruze, Govender and Cowden (2021) bring in a new concept when they explain the link between poor adherence on treatment, and body appreciation or a component of positive body image which is a major concern among adolescents, including those who are HIV positive. Body appreciation is a concept of being respectful, approving, and appreciative of the characteristics of one's body, regardless of shape, weight, and imperfections. An earlier study by Nyamuruze and Govender (2020) showed how vital it is to note that a variety of physical and psychological complications commonly accompany HIV infection, including weight loss, skin lesions, depression, and suicidal ideation. More research on the same has shown that such bodily changes like weight loss, stunted growth and skin scars from lesions affects the image and self-perception of these adolescents.

2.2.2 Caretakers' attitude towards the ALHIV

Attitudes serve a protective role in building or breaking our self-esteem and justifying our actions/beliefs, and this is greatly impacted by the words and actions of the people in our lives contribute and impact a lot on our self- esteem. Burton (2022) states that a child's self-esteem is guided by their parents or guardians. When these caretakers foster positive health and nurturing relationships with their children and adolescents, their self-esteem is improved. He further explains that adolescents develop a low self-esteem because of the attitudes of the caretakers, which causes rejection, hostility and negative criticisms.

Osinowo et al. (2023) make an observation that there is limited research on the attitude of caretakers of ALHIV, especially because the words caretakers and caregivers are used interchangeably in the literature to either mean the guardians at home, or the health providers. They however report that globally, in low income generating homes, the attitude of the ALHIV is poor, as compared to the richer families. In poverty stricken homes, caretakers look at the task of caring for these adolescents as burdensome due to lack of basic needs like food, which results into a negative attitude. Caring for ALHIV is a demanding task that requires economic stability. Singh et al. (2011) also states that caretakers who have support from other family members, and community have taken on the task of caretaking for ALHIV with enthusiasm and have a good attitude towards them. The reverse is true for those who do not have this support. This means that the attitude of the caretakers off ALHIV is prominently dependent on external factors, and slightly on someone’s personality.

Furthermore, in evaluating the attitude of caretakers, Chem et al. (2022) noted that the attitude of caretakers of ALHIV is generally poor due to failure to understand their health-related needs and challenges, which is critical for effective treatment outcomes in SSA, with key areas of focus being stigma reduction, disclosure and mental health. Interventions that address these health needs have often times failed because they are dependent on the perspective and attitude of caretakers, which is not good because they are not willing to go an extra mile to see to it that this vulnerable group needs that additional support.

More to that, a study conducted in Kenya by Mbiyu, Kikuvi and Amukoye (2013) affirms that the practices and attitude of the caregivers of ALHIV is generally negative and has an impact on their adherence levels. This is because, even when these caretakers are HIV negative, they are also susceptible and do suffer stigma from the community and in some schools where these adolescents have been denied vacancies. Poor adherence can lead to a high morbidity and mortality rate, as well as poor mental health outcomes among the CLHIV and ALHIV.

Surprisingly, according to Mandalazi, Bandawe, and Umar (2014), majority of the caretakers of ALHIV in Malawi, and Africa in general, are actually not the biological parents, but guardians from extended families like grandparents. This is not because they are all orphaned, but because the biological parents have a negative attitude towards them and do not want to directly associate with them, and the fact that they have not yet forgiven themselves for infecting their disclosure process becomes hard to initiate, yet the on the other hand feel that the biological parents have abandoned them.

Atanuriba et al. (2021) make an observation similar to that of Rujumba, Mwaka and Ndeezi (2010), where they both noticed that majority of the researchers have concentrated on the PLHIV/ALHIV and health workers, ignoring the experiences, knowledge and attitudes of the caretakers/guardians. In a descriptive study conducted in Uganda, it was found out that the attitude of the caretakers and health workers towards ALHIV is negative and they have not done anything to bridge this gap because they think the adolescents and the children are young and do not notice this attitude.

Lorenz et al. (2016) also conducted a study in rural Uganda and found out that caretakers' attitudes towards the HIV status of ALHIV were frequently negative, with the overwhelming majority believing that the adolescent's life is about to end, and do not deserve to be taken to school or treated like their peers. A similar observation was made in the research conducted by Kimera et al. (2020) who noted that the proportion of ALHIV who drop out of school is high as compared to their peers who are HIV negative. One of the reasons for this is the caretaker's poor or negative attitude towards the ALHIV. Caretakers believe that educating these ALHIV is a wastage of resources because the caretakers themselves do not have hope that these adolescents have a future to plan for. However, the impact of such beliefs and misconceptions from caretakers is not seen in the literature when talking about the low self-esteem of the ALHIV.

2.2.3 Challenges caretakers face while taking care of ALHIV

Despite the intense declines in pediatric HIV incidence and death rates globally, caregivers of HIV-infected children and adolescents continue to face uncountable challenges while taking care of them and often times they do not know how to handle these challenges. Eneh (2010) states that HIV has profound personal and deeply social impact not only on the children it affects, but also on their entire family/caretakers. Typically, children and adolescents who are dependent on their parents face greater danger because of HIV/AIDS, and these families are overwhelmed with countless pre-existing social problems. For instance, in the USA, many of these children and their families are more likely to live in inner cities where illicit drug use, poor housing, and limited access to medical treatment and essential social services pose a challenge.

The HIV/AIDS epidemic in sub-Saharan Africa has had both direct and indirect effects on the population, and the caregivers, especially from the extended family of HIV infected persons have been severely affected. Osafo et al. (2017) noted that the burden is heavier on older persons who have a double burden of caring for their sick and dying adult children, as well as orphaned grandchildren. They further state that such involvement has been observed to negatively affect their domestic economy, health, physical and psychological wellbeing which has in the long run led to weight loss, pain, and depression.

A study conducted in Cape (South Africa), showed that approximately 40% of caregivers reported high levels of orphan caregiving burden.

Feelings of stress and inadequacy concerning their responsibilities as well as anger towards the CLHIV and ALHIV were common (Kidman and Thurman, 2014). To justify for this, household food insecurity and low income were important significant determinants, according to the study. These scholars concluded by saying that caregivers with economic vulnerability and those struggling with their own AIDS-related illness feel most overburdened, as compared to the wealthier caregivers.

More to that, an ethnographic study in two semi-rural communities in South Africa, which examined the experiences of informal caregivers of people living with HIV, reported that the caregivers of ALHIV, who were predominantly women, were poor, unemployed and unmarried, and combined their care-giving role with their traditional roles as homemaker, household head and breadwinner (Akintola, 2009). The extra care needed for proper upbringing of these adolescents is a challenge to the already needy caretakers. The report further indicates that these caretakers experienced physical strains and emotional problems, with risks for being infected with HIV and TB. Important to observe, is that these scholars reveal that there was a dominance of women and the near absence of men in the caretaking of the ALHIV, which resulted from the uncompromising traditional gender divisions of labour.

As if that is not enough, studies have reported on the mental health distress of caregivers of ALHIV in the Niger Delta region of Nigeria who were found to be experiencing stress, anxiety, depression and even suicidal tendencies (Abasiubong, 2011). These findings explain the negative attitude these caregivers develop, ending up verbally spilling abusive words to the ALHIV and they are rarely praised or appreciated, but rather are seen as a burden. The situation is similar in Kinshasa, DR Congo, according to Kipp et al. (2006) where caregivers’ self-reported health status was generally poor and they experienced a great burden from caregiving.

Lindsey, Hirschfeld, and Tlou (2003) had given a similar report in an exploratory and descriptive study which investigated the experiences of caregivers of ALHIV and other chronic and terminal illnesses at home in three districts of Botswana. Caregivers have reported feeling overwhelmed with the demands of caregiving which included physical, psychological and emotional difficulties comprising of feeling exhausted, depressed, and often neglected to attend to their own health.

Lentoor (2015) also found out that caregiving of ALHIV is compromised by inadequate financial resources and single-headed households where mainly grandparents assume the role of primary caregivers. This is because HIV remains a stigmatized illness that weakens support networks, which have a negative impact on the mental health of the caregivers with the majority of women in the study displaying symptoms of depression. As long as the caregivers are not mentally okay, the ALHIV they care for will not be mentally healthy and yet, literature is silent about how the caregivers impact on the self-esteem of the ALHIV.

Caregivers of ALHIV in Ghana were also found to be overwhelmed and under-resourced, yet they are believed to be the primary source of support for children living with HIV/AIDS (Yiryou et al. 2024). Ghanaian family caregivers experience different challenges that affect their children’s antiretroviral therapy (ART) adherence, physical and mental health. They experience overwhelming challenges in their quest to care for their children, which prompted the scholars to suggest that governmental and non-governmental HIV/AIDS program support should include small business skills training and acquisition including capital to help set up small-scale businesses for such caregivers to reduce their financial challenges.

In Kenya, studies provide critical insights to understand the challenges faced by caregivers of ALHIV. The challenges of not being able to navigate care and treatment have resulted into ALHIV becoming lost from care (Lost to Follow Up) (Magak, 2022). Navigating care and treatment means moving to facilities, supervising ART adherence (providing Directly Observed Therapy), reminding the adolescent of facility appointments or accompanying them to clinic, disclosure, among others. All these responsibilities demanded from these caretakers are overwhelming and pause a burden because they are added onto the already existing tasks of taking care of the ALHIV needs apart from HIV related issues.

On the other hand, caregivers in Uganda have reported caregiving burdens including radical disturbances of living arrangements, prolonged travels and absences from their homes. In the study conducted by Osafo et al. (2017), it was found out that taking care of ALHIV in Uganda is burdensome to the caregivers. Their struggles have been found to be centered on material scarcity such as food and funds for daily provisions, illustrating the culture of poverty among these caregivers.

Nasuuna et al. (2019) give a more comprehensive report from the study conducted within the Infectious Diseases Institute pediatric ART program in Kampala and Hoima districts. The elicited challenges of caregivers were more individual than health system based. They included environmental challenges (where some ALHIV are in boarding school or the caretakers work away from home, making it difficult for the caretakers to do close monitoring); personal challenges (failure to disclose to the ALHIV and stigma);

psychological challenges (guilt and depression); financial challenges (lack of food and transport to the facilities); and child-related challenges (treatment fatigue, pill burden and peer influence). All these challenges pause a burden to the ALHIV caregivers, making them fed up and tired of th`e responsibility of caretaking.

2.3 Summary of Knowledge gap

It was evidenced from the literature reviewed that majority of the ALHIV have a low self-esteem greatly caused by the physical, social and psychological environment surrounding them. However, the significance of the caregivers of ALHIV is not documented in the literature. For example, most caretakers are not knowledgeable about HIV/AIDS, they have a poor attitude and face a lot of challenges; all these have been recognized, but their impact on the self-esteem on the ALHIV has not been recorded.

2.4 Conclusion

This chapter has reviewed literature under the different objectives that informed the research questions which were answered. These objectives were; assessing caretakers' knowledge on HIV/AIDS and its impacts on the self-esteem of ALHIV, caretakers' determining the attitude towards the ALHIV and establishing the challenges caretakers face while taking care of ALHIV. The summary of Knowledge gap has also been clearly elaborated.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

A research method is a systematic plan for conducting research. Denscombe (2014) explains that this section describes actions to be taken to investigate a research problem and the justification for the application of specific procedures or techniques used to identify, process and analyze information applied to understanding the problem, thus, allowing the reader to critically evaluate a study's overall validity and reliability.

The methodology section elaborates how the data was collected and how it was analyzed. Without methodology, the reader cannot understand what affected or influenced the findings got. The techniques used must be appropriate to fulfil the overall aim of the study, with articulate reasons why these particular techniques were chosen (Lunenburg and Fredrick 2008). The methodology used can be adopted by other researchers doing a similar research.

This chapter therefore describes the research design, scope of the study (content, geographical and time scope) study area, population of the area, sampling procedures, sampling size and sampling technique. It is also an overview of the data collection methods and instruments, quality control measures, ethical consideration, data analysis and constraints that are anticipated, so as to help the reader understand how the findings were got.

3.2 Research Design

A research design is a structure of a research undertaking the overall plan of the empirical study (Katebire 2007). A design is used to structure the research, to show how all the major parts of a research work together to address the central objective.

This study therefore employed a qualitative single case study design, and qualitative methods of data collection and analysis were used because these enabled the researcher to assess the caretakers' knowledge, attitude and challenges they face while caretaking for ALHIV.

According to Sofaer (1999), qualitative research methods are valuable in providing rich descriptions of complex phenomena; tracking unique and unexpected events. He further states that the best Qualitative research is organized and rigorous, seeking to reduce bias and error to identify evidence that disconfirms initial hypothesis.

3.3 Area of the Study

A study area in research is a broad domain of study encompassing related topics and questions within a particular discipline, defining the scope of investigation, providing a framework for focused inquiry (Luskin 2023). He further states that the area of the Study facilitates organized exploration, collaboration, and knowledge development across diverse subjects.

The area of the study was to analyze the significance of the contribution of the caretakers to the low self-esteem of adolescents living with HIV/AIDS at Lukaya Healthcare Centre in Kalungu District. Indicators to low self-esteem in this study area will be caretaker's knowledge, attitude and challenges of caretakers.

This study area was chosen because it accommodates adolescents and caretakers in relation to the low self-esteem of ALHIV which studies have reported. Different reasons for the occurrence of low self-esteem among ALHIV have been given in these study reports by scholars like Manjula (2021); Ke et al. (2020); and Orth and Van-Wyk (2022); but the caretakers with whom these adolescents stay with has been undermined. This study area therefore helped answer the research questions effectively.

3.4 Population of the Study

The study population according to Ahmad, Alias and Razak (2023) is the complete set of chosen individuals or objectives that are representative in order to enable the researcher to gather and make evidence-based decisions and draw conclusions applicable to the broader context.

The study population included male and female adolescents and caretakers from the age of 18ys and above. The reason for choosing this age was that it is the consensus age for adulthood, and these people were able to give relevant information in relation to the stated research objectives of assessing the caretakers’ knowledge on HIV/AIDS and its impact on the self-esteem among ALHIV, determining the caretakers’ attitude towards the ALHIV and to establish the challenges caretakers face while taking care of ALHIV in Lukaya Healthcare Centre in Kalungu District.

A study population ranging from 18yrs and above represents a key developmental period in terms of decision-making around different areas (Singh 2023).

3.5 Sampling procedures (Sampling size and techniques)

Sampling is the selection of a subset or a statistical sample of individuals from within a statistical population to estimate characteristics of the whole population. Ogula (2005) defines sampling as a process or technique of choosing a sub-group from a population to participate in a study, through selecting a number of individuals that represent the large group.

The researcher in this study used a non-random sampling procedure to be able to answer the research questions got from the objectives. This helped the researcher to get a clearer insight addressing the gap in the literature from the smaller sample being representative of the bigger population of the same category.

According to Dawson (2009), quantitative researchers seek to describe or explain what is happening within a smaller group, unlike quantitative researchers who generalize the result of the research to the whole research population. Qualitative researchers believe that everyone is different and that the same research done on different groups may produce different results. This is the reason they use sampling procedures to be able to generate more meaningful findings.

3.5.1 Sample size:

A sample size is the number of individuals/observations included in a study. It is the number of individuals or items selected to represent a larger population statistically (Staff 2024). The sample size is a critical deliberation in research because it directly impacts the reliability and extent to which the researcher can generalize those findings to the larger population.

The researcher therefore used an absolute size of 100 respondents, because this number is researchable and it will help answer the research questions that will be directed to 50 ALHIV (Adolescents Living with HIV/AIDS) and 50 caretakers

The reason for choosing 100 respondents was that most statisticians agree that the minimum sample size needed to get any kind of meaningful results is 100 (Fox 2024). Bryman (2012) also points out that it is the absolute sample size that is important, not the relative size.

3.5.2 Sampling techniques:

Bryman (2012) defines a sampling technique as a method used to select a subset of a population for research purposes, aiming to represent the larger group. This process involves identifying the specific units, individuals to be included in the study, based on the research questions.

A purposive sampling technique was used in this study because it is strategic and helped in identifying samples which were relevant in answering the research objectives of assessing the caretakers' knowledge on HIV/AIDS and its impact on the self-esteem among ALHIV, determining the caretakers' attitude towards the ALHIV and establishing the challenges caretakers face while taking care of ALHIV in Lukaya Healthcare Centre in Kalungu District.

According to Bryman (2012), the goal of purposive sampling is to select participants in a strategic way so that those sampled are relevant to the research. These participants will include 50 adolescents and 50 caretakers.

3.6 Data collection methods and instruments:

Data collection is the process of collecting and evaluating information or data from multiple sources to find answers to research problems, answer questions, evaluate outcomes and forecast probabilities (Jain 2025).

This section therefore explains how the researcher will generate data from respondents using the selected research method and instruments.

3.6.1 Interviews:

An interview is a qualitative research method that relies on asking questions in order to collect data (George 2023). Interviews allow researchers to explore issues that may not be fully understood or captured through data collection methods.

The researcher used interviews as a method, with an interview guide as the instrument. The targeted groups for this method were the adolescents and the caretakers. The reason for this is that most caretakers are not eloquent, and some adolescents did not reach secondary as most of them dropped out of school due to covid-19 pandemic. Hence generating data from them verbally will help them to express themselves better when answering the research questions using tools like questionnaires.

The researcher used one on one unstructured interviews because according to Katebire (2007), such interviews are based on respondents' experience and understanding on a particular subject they can elaborate. The researcher based on this to interview respondents with open ended questions and probing techniques.

Interview guides have a disadvantage of relying on memory which is fallible and can suffer loss (tendency to forget), according to Katebire (2007). As a way of overcoming these sort falls, the researcher allowed participants time to think before they spoke and reflecting respondents' answers back to help check understanding of what they are saying.

3.6.2 Adolescent Self Esteem Questionnaire

It was prudent for the researcher to first measure the self-esteem of the adolescents that will participate in this research so as to make sure the respondents have a low self-esteem.

The most widely used tool for measuring self-esteem is the Rosenberg Self-Esteem Scale (RSES) which is particularly for adults. However, the researcher used the Adolescent Self-Esteem Questionnaire (ASQ) because the target population for this study was adolescents. The ASQ tool is specifically for adolescents and has been found to be more relevant for this age group (Hafekost et al. 2017).

3.7 Quality Control Measures

Quality control in research refers to the procedure and methods used to ensure the reliability, validity, and accuracy of research findings (Enago Academy 2019).

Data tools were carefully designed and pre-tested before using them. This ensured internal reliability and internal validity. The pre-test was done to find out whether even those who are not to participate in the research understand the questions in the interview guide. The researcher also soght to find out whether there was a similarity between her observation and theoretical finding they ought to develop (Bryman 2012).

Enago Academy (2019) sate that it is a vital process for maintaining data integrity, minimizing errors, and ensuring that research results are dependable and reproducible

3.8 Data Analysis Techniques

Data analysis techniques are procedures used to transform raw data into meaningful insights, aiding decision-making and so as to analyze, interpret and draw conclusions from

data (Saharawat 2023).

This study used thematic analysis to draw meanings and concepts which were extracted from the data collected through examining the recording patterns and themes. These themes were drawn following the different objectives.

Thematic analysis is a method for detection, analysis and reporting the themes in the data. This method of data analysis is not just about coding, but the outcome of the coding. It is a clear, uncomplicated and straightforward form of analysis used in qualitative research (Javadi and Zarea, 2016). This state of theme emerging helps the researcher in reflecting and clarifying the reality.

3.9 Ethical Consideration,

Ethical consideration involves examining the moral principles that guide decision-making and actions ensuring actions align with what is right and fair, considering, considering potential consequences, and striving to benefit everyone involved (Javid 2024).

As Dawson (2009) discusses about recognizing overt research, the researcher must be open and honest about who they are and what they do. This will enable participants to make informed choice about taking part in the research.

In this particular research, verbal consent was sought, explaining who the researcher is and the purpose of the study. This allowed voluntary participation for the respondents.

The researcher also ensured anonymity and confidentiality, treating respondents with respect.

3.10 Limitations of the Study/Anticipated constraints and the way they will be overcome

Limitations/anticipated constraints are restrictions that are foreseen and potentially expected to impact the study’s design, implementation, or results (Gupta 2024). These anticipated constraints define the boundaries within which a project must be executed.

With the use of interviews which are verbal, the major anticipated constraint was language barrier especially in the interaction with the caretakers because majority do not understand English. The researcher interpreted the questions without altering the meaning.

3.11 Conclusion

In conclusion, this chapter has detailed the planned research approach, which included the research Design, area and population of the Study sampling procedures (Sampling size and techniques and data collection methods and instruments (interviews and adolescent Self Esteem Questionnaire). It has also described the quality control measures, ethical consideration, and limitations of the Study.

CHAPTER FOUR

PRESENTATION, INTERPRETATION, AND DISCUSSION OF FINDINGS

4.1 Introduction

The purpose of this study was to find out the contribution of the caretakers to the low self-esteem of Adolescents Living with HIV/AIDS (ALHIV). The study further sought to analyze the relationship between the low self-esteem of ALHIV and their caretakers. For this particular study, objectives/determinants were to assess the caretakers’ knowledge and its impact on the self-esteem among ALHIV, to determine the caretakers’ attitude towards ALHIV and to establish the challenges caretakers face while taking care of ALHIV at Lukaya Healthcare Centre in Kalungu district.

This chapter presents, interprets and discusses the findings obtained from interviews from 100 participants aged 18yrs and above, who included 50 ALHIV and 50 caretakers of ALHIV.

All the 50 ALHIV who were interviewed scored low on the Adolescent Self-esteem Tool. 10 of them did not know the real meaning of self-esteem and could not explain what it was, while the 40 did not admit in their responses during the interviews that they have a low self-esteem. This could be that they either did not know that they had a low self-esteem, or they were in denial and did not want to submit it. Whalley and Kaur (2021) state that some people with low self-esteem do not know that they have it, while others with low self-esteem hold on to their negative beliefs so strongly that they can feel like it is normal and the way to go.

This is also known as a respondent bias or response bias which is a universal term for a wide range of predispositions for participants to respond incorrectly to questions especially questions inquiring participant self-report. Nikolopoulou (2022) defines response biases as a term describing situations where people do not answer questions tactfully for some reason usually when the answer portrays a negative image about the respondent. He further states that other reasons for respondent biases can be the desire to perform in line with the research objectives, that is if the aims of the study were guessed, and the desire to complete survey questions quickly due to lack of interest.

Out of the 40 ALHIVs who said they have a high self-esteem when asked to comment about their self-esteem, 37 of them contradicted themselves when their explanations in the other questions that followed depicted that they have a low self-esteem, while the 3 maintained their stand even in the other questions. All the 10 ALHIV who did not understand what self-esteem was, illustrated to be having a low self-esteem in the other questions.

All the 50 caretakers and 49 ALHIV explained how vital the role of the caretaker is in boosting the self-esteem of the ALHIV. Only one ALHIV who is among the 10 who do not understand the meaning of self-esteem said that caretakers do not have any role to play in boosting the self-esteem of ALHIV, instead it is the adolescents to help themselves to boost their own

self-esteem.

This chapter is sectioned according to the themes derived from the objectives, which also act as answers to the research questions: how does the caretakers’ knowledge on HIV/AIDS impact the self-esteem of the ALHIV, what is the caretakers’ attitude towards the ALHIV and what challenges do caretakers face while taking care of ALHIV?

4.2 Assessing the caretakers’ knowledge on HIV/AIDS and its impact on the self-esteem among ALHIV

The research question that generated the analyzed data presented, interpreted and discussed in this subsection was, how does the caretakers’ knowledge on HIV/AIDS impact the self-esteem of the ALHIV? The responses to the question have been categorized under caretaker’s knowledge on HIV/AIDS, and impact of caretaker’s knowledge on the self-esteem of ALHIV.

4.2.1 Caretaker’s knowledge on HIV/AIDS

Before engaging the respondents on assessing the caretaker’s knowledge on HIV/AIDS and its impact on the self-esteem of ALHIV, the researcher thought it wise to first assess the caretaker’s knowledge on HIV/AIDS, with an intention of finding out whether the caretakers are knowledgeable or not. This was done in odrer to engage the views of Wandunde et al. (n.d.), Nassuna et al. (2019) and Kasande et al. (2022).

Just like the opinions of the above scholars, the researcher found out that most of the caretakers and adolescents who participated in this research were not knowledgeable about basic HIV/AIDS information. 17 caretakers, 6 of which were male, admitted that they do not have the adequate knowledge about HIV/AIDS especially ART because they feel that the ALHIV they are taking care of are old enough to take full responsibility of their health. Participants C4, C6, C11, C20, C32, C36, C40 and C43 were not the caretaker who had primarily stayed with the ALHIV from their childhood. The researcher found out that these caretakers had stayed with the ALHIV for a short period, from months to less than 5years. One of the caretakers reported that;

> “Mine is a bright girl and *is old enough to take care of herself. She can ably follow instructions given by the health workers.”*

As reported by caretaker C11 on 4th June, 2025 at Lukaya.

The researcher further found out that all these 17 caretakers do not escort the ALHIVs to the facility to pick their medicine. One of the caretakers explained that:

> *"I am not the one who has been staying with this adolescent since childhood, she has just relocated to my home after the recent death of her mother. She knows every important thing in concerning her treatment."*

As reported by Caretaker C11 on 4th June, 2025 at Lukaya.

Note that other caretakers like C6, C32 and C40 also had the same opinion. What this meant to the researcher is that caretakers who are not the biological parents to the ALHIV and caretakers who have not stayed with the ALHIV since childhood find it easy to let the ALHIV stand on their own in relation to their medication.

Interestingly, the reasons for this relocation or change of caretakers which included death of the primary caretaker, need for the adolescent to get a job or join a new school, and need for the primary caretaker to go to the city to look for a job so as to be able to earn a living.

Nonetheless, 4 caretakers had adequate information about HIV/AIDS and these included C2, C33, C49 and C50. They knew how knew how HIV is transmitted and prevented and the importance of ART. All the caretakers were also HIV positive and on ART. The other 29 caretakers who said they were knowledgeable about HIV/AIDS could not elaborate or explain the basics of this pandemic. Just like Biadgilign et al. (2011) and McHenry et al. (2016) stated, what these caretakers explained were myths and misconceptions, which they thought was knowledge. Caretaker C38 brought in a new concept when she said that she handles this ALHIV carefully because she is sick and does not need to be "stressed." When told to elaborate more on what she meant by saying she handles the ALHIV carefully, she said she does not allow them to do housework because they are weak. A similar observation by Kasande et al. (2022) was made when they stated that because of the vulnerability of the chronic illness faced by the ALHIV, caretakers who lack knowledge on how to handle the challenges that come with raising these adolescents fail to raise them in a socially acceptable manner as they feel these adolescents already have enough burden and should be left to live their life as they wish. The researcher however thought that this is being unfair to the ALHIV because they will become adults who cannot look after themselves.

Other caretakers like C14 and C24 had gone an extra mile and gave this information to the teachers in schools where the ALHIV go to, cautioning them not to beat them in the name of disciplining them because they are sick. ALHIV like A1 said the issue of involving teachers without first health educating them about HIV/AIDS was a mistake as some of the ended up gossiping about them or making public announcements in class; like *"all of you lie down apart from you with the virus."* ALHIV A1 went ahead to explain that when she was still young, she used to enjoy the benefit of not being beaten. But when she became older, she could not interact freely in the community as everyone seemed to know her sero status, and all this happened because the parent thought she is protecting the ALHIV.

As the discussion on adequate caretakers' knowledge on HIV/AIDS continued, the researcher found out that the parents did not think of HIVAIDS as the first disease when the health of their CLHIV was deteriorating, yet they were in and out of hospital. ALHIV like A4, A11 and A23 clearly recall how they were taken to traditional healers to seek for a remedy which delayed their ART initiation, making them look clinically ill with infectious skin diseases, stunted growth and being underweight; which made them appear different from their peers. Kasande et al. (2022) made a similar observation when they stated that mothers living with HIV themselves do not think of HIV as the illness disturbing their children much as they are in and out of hospital. This is either because they were still in denial, or they do not want to associate their children with this pandemic. To the researcher, this meant that these parents lacked the information on HIV transmission that even children can get infected with HIV, if not protected.

More to that, some of the information given by the caretakers who said they are knowledgeable was general knowledge and not specific to HIV. A case in point was caretaker C1 who said that;

"*what I know about ART is that someone is supposed to drink a lot of water when taking his/her medicine.*" This is a true statement which however applies to every medicine used by humans, not just ART. Some caretakers like C11, C20 and C32 did not even know the time the ALHIV take their medication, and were not participating in their adherence. This meant that these adolescents could sometimes miss taking their ARVs without the caretakers noticing. It should be noted that these are some of the caretakers who earlier said that the ALHIV in their care are old enough to take care of themselves and can ably follow instructions given by health workers. This confirms the arguments of Wadunde et al. (n.d.) and Nasuuna et al. (2019) who stated that inadequate caregiver knowledge of HIV/AIDS in one of the major reasons for poor adherence on ART.

4.2.2 Impact of caretaker's knowledge on the self-esteem of ALHIV

In response to the conception of how caretaker's knowledge impacts on the self-esteem of ALHIV, the researcher bared in mind the scrutiny made by different scholars like Vranda & Mothi, (2013) and Agyemang et al. (2020) about the high prevalence of low self-esteem of ALHIV as compared to their peers, and the reason for this, according to them is due to the stigma and discrimination as a result of unpleasant treatment and isolation given to them by their peers and their extended family members.

From the debate raised above, relating to the caretakers’ knowledge on HIV/AIDS, it is evident that the researcher found out that most caretakers were not knowledgeable about basic information on HIV/AIDS, and thus the discussion continues on how this lack of knowledge impacts on the self-esteem of the ALHIV. The researcher however thought it prudent to first assess whether this lack of knowledge had any impact on the self-esteem of ALHIV anyway, before assessing the how. Important to note is that 99 participants out of the 100 interviewed stated that it is important for caretakers of ALHIV to be knowledgeable on the basics of HIV/AIDS and ART because according to them, this has a great impact on the self-esteem of ALHIV. This was done in order to bring the views of Kimera et al. (2021) on board, who argued that the matter of knowledge has greatly impacted on the mental health and self-esteem of the ALHIV.

However, one ALHIV had a different opinion from the rest of the respondents when he argued that

“*whether caretakers are knowledgeable or not, the notion of self-esteem is an inner belief where someone can choose to have it high or low, regardless of the circumstances around them.*”

As reported by ALHIV A40 on 10th June, 2025 at Lukaya.

Although not part of the literature reviewed, this respondent involved the opinion of Cikanavicius (2017) who indicated that our sense of self-esteem actually starts from inside, and not outside. He continued to state that we don’t rely on others to validate or define us. Other ALHIV however differed from this opinion and argued that in order for caretakers to impact positively on the self-esteem of ALHIV in their care, having the knowledge about HIV/AIDS and ART is very important.

In a qualitative study conducted in West Africa by Atanuriba et al. (2021), it is the lack of knowledge that a child born with HIV can live a normal healthy life that makes caretakers perpetrate stigma by reacting badly to their children's HIV-positive status with fear, shame, guilt and even suicidal ideation. They end up abusing and discriminating the ALHIV, which in the long run impact on their self-esteem as they grow up. ALHIV like A3, A9, A17, A25 and A30, had a similar argument like that of ALHIV A44 who said that;

> *"A parent who does not have adequate knowledge about HIV/AIDS, not only can't he/she help boost the self-esteem of the adolescent, but also can't help them in other related spheres like adherence, positive living and disclosure."*

As reported by ALHIV A44 on 12th June, 2025 at Lukaya.

The reason for this was obvious to the researcher, that if the caretaker does not have adequate knowledge on HIV/AIDS, he/she will not know what to do when faced by a challenge, helping the adolescent, or even merely guiding them.

More to that, Wadunde et al. (n.d.) have the same perception like caretakers C50, C47, C39, C21, C25, C26, and ALHIV A7, A18, A22, A29, A40 and A35 which was brought out very well by ALHIV A50 who stated that;

> *"Inadequate caretaker knowledge on HIV/AIDS leads to mismanagement of the adolescent as well as poor adherence, which in the long run impacts on the health of the ALHIV."*

As reported by ALHIV A50 on 17th June, 2025 at Lukaya.

When ALHIV have a compromised health, they will get diseases like persistent productive cough or tuberculosis (TB), skin infections including cancers like Kaposi's Sacorma, and wasting syndrome. Some of these diseases are stigmatizing because health workers will require anyone who has them not to freely interact with peers in the society because they are contagious; a case in point is TB which is airborne. ALHIV with such signs and symptoms due to poor adherence and mismanagement of caretakers due to their lack of knowledge causes the them to have self-isolation which begets low self-esteem.

Nasuuna et al. (2019) confirms this when they state that this inadequate knowledge by caretakers due to failure of these caretakers to attend the counselling and general health education sessions the facilities makes them not know how to help the ALHIV adhere to their treatment. Caretaker C50 elaborates this subject better when she argues that;

> "*When ALHIV are not supported by caretakers especially in the journey of adherence to ART, they feel lonely and lose hope and find no reason to live.*"

As reported by Caretaker C50 on 19th June, 2025

It is obvious that someone who has no reason to live is depressed, and is this depression impacts negatively on their wellbeing and self-esteem. Orth et al. (2009) explains that low self-esteem and depression are closely linked because depression makes individuals feel inadequate, worthless, and pessimistic about themselves. On the contrary, low self-esteem can also be a risk factor for mounting depression

ALHIV A50 emphasizes how adolescents mind the way they appear especially to fellow peers and the public as well, when she states that "*…my self-perception and self-esteem depends on how I appear in public and how the people around me view me*." She said this while explaining that some caretakers still don't believe that a child born with HIV can live long and have a bright future. She also said that such parents do not take the ALHIV to school and keep belittling them with their words and actions, which makes them lack confidence and have a poor self-perception and a low self-esteem, just like Nyamuruze and Govender (2020) had noted earlier.

Backes and Bonnie (2019) give a similar view with that of participant A50 when they state that adolescence is a stage where individuals are most concerned about their physical, emotional, and social changes. Peer relationships and caretakers remain a key source of support for adolescent's health and wellbeing. Participant A50 gave a dejected story of how her father used to verbally abuse her using discouraging words because he did he thought that she would die any time soon, just like her mother had died. He educated her only up to primary three yet according to this participant, he had the ability to educate her further. This forced her to leave home at the age of 16 to try and find a peaceful environment. She first worked as a house help and later moved in with her boyfriend at the age of 17. Both environments were not hospitable because she feared disclosing her status to her boss or boyfriend for fear of being rejected as her caretaker the biological father had done. She continued to stay that "*I am careful about disclosing my status because it sometimes worsens the situation, bringing regret*."

This story brings the arguments of scholars like Mathew and Manjula (2021) and Ke et al. (2020) who stated that the low self-esteem of ALHIV is caused by factors like discrimination and disclosure, however, they did not explain that the genesis of this non-disclosure is that way the caretaker handled the issue of the adolescent's sero-status. However, what this whole story meant to the researcher was that the way caretakers understand HIV/AIDS has a lot to do with how they will nurture the ALHIV, and the ALHIV upbringing influences positively or negatively on their self-esteem.

4.3 To determine the caretakers' attitude towards the ALHIV

The research question that generated the analyzed data presented, interpreted and discussed in this subsection was, what is the caretakers' attitude towards ALHIV? The responses to the question have been categorized under attitude of ALHIV towards caretakers, and caretaker's attitude towards ALHIV.

4.3.1 Attitude of Adolescents Living with HIV/AIDS towards caretakers

In psychology, an attitude entity can be anything a person discriminates or embraces in mind. Gerd and Michaela (2011) argues that attitude includes beliefs (cognition), emotional responses (affect) and behavioral tendencies (intentions or motivations). They further state that attitudes may vary depending on the situations, context and moods. This means that the caretakers' attitude towards that ALHIV can largely be influenced by the attitude of the ALHIV towards the caretaker. The researcher therefore thought it wise to first understand the attitude of the ALHIV towards caretakers, before determining the caretakers' attitude towards the ALHIV, as the second objective states.

When asked about their attitude towards caretakers, most ALHIV like A39 and A4 mentioned that they just look on and let things be. What this meant to the researcher was that they respond towards their caretakers' attitude. If it is positive, they will communicate their feelings and respond positively, and the reverse on the negative attitude is true. ALHIV A50 gave a more descriptive explanation on this when she said that

> *"…in African setting, an elderly person is to be treated with at most respect and how they view or treat you as a child is not questionable and you have no opinion about it, especially when they don't like you."*

As reported by ALHIV A50 on 19th June, 2025 at Lukaya.

The researcher supposed that this was an indirect way of saying that when a caretaker displays a bad attitude towards the ALHIV, the adolescent might not show the same attitude physically in actions, even when they would love to, but deep inside them, they are suffering silently, which suffocates their freedom of expression and assertiveness, and hence the low self-esteem.

Backes and Bonnie (2019) give a similar view with that of ALHIV A50 when they state that adolescent relationships with caretakers remain a key source of support for adolescents' health and wellbeing, attitude and mental health. Bernays (2023) also shows how this impacts the self-esteem and the lives of the ALHIV in general when she says that globally, adolescents still suffer relatively poor treatment and social outcomes. Surprisingly, caretakers like C4, C10, C28 and C50 also gave stories of how ALHIV are suffering in the hands of their guardians especially those who are not the biological parents.

Caretaker C10 shared a story of a certain ALHIV is about to lose his life because he refused to take his ARVs, and the reason for this is because the caretaker who does not give him food, yet he cannot take medicine on an empty stomach. Mbiyu, Kikuvi and Amukoye (2013) affirm this when they state that the practices and attitude of the caregivers of ALHIV is generally negative and has an impact on their adherence levels. Participant C10 went on to say that the caretaker and the ALHIV keep exchanging words and quarreling because they both do not understand each other, to the extent of the child promising to do something bad to the caretaker. This left the researcher wondering whether the adolescent does not plan to harm himself as well.

Participant A33 is one ALHIV who seemed to have a lot on information, but it was not easy to extract it from him. He kept nodding his head or keeping quiet when asked some questions during the interview. When asked whether he has ever expressed how his caretaker's support makes him feel, he kept quiet and did not answer. When asked how his caretaker has showed him love and care, he broke down and cried. These responses were not verbal but spoke volumes to the researcher, and although not part of this study, the researcher asked ALHIV A33 whether if given opportunity, he would have loved to be relocated to another caretaker, and he quickly answered in affirmative. This was a clear indication of an ALHIV who is has a negative attitude towards his caretaker more so because of the caretaker's attitude towards him.

Caretaker C50 on the other hand brings in a new concept to this subject when she stated that the ALHIV in her care is a granddaughter yet both parents are still alive. She said the parents separated, the mother has never returned to see her child, and the father calls her 'a moving dead body' even in her presence. Mandalazi, Bandawe, and Umar (2014) also noted that majority of the caretakers of ALHIV in Africa in general, are actually not the biological parents, but guardians from extended families, not because they are all orphaned, but because the biological parents have a negative attitude towards them. Important to note is that most of the children and adolescents who have been rejected by caretakers find it hard to believe in themselves.

Although participant A50 noted the attitude of elders or parents in African setting is not questioned or even supposed to be noticed by children or adolescents under their care, Atanuriba et al. (2021) and Rujumba, Mwaka and Ndeezi (2010) make a remarkable observation when they state that the attitude of the caretakers and health workers towards ALHIV is negative and they have not done anything to bridge this gap because they think the adolescents and the children are young and do not notice this attitude. ALHIV

A50 sustained this by saying *"…here in our setting, an elderly person does not make mistakes."*

On the other hand, however, the researcher found out that not all ALHIV have a negative attitude towards their caretakers. Some participants like A1, A8, A14, A29, A44 and others have a good relationship with their caretakers and they reported having a good attitude towards them, as ALHIV A8 said;

> *"…I love my mother because she also loves me and has taken good care of me by making sure I take my medicine daily, I get what to eat and has also take me to school."*

As reported by ALHIV A8 on 4th June, 2025 at Lukaya.

4.3.2 Caretaker's attitude towards Adolescents Living with HIV/AIDS

Many scholars like Burton (2022) state that a child's self-esteem is guided by their parents or guardians through fostering positive health, nurturing relationships with their children and adolescents, and having a positive attitude towards them. The researcher therefore found it vital in this study to delve into the attitude of the caregivers towards ALHIV in their care.

When discussing caretakers' attitude as a theme, the researcher found out that respondents easily discussed other people's negative attitudes and behaviors, using examples, rather than talking about themselves. This was a pattern with all the caretakers interviewed. The reason for this was either Perspective shift which allows us to analyze without the weight that comes with self-reflection, Self-protection due to vulnerability and the fear of being exposed to judgement and criticism, or Fear of the complexity that comes with articulating our own thoughts/feelings and actions. Peters, Kashima and Clark (2009) argue that people are more likely to share stories about other people other than themselves to the extent that they arouse emotions. They continue to say that people are more willing to share social narratives that arouse interest, happiness, surprise and disgust.

Scholars like Mbiyu, Kikuvi and Amukoye (2013) and Lorenz et al. (2016) found out that the attitude of the caretakers of ALHIV is generally negative with the overwhelming majority believing that the adolescent's life is about to end. Most caretakers and ALHIV like A2, A6, A12, A13, A17, A20, A23, A30, A40, A50 C50, C44, C40, C38, C33, C27, C24, C20, C18, C13, C8 among others explained that most caretakers in general have a negative attitude towards ALHIV. Different stories were shared by different participants and some of the ways they were able to tell that the caretakers had a negative attitude were the words they use when talking to them, not wanting to associate with them, not giving them food and giving punishments bigger than the offence. ALHIV A49 stated that "*…a parent can beat the ALHIV so severely like she is beating a co-wife.*" This statement ably elaborated to the researcher how bitter some caretakers are towards ALHIV, because it is the relationship between co-wives is usually unpleasant.

In the study conducted by Atanuriba et al. (2021), it is the lack of knowledge that a child born with HIV can live a normal healthy life that makes caretakers perpetrate stigma and a negative attitude towards their CLHIV and ALHIV. They end up abusing and discriminating the ALHIV, which in the long run impact on their self-esteem. When caretaker C50 was told to explain more on the story she shared of a biological father who calls his HIV positive daughter 'a moving dead body', she said the father is HIV negative and does not want to be identified with an ALHIV. She actually said "*…he even said, that she is not her daughter.*" This is not surprising because most people are not aware that a baby born with HIV is a vertical transmission from the mother to the child, and not the father. Even when the father is HIV positive, the child can only be infected during pregnancy, during delivery and during breast feeding. In all these three avenues, the father's contribution is not there.

The argument brought about by Osinowo et al. (2023) is that in low income generating homes, the attitude of the ALHIV is poor, as compared to the richer families due to the task of caring for these adolescents as burdensome due to lack of basic needs like food, which results into a negative attitude. A case in point was the story ALHIV A10 shared of an ALHIV who is about to lose his life because the caretaker does not give him food. ALHIV A10 said that *"… this adolescent's caretaker has food to eat herself, but says she does not have enough food to give to the ALHIV."* This participant went ahead to say that maybe she hates the ALHIV and will be happy when he dies. Shockingly, the caretaker being talked about is the biological mother to the ALHIV.

ALHIV A49 gave a similar experience from her biological mother who kept abusing her verbally that she is a good for nothing useless child. The parents had separated and the father married another woman, leaving the children with the mother. Although the mother was also HIV positive, she denied having infected the respondent, saying she got HIV on her own. As the only child who had HIV among her siblings, she reported having been discriminated by the entire family members because of her sero-status. She said

> *"When counting her children, my mother used to say that she has 7 children yet we are 8. According to her, I was already dead and she always promised to have another child to replace me."*

As reported by ALHIV A8 on 4th June, 2025 at Lukaya.

She was forced to leave her home and moved in with a boyfriend, and actually became a mother at the age of 16. She continued to say *"…my story is long, but currently working as a peer at this facility, I would rather stay alone than with my mother a* *terrorist."* The researcher perceived this mother's attitude to be a result of denial because, for an ALHIV who started ART at the age of 6yrs, chances of having been infected by her mother are very high, yet she denies having infected her child! However, there other ways a child can get infected with HIV apart from being infected by the mother like sharing sharp objects with an infected person, which can happen by the carelessness on the health worker during birth.

Singh et al. (2011) differs from the scholars above when he states that caretakers who have support from other family members and community have taken on the task of caretaking for ALHIV with enthusiasm and have a good attitude towards the ALHIV, and the reverse is true. All the participants talked about both sides of the positive and negative attitude of caretakers towards the ALHIV, but emphasized the negative side. However, ALHIV like A1, A20, A50 and caretakers like C4 and C23 explained that not all caretakers have a negative attitude towards the ALHIV. Some of the caretakers have a positive attitude and have hope that these ALHIV will grow and become important people. Thus they are loved and given similar opportunities like their peers in the community.

ALHIV like A33 emphasize that very few caretakers have given the ALHIV an equal opportunity with that of their peers. Some have not been given even the chance to be fully educated. One ALHIV said that;

> *"The words caretakers use when the ALHIV has made a mistake, just like any other child, are demeaning and automatically lower their self-esteem."*

As reported by A49 on 17th June, 2025 at Lukaya.

A similar view was given by caretaker C50 when she said that one day the ALHIV annoyed her and she abused her saying "*…I think the virus has taken over your brain, that is why you are becoming* *stupid.*" She continued to say she regretted and promised herself not to abuse the ALHIV again. The researcher, however, admired caretaker C50 for the fact that she was able to realize her mistake, in an African setting where some ALHIV said an elderly person does not make mistakes.

ALHIV A49 said that other caretakers use words like "*you are going to die like your parents, or why are you wasting time in school when HIV does not cure?*" She continued to say that such statements make the ALHIV eel like he/she is dying anytime, and has no time to waste before fulfilling whatever he/she would have loved to fulfill. This gave the researcher a clearer insight to the findings of Kimera et al. (2020) who reported that the proportion of ALHIV who drop out of school is high as compared to their peers who are HIV negative.

Mandalazi, Bandawe, and Umar (2014) bring in a new concept when they state that majority of the caretakers of ALHIV in Africa in general, are actually not the biological parents, but guardians from extended families like grandparents, not because they are all orphaned, but because the biological parents have a negative attitude towards them. This is not different from the findings the researcher noticed from the study. For instance, participant A50 who is a paternal grandmother of the ALHIV she stays with, yet both parents are still alive and not only are they not interested, but also verbally abuse the adolescent.

4.4 To establish the challenges caretakers face while taking care of ALHIV

The research question that generated the analyzed data presented, interpreted and discussed in this subsection was, what challenges do caretakers face while taking care of ALHIV? The responses to the question have been categorized under challenges faced by ALHIV, and challenges caretakers face while taking care of ALHIV.

4.4.1 Challenges faced by Adolescents Living with HIV/AIDS affecting their self-esteem

Adolescence is a period for developing knowledge and skills, learn to manage relationships and emotions, and to attain qualities and abilities that are vital for enjoying the life ahead of them. How this transition from childhood to adulthood is defined, recognized and understood varies depending on different societies. All adolescents regardless of socio-economic status, level of education, cultural and religious background, face challenges that include the myth of a perfect life, family expectations, academic pressure, concerns of body image and appearance, peer pressure among others (Hayes, 2025). This study however does not seek to discuss the general challenges of adolescents, but rather a special category of Adolescents Living with HIV. Again ALHIV have so many challenges but challenges affecting their self-esteem will be discussed in this sub-section.

This study found out that the biggest challenge ALHIVs face affecting their self-esteem is the negative attitude of caretakers, who speak/tell them words that are discouraging. According to ALHIV A1, A10, A49, A22, A30 and A50, caretakers of ALHIV are supposed to be cheerleaders, giving them hope and encouraging them to move to greater heights, like any parent would tell their child. On the contrary however, for most of them, the reverse is true. Instead of being the ones to encourage the ALHIV they have lost hope in them and think they have no future. The unfortunate part is that even when health workers tell these ALHIV that there is light at the end of the tunnel, the caretakers at home keep watering these efforts, yet they spend more of time with them at home than the health workers who meet them once in a while.

Talking of health workers, not all of them encourage these ALHIV, some of them especially those who are not directly involved in HIV-ART clinics also do not have hope in these ALHIV and sometimes do not speak kindly to them, something that lowers their self-esteem. For example, ALHIV A5 mentioned that she went to a health centre to get family planning services, but instead of the nurse health educating her on the best method to use, she told her *"…you are HIV positive and yet you are the same person having sex which is going to reduce your lifespan…"* This ALHIV said that since that encounter, she fears to seek help on issues concerning sexual reproductive health, and mentioned that so many ALHIVs out there are facing the same challenge, to the extent of using emergency pills more often than expected, just because they lack the audacity to seek help. An adolescent who is not assertive or lacks the audacity to discuss vital issues like matters concerning health, cannot have a high self-esteem.

Kipp et al. (2006) and Abasiubong (2011) made an observation on the mental health distress of caregivers of ALHIV who were found to be experiencing stress, anxiety, depression and even suicidal tendencies, caused them to develop a negative attitude, ending up verbally spilling abusive words to the ALHIV and they are rarely praised or appreciated, but rather are seen as a burden. ALHIV like A33 and A49 are an example of ALHIV who were verbally abused by their caretakers, to the extent of prematurely leaving their parents' homes in search for a peaceful environment.

In the study conducted by Nasuuna et al (2019), the reported findings were related what almost all the ALHIV like A1, A2, A3, A6 and A50 shared that they experience treatment fatigue and the challenge of the pill burden. They reported that they cannot go to visit some relatives due to fear of being seen taking the pills, some mentioned having poor adherence when taken to boarding schools because they fear being seen with pills by their peers, others have failed to accept certain jobs because they are not willing to disclose to their bosses. With all this, it does not surprise the researcher that these ALHIV have a low self-esteem. Most of them are actually tired of the treatment and have hope that one day, there will be a cure and a solution to these challenges.

ALHIV A39 said they stay far from the facility and transport is a challenge, since the caretaker is an old granny who is also she bread winner of 6 other grandchildren yet she is a casual laborer who does not have a stable income. This has caused her to always miss her appointments and sometimes she runs out of pills. The health works at the facility seem not to understand even when she explains to them. Whenever she falls sick, complain that she has deliberately refused to adhere to her treatment, opening up her body to opportunistic infections and diseases. Magak (2022) made a similar observation when he stated that the challenges of not being able to navigate care and treatment have resulted into ALHIV becoming lost from care (Lost to Follow Up), becoming ill and having poor clinical outcomes which makes them begin to have signs and symptoms of HIV. This physical clinical presentation makes them lose their self-esteem because their bodies are not looking good.

On top of that ALHIV A50 brought on board an interesting discussion when asked to explain the challenges faced by ALHIVs in trying to boost their self-esteem. She explained that;

> "*The biggest challenge we face as HIV positive young people is the issue of disclosure, especially in sexual relationships, and sometimes to our bosses in case you get a job and need to come to the facility to pick medication.*"

As reported by ALHIV A50 on 17th June 2025 at Lukaya.

This is brought about by the fear of being rejected. Just like ALHIV A50, ALHIV A49 also had a similar experience whereby whenever she would disclose her status to a suitor, he would dump/leave her. This is something that has reduced the self-confidence and esteem of these ALHIV to the extent that some of them are in discordant relationships, but the spouses are not aware of the sero-status of these partners.

4.4.2 Challenges faced by caretakers while taking care of Adolescents Living with HIV/AIDS

Taking care of any child regardless of their HIV status comes with responsibility and challenges like the need to provide basic needs (food, shelter, health, education and clothes), managing emotional outbursts, handling sibling rivalry, setting consistent rules and discipline, managing parental stress and burnout, and dealing with academic pressure, just to mention but a few (Page et al. 2020). There are however, challenges that caretakers of ALHIV face alongside the ones mentioned above which the researcher decided to navigate in order to engage the views of Eneh (2010), Osafo et al. (2017), Akintola (2009) and Hilschfeld and Tlou (2003).

The commonest challenge mentioned by all both caretakers and ALHIV was economic challenges. This came out using different statements like poverty, lack of food, lack of school fees/scholastic materials, lack of money to treat some co morbidities/diseases which the facility does not cater for, as mentioned by respondents A50, A49, C50 and C12 respectively. The burden is heavier on elderly persons who have a burden of taking care of their own health, other children, as well as grandchildren who are sometimes orphaned (Osafo et al. 2017). Most of these elderly people are not into formal employment and are a bit weak to handle businesses, thus they are involved in farming, sometimes for home consumption, and not cash crops. Others are not employed and live at the mercy of provision from other relatives or their children who also have personal responsibilities.

Psychological and emotional challenges were also reported by caretakers like C11, C19, C26, C34, C48 and others. These included stress, anxiety, depression, anger and bitterness due to the concern of not being able to fulfill their responsibilities as parents. The presence of household food insecurities and low income were the triggers of these psychological and emotional stressors. Caretaker C11 requested the facility to provide some food alongside the drugs they give to patients so as to accelerate good adherence. This is similar to the recommendation Yiryou et al. (2024) gave as a solution to the challenges caregivers face. They said that governmental and non-governmental HIV/AIDS program support should include small business skills training and acquisition including capital to help set up small-scale businesses.

Kidman and Thurman (2014) made a similar observation in their study, and concluded by saying that caregivers with economic vulnerability feel most overburdened and are prone to facing mental health challenges, as compared to the wealthier caregivers.

Abasiubong (2011) gave similar findings explaining the psychological and emotional stressors, but mentioned caretakers having suicidal tendencies, something caretaker C10 also expounded that;

> "When the nurse told me that my daughter is HIV positive, I felt like I have failed as a parent, I felt useless and thought committing suicide was the only option… I was still digesting the fact that I am also HIV positive and I am going to be on medication for the rest of my life, something I couldn't forgive myself for involving my child into."

As reported by Caretaker C10 on 4th June, 2025 at Lukaya.

The researcher found out that most caretakers especially biological parents live with the challenge of guilt for having infected their children and have not yet forgiven themselves, to the extent that even failed to disclose to them.

Akintola (2009) and Hilschfeld and Tlou (2003) made an observation similar to that of caretakers C1, C25, C48 and ALHIV A3, A8, A14 that caregivers of ALHIV are predominantly women who are poor, unemployed and unmarried single parents; who have combined their care-giving role with their traditional roles as homemaker, household head and breadwinner.

Most caretakers and some ALHIV like C4, C10, C16, C17, C21, C27, C30, C36, C38, C41, C44, C50, A48, A30 and A4 stated that HIV does not only affect CLHIV and ALHIV only, but the all the family members as a whole. This is the debate Eneh (2010) brought bout when he stated that HIV has profound personal and deeply social impact not only on the children it affects, but also on their entire family/caretakers. The stigma that the family faces for having an HIV positive child is also contributing factor to this negative social impact, just like Participant C30 explained;

> "What hurts most is that as a maternal auntie taking care of my late sister's son, my friends and neighborhood think I am also infected with HIV yet I am not."

As reported by caretaker C30 on 17th June, 2025 at Lukaya.

More to that, Nasuuna et al. (2019) give a more comprehensive and summarized report from the study they conducted where they mentioned that the challenges of caregivers were more individual than health system based. They included environmental challenges (where some ALHIV are in boarding school or the caretakers work away from home, making it difficult for the caretakers to do close monitoring); personal challenges (failure to disclose to the ALHIV and stigma); psychological challenges (guilt and depression);

financial challenges (lack of food and transport to the facilities). All these were mentioned by most caretakers like C50, C10, C30, C1, among others, as discussed in the findings above.

4.5 Conclusion

This chapter has presented interpreted and discussed the findings obtained from interviews from 100 participants who included 50 ALHIV and 50 caretakers of ALHIV. The discussion of findings was categorized under different themes that were derived from the objectives that guided the study. These themes are caretaker’s knowledge on HIV/AIDS, impact of caretaker’s knowledge on the self-esteem of ALHIV, attitude of ALHIV towards caretakers, caretaker’s attitude towards ALHIV, under challenges faced by ALHIV, and challenges caretakers face while taking care of ALHIV.

CHAPTER FIVE

SUMMARY OF FINDINGS, CONCLUSIONS AND RECOMMENDATIONS.

5.1 Introduction

This chapter is comprised of the findings of the data collected using the interview guide as the main method of data collection. Conclusions are made and recommendations drawn from the discussions concerning the contribution of caretakers to the low self-esteem of adolescents living with HIV/AIDS.

5.2 Summary of findings in relation to the contribution of caretakers to the low self-esteem of adolescents living with HIV/AIDS.

This section looks at the summary of the findings from the study.

5.2.1 Duration the ALHIV have stayed with their current caretaker

The study found out that all of the ALHIV who stay with their biological parents have stayed with them since they were born. Some who stay with relatives form the extended family have stayed with them between 2 to 15 years. Most of the ALHIV from this category find themselves changing location from one caretaker to another or different reasons like the caretaker’s need to shift the burden to another person, or relocation of the LHIV to another school. Sometimes the health workers also recommend change of caretakers especially when they realize the current caretaker is too busy to monitor adherence especially for ALHIV who are taking pills twice a day. 3 ALHIVs who were interviewed currently stay alone, one for 2yrs now, and the other 2 ALHIVs for 7months and 9 months respectively, since they left their homes for different reasons.

This is the case with caretakers as well, where by the biological parents have stayed with their children ever since they were born, while other caretakers from extended families have stayed with the ALHIV in their care from 2-15 years. Some of these are orphaned children, others are adolescents whose parent separated, while others are children whose parents left them in the care of extended family relatives because they went to the city to work.

5.2.2 Description of the relationship between the ALHIV and Caretakers

This study found out that majority of the ALHIV including those who stay with their biological children do not relate well with their caretakers. They only stay with the caretakers because of their vulnerability and because they have no choice, however, given a chance, some of them would have loved to change location and caretakers. The reason for this is that the caretakers keep abusing them verbally, calling them dead bodies, or good for nothing people. Even when they make any mistake or miss taking their pills, some caretakers are quick to ask them whether they want to die like their parent died, or remind them that they are just helping them and they need to behave.

Although they are mature and are expected to know the implication of their statements, some few caretakers said they find themselves making those statements by mistake, but the intention is not to hurt the ALHIV. Having noted that caretakers are key stakeholders in the self-esteem of ALHIV, majority of the caretakers described their own relationships with the ALHIV as good, but described other caretaker’s relationship as bad. They found it easy to elaborate on the relationship of others, but not their own.

5.2.3 Remark on the self-esteem of ALHIV

Although all the ALHIV who were interviewed had a low self-esteem according to the Adolescent Self-Esteem Questionnaire Tool, when asked to comment on their own self-esteem; some of them did not know the meaning of self-esteem, and thus could not easily comment, others who knew what it meant said they have a high self-esteem, which the researcher noted as a respondent bias.

The researcher further found out that most of the caretakers also did not know what self-esteem was, and some of those who knew it had not taken time to analyze whether the ALHIV in their care had a high or low self-esteem. Very few of the caretakers could comment on the self-esteem of the ALHIV in their care, and they reported it to be good.

5.2.4 Effect of the HIV sero status on the self-esteem of ALHIV

Although some ALHIV said that the positive HIV sero status did ot affect their self-esteem, the researcher found out that they were negatively affected, especially those who are trying to go into romantic relationships. Whenever they try to disclose and the other party leaves them, they feel stigmatized and discriminated, to the extent that some of them opted not to disclose their status again, which I dangerous to the HIV negative partner.

The few ALHIV who have not yet started to engage into romantic relationships have also had their self-esteem negatively affected because they are not allowed to visit relatives as the other children in their homesteads, just because the caretakers feel they will not adhere well if they go to other places away from the caretakers’ homes.

5.2.5 Ways through which ALHIV can improve their self-esteem

All the ALHIV who were interviewed had a low-self, however, they did not know that their self-esteem is low. Majority of them did not really have a clear answer because someone who does not know that they have e problem, cannot find a solution to it. The commonest answer that they gave as a way of improving their self-esteem was that they should have hope, to which some added that one day the HIV cure will be got.

5.2.6 Role of caretakers in boosting the self-esteem of the ALHIV.

Apart from one ALHIV who believed that the caretakers do not have a role in boosting the self-esteem of the ALHIV, all the caretakers and the ALHIV who were interviewed believed that caretakers have a role in boosting the self-esteem of ALHIV, however, some of them have not played this role well and have not done their work.

5.3 How caretakers' knowledge on HIV/AIDS impacts on the self-esteem of ALHIV

The study found out that the majority of the caretakers were not knowledgeable on the basics of HIV/AIDS. They have left the responsibility of gaining this knowledge to the ALHIV. They no longer escort them to the facility, while others are too busy to attend counselling sessions to be health educated. Even those who said they are knowledgeable were explaining myths like how HIV can be transmitted through sharing a sponge, and general knowledge like taking plenty of water when taking ARVs, which is true, but a general knowledge used when taking any type of medicine like pain killers. Only a handful of the caretakers were able to give the basic knowledge on HIV/AIDS, explaining what it is, how it is transmitted, importance of ARVs and meaning of adherence. Surprisingly even the ALHIVs know that their caretakers are not knowledgeable about HIV/AIDS and most of them have taken longtime in control of their medication where by caretakers have entirely left this responsibility to the ALHIV themselves.

This lack of knowledge impacts negatively on the self-esteem of ALHIV due to the fact that there is no way they can support the ALHIVs without knowledge on how to support them. They also cannot nurture them or help them to excel academically because they are not aware that they have the potential to live long. They will therefore not encourage them or speak positively into their lives because they have no hope in them.

5.4 Caretakers' attitude towards the ALHIV

This study found out that while some few caretakers have a good attitude towards the ALHIV, most of them have a negative attitude towards these HIV positive adolescents. Although most caretakers found it easy to elaborate how fellow caretakers have a negative attitude towards the ALHIV. Even the ALHIV explained how their caretakers abuse and belittle, calling them names like moving dead bodies and good for nothing people. Some caretakers do not mind giving food to the ALHIV even when they know they have to take their mediation, something the ALHIV interpreted as not seeing any value in them. Some biological parents have denied their children because of their sero-status and do not want to identify with them.

5.5 Challenges caretakers face while taking are of the ALHIV

This study found out that the biggest challenge caretakers face while taking care of the ALHIV is the economic challenge. Most caretakers are elderly grandparents who are unemployed or practice farming on a small scale which cannot sustain the home. To make matters worse, these homes usually have other grandchildren and sometimes biological children who also need the care. This makes it difficult to secure things like food, school fees, buying clothes, getting medication for other diseases that the facility does not cater for. To some caretakers, even transport to the facility is a problem.

Apart from economic challenges, there are other challenges caretakers face while taking care of the ALHIV include environmental challenges which make monitoring adherence for ALHIV difficult especially those in boarding schools, personal challenges like fear to disclose to the ALHIV their status, psychological challenges like guilt and shame of having infected the ALHIV, depression, stress and anxiety, and social challenges like stigma.

5.6 Conclusion

In a nutshell, the study found out that most ALHIV have a low self-esteem, according to the scores from the Adolescent Self-Esteem Questionnaire Tool, much as some of them do not know that their self-esteem is low. Caretakers have played a big role and have contributed greatly to the low self-esteem of these ALHIV because they have spent most of their time with them while growing up, nurturing them and talking into their lives. Their lack of knowledge as caretakers in general on the basics of HIV/AIDS, negative attitude towards the ALHIV and the challenges they face as caretakers while taking care of the ALHIV are some of the things that have caused the caretakers to make this great contribution of to the low self-esteem of adolescents living with HIV (ALHIV).

5.7 Recommendations

- Both ALHIV and caretakers should be sensitized on what self-esteem is, as well as the meaning of high and low self-esteem. This will enable the ALHIV to improve on their self-esteem and also enable caretakers to help ALHIV to improve on their self-esteem.
- Improve on the sensitization of the public on the basics of HIV/AIDS; its meaning, means of transmission, prevention measures, the components of care and treatment for those who are HIV positive and ironing out the myths on HIV/AIDS. This will enable caretakers and the general public to know how to manage and support ALHIV. The general public should be

sensitized because anyone can be a potential caretaker of ALHIV in future.

- Conduct health education sessions with caretakers and caution them on their attitude and how they verbally and non-verbally communicate it to the ALHIV. This will enable them to first think through before they speak and to have self-control even when they are angry.
- There is need to support the caretakers with income generating activities especially those who are jobless, through seeking help from Community Based Organizations (CBO), benefitting from opportunities like Parish Development Model (PDM), and joining groups like Saving and Internal Lending Communities (SILC) or cash rounds. This will help boost the economic backbone of the caretakers so as to enable them support the ALHIV swiftly.
- There is need for more research on other life skills like self-awareness, decision making skills, critical thinking, effective communication, interpersonal relationships among others, in relation to people living with HIV/AIDS (PLHIV).

5.8 Suggestions for Future Research

Through this study, the researcher found out that more research could be done to improve on the wellbeing and treatment outcomes of children living with HIV (CLHIV) and adolescents living with HIV/AIDS (ALHIV). Further research on the following can be done.

- ➢ What is the contribution of health workers on the low self-esteem of ALHIV?
- ➢ What is the contribution of children and adolescents living with HIV to the UNAIDs goal of ending AIDS as by 2030?
- ➢ What is the relationship between disclosure and improvement of retention in care?

- How has the integration services in health centres impacted on the ART adherence of ALHIV?

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APPENDICES

Appendix I: ADOLESCENT SELF-ESTEEM QUESTIONNAIRE TOOL

These questions ask you how you feel about yourself. Please answer each question. Remember there is no right or wrong answer.

YSE1. I am able to stand up for myself and what I believe in

1 – Almost all of the time

2 – A lot of the time

3 - Some of the time

4 - A little of the time

5 – Hardly ever

YSE2. How I feel about myself depends on what others think of me

1 – Almost all of the time

2 – A lot of the time

3 - Some of the time

4 - A little of the time

5 – Hardly ever

YSE3. I feel I can be myself around other people

1 – Almost all of the time

2 – A lot of the time

3 - Some of the time

4 - A little of the time

5 - Hardly ever

YSE4. Overall I feel good about my abilities compared to others (e.g. at school, playing sports or socially)

1 - Almost all of the time

2 - A lot of the time

3 - Some of the time

4 - A little of the time

5 - Hardly ever

YSE5. If I make an innocent mistake I let it get me down

1 - Almost all of the time

2 - A lot of the time

3 - Some of the time

4 - A little of the time

5 - Hardly ever

YSE6. I feel useless

1 - Almost all of the time

2 - A lot of the time

3 - Some of the time

4 - A little of the time

5 – Hardly ever

YSE7. Overall I like who I am

1 - Strongly agree

2 - Agree

3 - Neither agree nor disagree

4 - Disagree

5 - Strongly Disagree

YSE8. I am a good person who has a lot to offer

1 - Strongly agree

2 - Agree

3 - Neither agree nor disagree

4 - Disagree

5 - Strongly Disagree

YSE9. I feel that I am a valuable person who is at least equal to other people

1 - Strongly agree

2 - Agree

3 - Neither agree nor disagree

4 - Disagree

5 - Strongly Disagree

YSE10. How I feel about my body makes me feel less confident

1 - Strongly agree

2 - Agree

3 - Neither agree nor disagree

4 - Disagree

5 - Strongly Disagree

YSE11. I feel confident in my abilities to achieve the things I set my mind to

1 - Strongly agree

2 - Agree

3 - Neither agree nor disagree

4 - Disagree

5 - Strongly Disagree

YSE12. I think other people like me

1 - Strongly agree

2 - Agree

3 - Neither agree nor disagree

4 - Disagree

5 - Strongly Disagree

Appendix II: INTERVIEW GUIDE FOR ADOLESCENTS LIVING WITH HIV.

Title: Contribution of Caretakers to the Self-Esteem of Adolescents Living with HIV

Introduction: My name is Zalwango Rebecca, I am a continuing student of Masters of Mental Health Counselling Psychology at Uganda Martyrs University.

Thank you for participating in this research study. Your valuable insights will contribute to a better understanding of the role of caretakers in the self-esteem of adolescents living with HIV. Please answer the following questions honestly and to the best of your ability. Your identity will be anonymous and your answers will be kept confidential.

General Information

1. How long have you stayed with your current caretaker?
2. How would you describe your relationship with your caretaker?
3. Do you think self-esteem is an important issue to you as an adolescent? If Yes, WHY?
4. How would you comment on your self-esteem?
5. Do you think your sero-status has affected your self-esteem in any way?
6. Suggest ways in which you can improve your self-esteem?
7. How has your self-esteem affected your overall well-being?
8. In your opinion, how important is the role of a caretaker in boosting the self-esteem of ALHIV?

9. Do you think caretakers have played their role in helping the ALHIVs to achieve a positive self-esteem? How?

Objective 1: Knowledge on ART and its impact on the self-esteem of ALHIV

10. What do you know about anti-retroviral therapy (ART)?

11. Is your caretaker knowledgeable about the basics of HIV treatment, specifically Anti-Retroviral Therapy?

12. Is your caretaker interested in seeking new knowledge or health education about ART? If Yes, how has he/she sought this knowledge?

13. Do you feel it is important for your caretaker to have this knowledge about ART so as to be able to impact the self-esteem of ALHIV?

14. What is the effect of lack of ART knowledge of caretakers to the self-esteem of ALHIV in general?

Objective 2: Attitude towards Adolescents Living with HIV

15. Have you ever expressed how your caretaker's support makes you feel? If Yes, How? have you done this?

16. How has your caretaker shown you love and care?

17. In your observation, how do other caretakers of ALHIV view the adolescents in their care? What is their attitude towards them?

18. In what ways has this attitude/actions (From other caretakers) been displayed or shown towards ALHIV?

19. How can the caretakers improve their day to day relationship with the ALHIV?

Objective 3: Challenges and Support

20. What are some of the commonest challenges you have encountered as an ALHIV in trying to improve your self-esteem?

21. How have you overcome these challenges?

22. In your opinion, what are some of the challenges caretakers face as they try to boost the self-esteem of ALHIV in general?

23. How can the caretakers overcome the challenges named above?

24. What resources or support do you think would help caretakers to better support ALHIV and enhance their self-esteem?

Additional Comments

25. Is there anything else you would like to share regarding your self-esteem, or the self-esteem of fellow ALHIV?

Appendix III: INTERVIEW GUIDE FOR CARETAKERS.

Title: Contribution of Caretakers to the Self-Esteem of Adolescents Living with HIV

Introduction: My name is Zalwango Rebecca, I am a continuing student of Masters of Mental Health Counselling Psychology at Uganda Martyrs University.

Thank you for participating in this research study. Your valuable insights will contribute to a better understanding of the role of caretakers in the self-esteem of adolescents living with HIV. Please answer the following questions honestly and to the best of your ability. Your identity will be anonymous and your answers will be kept confidential.

General Information

1. How long have you lived with the Adolescent Living with HIV (ALHIV)?
2. How would you describe your relationship with the ALHIV under your care?
3. Do you think self-esteem is an important to these ALHIV? If Yes, WHY?
4. How would you comment on the self-esteem of these ALHIV?
5. In what ways do you support the ALHIV to improve their self-esteem?
6. How do you think the ALHIV’s self-esteem affects their overall well-being and management of their HIV condition?

7. In your opinion, how important is the role of a caretaker in boosting the self-esteem of ALHIV?

8. Do you think caretakers have played their role in helping the ALHIVs to achieve a positive self-esteem? How?

Objective 1: Knowledge on ART and its impact on the self-esteem of ALHIV

9. What do you know about anti-retroviral therapy (ART)?

10. Do you think other caretakers of ALHIV are knowledgeable about the basics of HIV treatment, specifically Anti-Retroviral Therapy?

11. How have you as caretakers of ALHIV sought new knowledge or health education about ART?

12. From your experience, how can this knowledge about ART impact the self-esteem of ALHIV?

13. What is the effect of lack of ART knowledge to the self-esteem of ALHIV?

Objective 2: Attitude towards Adolescents Living with HIV

14. Have the ALHIV ever expressed how your care and support make them feel? If yes, please share their feedback or comments.

15. How would you describe your relationship with the ALHIV under your care?

16. How do you show that you love and care for these adolescents?

17. In your observation, how do other caretakers of ALHIV view the adolescents in their care? What is their attitude towards them?

18. In what ways has this attitude (From other caretakers) been displayed or shown towards ALHIV?

19. Would you interpret these actions as showing love or hatred? Why?

20. Have the ALHIV that you have interacted with been able to interpret these actions and relate them with attitude? How?

21. Has the ALHIV ever expressed to you how the care and support from their caretakers make them feel? If yes, please share their comments.

22. How can you and other caretakers improve their day to day relationship with the ALHIV?

Objective 3: Challenges faced while taking care of ALHIV

23. What are some of the commonest challenges that you have encountered as you try to boost the self-esteem of the ALHIV?

24. How have you overcome these challenges?

25. In your opinion, how can the other caretakers overcome the challenges named above?

26. What resources or support do you think would help you as a caretaker to better support ALHIV and enhance their self-esteem?

Additional Comments

27. Is there anything else you would like to share regarding your role as a caretaker, concerning the self-esteem of adolescents living with HIV?