THE EFFECT OF EDUCATION PACKAGE ON CAREGIVERS KNOWLEDGE, AND PRACTICES TOWARDS CARING FOR ADOLESCENTS LIVING WITH HIV: A CASE STUDY OF A HEALTH CENTER IV IN MID-WESTERN UGANDA

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A DISSERTATION SUBMITTED TO THE FACULTY OF PUBLIC HEALTH, NURSING & MIDWIFERY IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE AWARD OF A DEGREE OF THE MASTER OF NURSING SCIENCE OF UGANDA CHRISTIAN UNIVERSITY

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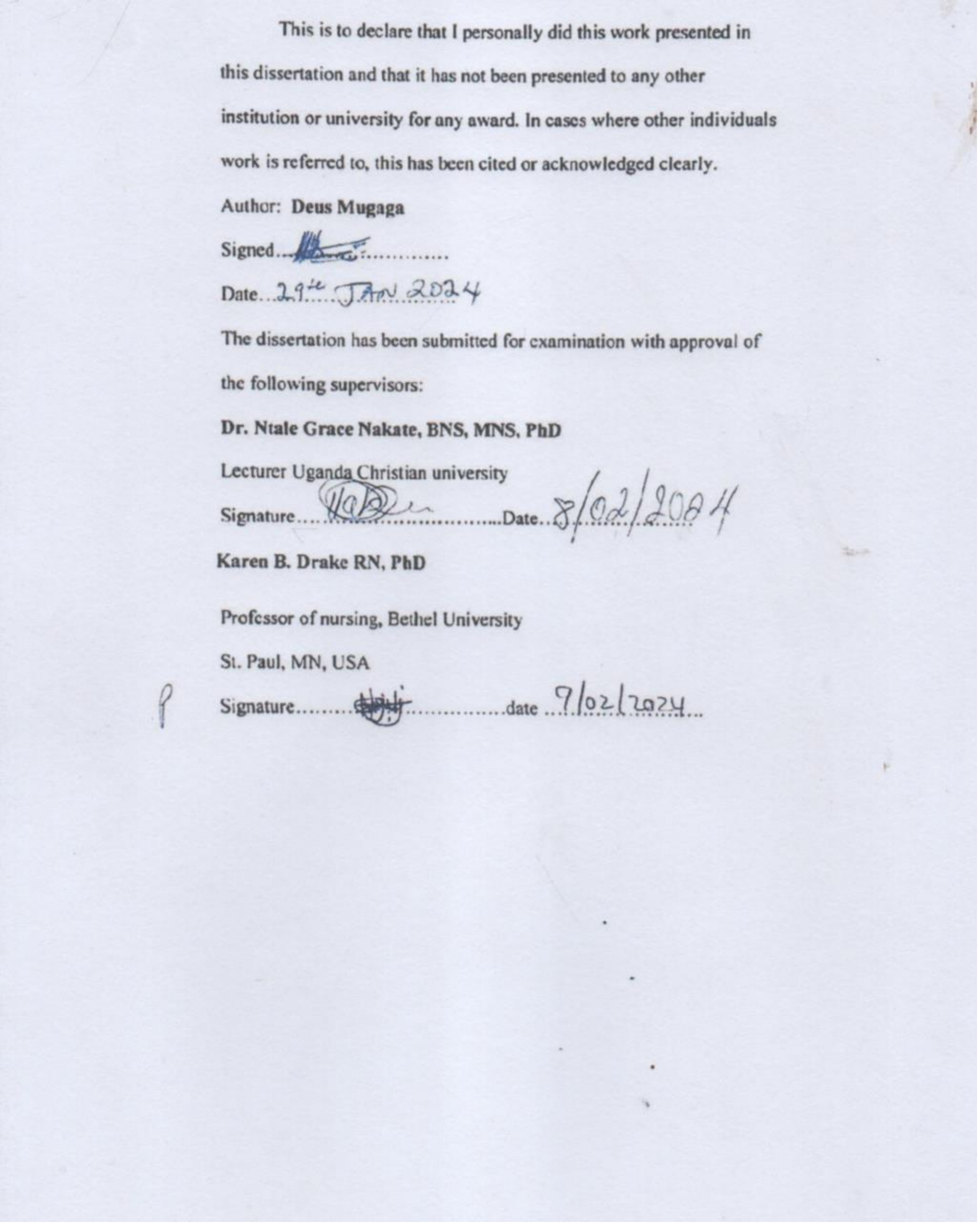
Declaration



This is to declare that I personally did this work presented in this dissertation and that it has not been presented to any other institution or university for any award. In cases where other individuals work is referred to, this has been cited or acknowledged clearly.

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Dedication

This book is dedicated to my lovely wife Nassanga Grace and children, Kobusigye Patience, Atuhaire Praise, Ainebyoona Cuthbert, Namara Precious, Kamukama Calvin, and my elder brother, Byamukama Remegio who supported me infinitely and bored with my absence from home at the time when they needed me most.

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The completion of this research study and compilation of this book is a recognition of people without whom I could not have made it far. The almighty GOD whom I treasure and glorify His Holy Name. My dear wife Nassanga Grace and lovely children Patience, Praise, Precious, Cuthbert, Kamukama, thank you for the tireless support, ever-loving, care and understanding. My beloved brother Byamukama Remmy and wife Byamukama Leticia you are such a blessing in my life.

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ABSTRACT

Background: Human Immunodeficiency Virus (HIV) is the virus that causes AIDS, which is the most advanced stage of HIV infection. Globally, an estimated 37.9 million people are currently living with HIV, of these, 36.2 million were adults and 1.7 million were adolescents, about 1.5 million (89 %) live in sub-Saharan Africa. In Uganda, an estimated 1.4 million people were living with HIV in 2018, about 9% were adolescents aged, and an estimated 1.6% Ugandans died of AIDS-related illnesses. Adolescents on ART need support in order to ensure the high level of adherence is achieved to maximize the benefits of the therapy. The support and guidance from their caregivers are crucial in improving their adherence on ART. However, caregivers' intent support to adolescents is a major challenge due to lack of adequate knowledge about the ever-changing drugs used in the treatment of HIV. This study therefore, was to find out the effect of an interventional education package to the caregivers on their knowledge about ART and their practices towards ART adherence among adolescents.

Methods: A sample of 98 caregivers were adopted for the study. Data collection was done before and after the education, intervention package slated for one month and this was done by use of an administered questionnaire that was translated into Runyoro. The data was finally analysed using descriptive and inferential statistics with the help of the statistical package for Social Sciences (SPSS).

Results: Analysis revealed that active drug level influenced adherence to ART among adolescents, caregiver's supportive of the adolescent on ART improved their adherence, and knowledge affects the way the caregiver enforces the dosages towards the adolescents, and enables them to plan effectively and empowers their ability to supervise their adolescents on ART.

Conclusion: Knowledge is a very fundamental factor among caregivers, education package enriches the caregiver's commitment to practices towards enhancing adolescent's adherence on ART, and the caregivers' knowledge has a significant relationship with their commitment when it comes to caring for adolescents on ART.

CHAPTER ONE

1.0 Introduction

Numerous adolescents globally confront a significant vulnerability to contracting HIV. Nevertheless, for those who contract the virus, their chances of survival have markedly risen due to the utilization and commitment to potent antiretroviral medications (ART). The key role played by caretakers is instrumental in achieving this outcome. Caregivers typically refer to individuals, often-family members or healthcare workers, who provide direct care, support, and assistance to adolescents living with HIV. Their responsibilities include managing medication, offering emotional support, and ensuring the adolescents' overall well-being (Riffin et al., 2020). Caregivers' recognition that ARV treatment extends the lifespan and enhances the well-being of young individuals significantly contributes to the elevated level of adherence. (Mbiyu, Kikuvi & Amukoye, 2017).

At least more than 95% adherence to ART adherence comes when caregivers accept the challenge and give the necessary support towards the patient that reduces stigma and improves self-confidence. (Adejumo et al, 2015). However, caregivers have often been wanting when it comes to updated knowledge and attitudes which determines their practices and this affects their ability to enhance adherence to them (Osafo, Loaknizek, Mugisha, & Kinyanda, 2017). Therefore, the study is seeking to establish the effect of education intervention on the caregivers’ knowledge, attitudes and practices towards adolescents on ART living with HIV/AIDS. The study focused on caregivers at Health Center IV in South Western Uganda, specifically those responsible for adolescents on ART (Antiretroviral Therapy) living with HIV/AIDS. These caregivers included mainly family members providing daily care and support.

1.1 Background

The cause of Acquired Immunodeficiency Syndrome (AIDS), the final stage of infection by the Human Immunodeficiency Virus (HIV), is attributed to this retrovirus. HIV appears in two variants: HIV-1 and HIV-2. On a global scale, about 37.9 million individuals currently grapple with HIV, with adults constituting 36.2 million and adolescents 1.7 million. The majority (89%) of these instances are concentrated in sub-Saharan Africa. In Uganda, the number of individuals living with HIV in 2018 was around 1.4 million, with approximately 9% falling within the age group of 10 to 19 years. AIDS-related illnesses accounted for an estimated 1.6% of deaths among Ugandans (UNAIDS, 2019). In the mid-western region of Uganda, 3% of adolescents are grappling with HIV. (Baylor ACE Bunyoro report, 2022). The study will mainly consider adolescents (10 to 19 years). An adolescent is defined as a person aged 10 to 19 years (WHO, 2015). A Caregiver is a person who is available and willing to support an ALHA. This may be a parent, family member, community volunteer, health care worker (Holstad, Pace, De, & Ura, 2006). Caregivers play major roles in promoting adherence to ART such as; following up the treatment regimen and encouraging them to take medication regularly in addition to providing the appropriate diet. Adolescents usually depend on their caregivers to disclose their HIV status, the reason for taking their medication, and report additional age-related issues to the relevant stake holders since they spend most of the time with them at home. This strong caregiver relationship promotes adherence (Bunnel et al, 2006).

In a study conducted in both South Africa and Ethiopia focusing on care and adherence amongst adolescents living with HIV (ALHIV), caregivers' practices came out as one of the key factors that determined adherence to Anti-Retroviral Therapy (ART) in adolescents (Fuge, Tsourtos & Miller, 2022; Grimwood et al., 2018). A research carried out in 15 Nigerian states by Adedokun and colleagues (2015) discovered that within the population of young individuals living with HIV, heightened stress levels linked to the enduring health challenges of HIV/AIDS were evident in households where caregivers failed to provide sufficient social support. The absence of adequate social support was correlated with both the physical and mental well-being of these individuals (Tumwikirize et al., 2015). The investigations also illustrated that caregivers possessed the capability to motivate those with HIV to adopt behaviors that enhance the efficacy of Antiretroviral Therapy (ART). (Genberg et al., 2016). Caregivers also had the potential to enhance adherence if given the required education package on HIV care (Genberg et al., 2016). However, this potential by the caregivers to support adolescents on ART towards adherence to medications often faces a challenge of lack of adequate knowledge about the ever-changing drugs used in the treatment of HIV. They also do not know how to manage HIV related infections, drug dosage, benefits and side effects of new ART regimen **(**Osafo, Loaknizek, Mugisha, & Kinyanda, 2017). For caregivers to effectively ensure the consistent adherence of adolescents to their prescribed medications, a research conducted in Durban, South Africa suggested the necessity of empowering caregivers to modify their approaches. (Grimwood et al., 2018).

Numerous studies have demonstrated the efficacy of educational initiatives in enhancing the understanding of individuals providing care. To illustrate, an investigation into the influence of educational interventions on caregiving outcomes among Jordanian caregivers of patients found that instructing caregivers about the necessary care elevated their knowledge, attitudes, and alleviated their burdens, resulting in improved caregiving outcomes (Alnazly, 2018). Similarly, a study in Brazil examining the impact of an educational intervention on the knowledge and practices of caregivers observed significant enhancements in both knowledge ($p<0.001$) and practices ($p<0.001$) (Moreira et al., 2018). Another study conducted to measure the effectiveness of interventions revealed that intervention effects were larger when it came to increasing caregivers' ability and knowledge eventually reducing their burden and depression (Sorensen, Pinquart, Habil & Buberstein, 2019).

Care providers need to possess essential skills necessary for involvement in and administration of the ART program and HIV care. This includes a grasp of HIV-related knowledge, confidence in self-management and skill development, personal convictions, objectives, anticipations, and the psychosocial welfare of the young individuals. (Schwartz et al., 2011). In Uganda, the state of knowledge and practices of the caregivers towards caring for adolescents on ART has been found wanting. It has been reported that some caregivers lack a clear assessment of the basic medical needs of their patients, are not good in providing companionship, many cannot prepare a care plan and are unable to monitor medications properly (Echiru, 2017).

In Kakumiro HC IV specifically, internal reports show that many of the practices of caregivers of adolescents on ART are inadequate. Many of them have difficulties in handling the transition stage, lack of knowledge in new regimen formulations and lack knowledge in general care for their children. They need a programmed education package from their health care providers to give them updated information about adolescents’ medication, and support needed for their adolescents (Piran, Khademi, Tayari, & Mansouri, 2017). It is against this background that the researcher is prompted to carry out an interventional education package to the caregivers. The intent is to determine how the education package improves the caregivers’ knowledge and practices towards facilitating ART adherence among adolescents at Kakumiro HC IV.

1.2 Statement of the Problem

Adolescents exhibit the least adherence to Antiretroviral Therapy (ART) compared to other age demographics, yet they account for more than half of all new HIV infections. The adherence behaviors of adolescents are significantly influenced by the caregiving practices they receive. Good basic practices by the caregivers to the adolescents on ART are essential. Nonetheless, assistance for adolescents might be constrained in situations where numerous caretakers possess insufficient understanding and dedication regarding the constantly evolving anti-retroviral medications. A considerable number of them also lack awareness concerning the handling of HIV-associated infections, as well as information on the recommended dosage, advantages, and potential side effects of recent ART regimens.

In Kakumiro HC IV, it has been revealed that the practices of the caregivers when caring for adolescents on ART is inadequate to effectively enhance ART adherence. Difficulties in handling the transition stage, lack of knowledge in new regimen formulations and their anticipated side effects and inadequate skills in adolescent’s HIV status disclosure are key areas of concern. Failure to meet their clinical appointments is also a major concern at the health facility. This study sought to find out the effect of an interventional education package to the caregivers on their knowledge, and practices towards ART adherence of adolescents on ART.

1.3 Purpose of the Study

The purpose of the study was to determine the effect of an education intervention package to caregivers on their knowledge, and practices when enhancing adherence among adolescents on ART.

1.4 Research Question

What is the effect of an education interventional package on the knowledge, and practices of the caregivers towards enhancing adherence of Adolescents on ART?

1.5 Objectives of the Study

- To determine the effect of the educational package to caregivers on their knowledge towards enhancing ART adherence by adolescents.
- To identify the effect of the education package to caregivers on their practices towards enhancing ART adherence.

1.6 Significance of the Study

The research aims to assist healthcare professionals and administrators of health facilities in enhancing and upholding strategies to ensure consistent adherence to treatment among adolescents within healthcare settings, utilizing accessible and cost-effective primary medications. Consequently, this initiative is anticipated to enhance the well-being of adolescents and decrease the incidence of illness associated with the failure to adhere to antiretroviral therapy (ART).

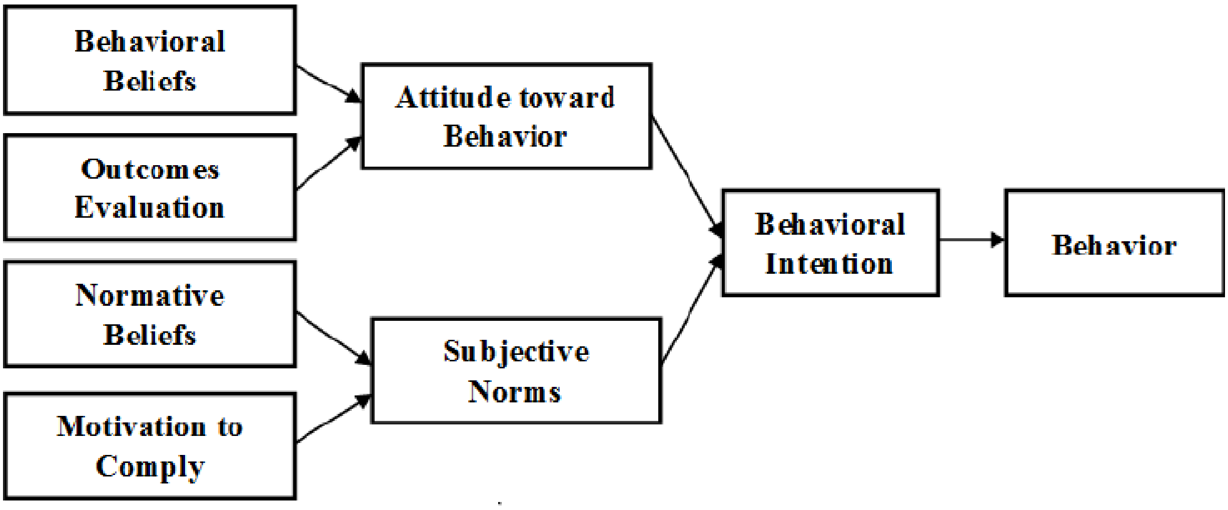
The research also aims to provide valuable insights to caregivers nationwide on optimal approaches for handling ALHAs. This information is crucial for supporting adolescents in adhering to their treatment, resulting in viral suppression, decreased opportunistic infections, and ultimately enhancing the quality of life for this vulnerable age group.

In addition, the study aims to offer a foundational reference point, anticipating that its findings will support the Ministry of Health in formulating an educational program for caregivers. This program will focus on enhancing the skills of nurses in handling HIV/AIDS among adolescents, thereby bolstering their capacity to raise awareness and provide effective care for individuals affected by ALHA.

1.7 Theoretical Framework

The research utilized the Theory of Reasoned Action (TRA; Ajzen & Fishbein, 1980; Fishbein & Ajzen, 1975), a cognitive framework designed to comprehend human behavior within specific contexts. TRA is grounded in the fundamental idea that individuals' actions can be anticipated based on their intentions. Essentially, people tend to follow through on what they intend to do and abstain from actions they do not plan to undertake. These intentions are termed behavioral intentions and generally serve as reliable predictors of future behavior. TRA underscores two key factors influencing intention strength: the perceived value of performing the behavior and subjective norms. In essence, individuals are more likely to form intentions to engage in a behavior if they view it positively and perceive it as significant within their social circles or society at large (LaCaille, 2013).

The Theory of Reasoned Action



The Theory of Reasoned Action (TRA) has found application in numerous research endeavors aimed at altering behavior, demonstrating its effectiveness. When individuals abstain from engaging in desired behaviors, a common response among healthcare practitioners is to attribute this to a lack of pertinent information or an unfavorable attitude. Consequently, many interventions for behavior change focus on shaping attitudes or delivering relevant knowledge. However, these interventions frequently fall short, as the underlying issue often lies in the inability of individuals to translate their intentions into actions.

If individuals have the inclination to engage in a certain behavior but are not translating those inclinations into actions, they possess the correct mindset. Consequently, the likelihood is low that they require additional information. The hindrance lies in either a lack of essential skills and capabilities or the existence of internal or external obstacles hindering the execution of their intentions. In such instances, the suitable intervention is not geared towards dispensing knowledge or methods but rather towards enhancing skills or aiding individuals in surmounting or sidestepping barriers. Conversely, when individuals refrain from a behavior due to a lack of intention, the nature of the issue is markedly distinct.

Three main factors contribute to the formation of intention: one's stance toward engaging in the specific behavior, the impact of social pressure in relation to the behavior, and the confidence in possessing the necessary skills and capabilities to carry out the behavior, even in challenging circumstances. This confidence is reflected in one's self-efficacy or perceived control over the execution of the behavior. The significance of these three psychosocial variables in shaping intention can vary depending on the behavior and the specific population under consideration. Some behaviors are predominantly guided by attitudes, while others may be more influenced by social norms.

A conduct influenced by attitudes within a specific cultural or societal group may be guided by norms in another setting. In certain cases, one of the three elements (attitude, norm, or perceived behavioral control) might not play a significant role in predicting intentions. In such instances, it suggests that, for the particular behavior and population being studied, the specific factor does not hold much importance in shaping intentions. Therefore, before implementing strategies to alter intentions, it is crucial to assess the extent to which attitudinal, normative, or self-efficacy factors influence those intentions in the target population. It is essential to recognize that interventions for behaviors driven by attitudes differ significantly from those influenced by norms or strongly linked to self-efficacy and perceived behavioral control. In this study, normative beliefs were represented by the caregivers' perceptions of societal expectations regarding their role in caring for adolescents on ART. Outcome evaluation referred to how caregivers assessed the benefits of improved care practices after the education intervention. Motivation to comply was reflected in the caregivers' willingness to follow through with recommended care practices based on the intervention.

1.8 Operational Definitions

Terms commonly used throughout the study were:

Acquired Immune Deficiency Syndrome (AIDS)**:** A compilation of various illnesses or malignancies that appear in the body of someone infected with HIV and experiencing a significantly compromised immune system, indicating the advancement of a more serious syndrome that, over time, could lead to mortality. (NIH, 2019).

Knowledge**:** This pertains to the verifiable knowledge within an individual's possession. In this instance, it denotes the data that the caregiver possesses in relation to the care of adolescents undergoing ART treatment.

Adherence**:** A method where a healthcare professional recommends a suitable course of treatment following a relevant discussion with the individual seeking medical advice. (Chakrabarti, 2014)

Antiretroviral Therapy (ART)**:** Antiretroviral therapy pertains to the administration of a combination of three or more drugs designed to combat HIV infection. In the context of this research, it denotes the specific HIV treatment regimen provided to adolescents diagnosed with HIV.

Adolescent. Adolescence denotes a period encompassing both psychological and physical growth, spanning from the onset of puberty to the attainment of maturity. An individual classified as an adolescent falls within the age bracket of 10 to 19 years, further categorized as early adolescence (10-14 years) and late adolescence (15-19 years). (Rashwan et al., 2015)

Practices. The actions and willingness to continuously take charge and support clients living with HIV/AIDS (Osafo et al., 2017).

Caregivers. Persons endowed with the responsibility of provision of physical and psychological care and support to patients living with HIV/AIDS (Nyando, 2014)

Educational Intervention Package. A training offered to caregivers to ensure that they acquire knowledge about HIV/AIDS making them better equipped to care for the patients. (Atanuriba et al., 2021).

Summary

This chapter has outlined the context of the research, addressing the issue of adherence to ART among adolescents, specifying the study's objectives, and examining the potential influence of caretaker knowledge and attitudes on adherence levels. The chapter has underscored the unique contributions this research could make in various settings. Additionally, it introduces the theory of reasoned action (TRA) and its relevance to the study.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter presents a summary of existing studies on the influence of an educational intervention initiative on individuals responsible for the care of adolescents diagnosed with HIV/AIDS. The primary focus is on elucidating how this program enhances their comprehension and efforts in promoting adherence to antiretroviral therapy (ART). The literature delves into the significance of adhering to ART among adolescents living with HIV/AIDS (ALHA), the gaps in caregivers' knowledge, and the impact of an educational intervention incorporating the theory of reasoned action. The section explores prior research aligned with the study's objectives, commencing with an introduction. It then proceeds to discuss the importance of ART adherence in adolescents, caregivers' knowledge, the influence of the educational initiative on ART adherence, and concludes by summarizing the findings from the literature review.

2.2 Importance of ART Adherence in Adolescents

Chakrabarti (2014) defined adherence as the act of following a treatment regimen recommended by a healthcare provider after a thorough conversation with the patient. Molloy and Carol (2017) argue that adherence, as a behavior, is crucial over the course of one's life for preventing and managing illnesses and sustaining well-being. Results from a previous study suggest that approximately 20% of people with HIV in Africa and 14% in the United States encountered treatment setbacks because of insufficient adherence to antiretroviral therapy (Safren et al., 2015). It has been observed that adolescents with HIV pose a significant demographic facing challenge in conforming to ART and dealing with associated complications globally (Adejumo et al., 2016). Hence, it is crucial to achieve optimal adherence to ART to enhance the quality of life for children and adolescents with PHIV (Kalomo et al., 2017).

In the realm of the comprehensive test and treat approach, the commitment to antiretroviral therapy (ART) holds significant importance in attaining the third target within the 95-95-95 initiative. This particular target emphasizes the achievement of viral suppression in 95% of individuals undergoing treatment. Iacob et al. (2017) asserted that achieving viral suppression stands as the ultimate objective and triumph of ART, proving advantageous on both an individual and societal scale. Ochieng et al (2015) also emphasize that virological failure can be strongly predicted by treatment adherence. Earlier studies conducted in South Africa and in Mumbai, India revealed that they were able to achieve optimal outcomes from HIV treatments by suppressing the growth of the virus when exceptional adherence above 95% to ART was observed (Coetzee et al., 2015; Govind et al., 2017). This means that good adherence to prescribed medicines curtails viral multiplication, stops disease progression and reduces the numbers of deaths. It’s therefore conclusive to say that the ultimate treatment for HIV patients has got to achieve viral suppression in the life of the patients and this cannot be achieved if the patients don’t adhere to the prescription guidelines that the medication follows.

Scanlon and Vreeman (2013) however point out that despite the ability of ART adherence to reduce morbidity and mortality; good clinical outcomes depend on access to treatment, a cause for concern in many developing countries. Lack of access to the drugs leads to poor adherence which becomes a costly endeavor. In this context, poor adherence leads to drug resistance. This is because when adolescents fail on their first line regimens, they have to be switched to more expensive second line drugs which increases pill burden on both the patient and the national governments (Bennett, 2019). Access to effective antiretroviral therapy is the most important intervention in terms of improving longevity and preventing opportunistic infections in adolescents with HIV infection. It therefore implies that efforts geared towards adherence to drugs must first consider accessibility of the drugs to the people in the communities before they can push the adherence agenda. This is because, adherence cannot be attained to a great extent without accessibility especially in sub-Saharan Africa.

2.3 Knowledge of the Caregivers in ART adherence

Sub-Saharan Africa still grapples with the most pronounced consequences of the human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS). The proficiency of caregivers stationed in households proves pivotal in motivating communities to pursue healthcare services for advice on HIV/AIDS and its management (Matwa, 2017). Caregivers of ALHIV also get engaged in mobilising them to attend health facilities, disclosure of their HIV status, providing nourishing support, facilitating consistent medication adherence, overseeing care during significant health challenges, and addressing emotional distress, societal bias, discrimination, and various other concerns (Bikako, 2016). As a result, they enhance the healthcare team's efforts in delivering diverse services and play a crucial role in enhancing clinical outcomes. Nevertheless, it is imperative for these caregivers to possess sufficient understanding of HIV/AIDS to effectively fulfill their responsibilities. Knowledge of how the virus works, medication formulations available, drug administration and common side effects, safety issues, psycho-social issues, and other key aspects of HIV care are key in improving adherence to treatment. (Mbiyu, Kikuvi & Amukoye, 2013). Insufficient hands-on experience among caregivers working in home settings regarding HIV/AIDS and anti-retroviral therapy (ART) results in suboptimal individual commitment to treatment.

According to Bikako (2016), insufficient education and training for caregivers based at home result in their inability to properly care for HIV/AIDS patients. Bikako contends that caregivers need to be educated on effectively managing HIV/AIDS-infected individuals, enabling them to identify and address minor health issues. The acquisition of knowledge and skills in this area is crucial and can be valuable in the provision of care for individuals with persistent illnesses. Bikako stresses the importance of caregiver training, emphasizing the need for practical guidance on home-based care, encompassing aspects such as overall hygiene, nutrition, and psycho-social support. A study exploring the experiences of caregivers of children living with HIV/AIDS in Uganda supports these assertions by Osafo et al. (2017) highlighted the need for training of caregivers about good practices while caring for adolescents on ART, the frequency of taking medication and why it is necessary to follow up on the taking of medicines. They also emphasized the need for training caregivers on how they handle the adolescence transition stage. Need for training on how to access side effects of drugs, advanced drug reactions, and seek medical attention from health workers (Osafo et a., 2017). The emphasis on knowledge of the caregivers according to Matwa (2017), Osafo et al (207), Bikako (2016) and Mbiyu, Kikuvi & Amukoye (2013) has portrayed that knowledge helps in overcoming their individual capacity hindrances towards caring for HIV positive adolescents.

Piran, Khademi, Tayari, & Mansouri (2017) emphasized in their research on the caregiving burden among young and adolescents with chronic diseases that a significant challenge faced by home-based caregivers is the insufficient practical knowledge regarding HIV/AIDS. Correspondingly, caregivers encounter obstacles such as lack of awareness, difficulties in diagnosis, disclosure of HIV positive status, intricacies of ART administration and adherence, limited accessibility to health services, underutilization of available services, and concerns about the quality of healthcare. In African nations, there appears to be a shortage of fundamental knowledge about HIV/AIDS. For instance, a study in Nigeria revealed that only 15% of the surveyed population could characterize HIV/AIDS as a fatal illness, and in Burkina Faso, 69% of young women were aware of the lethality of AIDS (Kendra & Barbara, 2018). Another research undertaken in the northern region of Kenya revealed that 64% of females recognized 'wasting' as an indicative sign of AIDS. Additionally, a prevalent misconception among numerous African women persists, suggesting that there exists a remedy for AIDS. Although an increasing number of African individuals acknowledge the transmission of HIV through unprotected sexual activities, awareness regarding alternative transmission modes, such as non-sterile injection equipment, blood transfusions, tainted instruments, and mother-to-child transmission, shows substantial variability (Mukui et al., 2016).

It is crucial to evaluate and consistently update the knowledge necessary for delivering home-based care in the dynamic global landscape of HIV/AIDS. The guidelines for home-based care outline in-depth knowledge prerequisites for caregivers, encompassing fundamental definitions of HIV and various transmission methods (Ministry of Health, 2021). Caregivers must distinguish between HIV and

AIDS, comprehend issues related to opportunistic infections, grasp basic nutrition for HIV-positive adolescents, and offer psychosocial support (Hudelson & Cluver, 2015). A cross-sectional study examining the execution of a community health worker program in rural Eastern Cape, South Africa, discovered a shortage of accredited training and uneven informal training for this category of healthcare providers. It followed suit that since the health-care providers had limited training, the knowledge of the caregivers was extremely low. Many of the caregivers couldn't even understand the basic principles in HIV care of patients on ART (Matwa, 2017).

Caregivers' Practices towards Enhancing ART Adherence

The detection of HIV disease occurred merely three decades ago. Since then, extensive research has centered around the prevention, management, and cure of HIV. Thanks to advancements in pharmacology and healthcare, HIV has undergone a transformation from a debilitating, life-threatening condition to a more enduring chronic state (Eticha & Berhane, 2014). Managing the disease involves daily tasks such as adhering to prescribed medications and maintaining proper nutrition to safeguard the immune system against weakening or destruction by the virus. Caregivers play a pivotal role in establishing routines for medication adherence, as highlighted by Coulibaly et al. (2016). Zikhathile and Atangana (2018) underscore the various responsibilities shouldered by caregivers in delivering services. These encompass caring for individuals confined to their beds in a domestic setting, delivering emotional and mental well-being assistance, administering hands-on care, addressing health and nursing requirements, managing household tasks, supervising medical interventions, directing patients to appropriate healthcare institutions, delivering guidance during periods of mourning, and assisting those who have lost their parents or guardians.

Recognition of caregiver adherence support has been evident in numerous studies, particularly within the context of research conducted in African nations (Zikhathile & Atangana, 2018; Denison et al., 2015; Dow et al., 2016). However, the outcomes exhibited variations across different countries. For instance, Gichane et al. (2018) highlighted in their investigation that every adolescent orphan residing with their mothers acknowledged receiving some manner of assistance. A majority of them noted direct aid from their mothers in medication management and clinic attendance. The same study also revealed that the mothers of paternal orphans were themselves living with HIV, indicating a possible empathetic response to their child's HIV status, motivating them to contribute to treatment adherence. It is evident, therefore, that caregiver support can be influenced by various factors. Consequently, the practices of caregivers need to be assessed with consideration for the specific country and context in which the study was conducted.

Caregiver support, particularly from mothers has been found to be instrumental in treatment maintenance (Dow et al., 2016). In scenarios where the caregivers of adolescents took their medications together, adherence to ART treatment was very high (Ramaiya et al., 2016; Ricci et al., 2016). This was particularly important, as studies indicated that caregiver’s non-adherence and poor physical health could negatively influence the adherence of the adolescents. While this study does not intend to collect information on caregivers’ treatment adherence, it is of relevance that assessment be done targeting HIV-positive caregiver’s adherence in order to improve adolescent’s adherence.

The caregivers’ practices of the HIV patients have also been found wanting on a number of occasions. For example, in a study by Kajubi et al. (2022) investigating the link between HIV positive children and their caregivers, it was discovered that caregivers rarely communicated about the ARVs and other medicines that were being taken by the children. This discovery aligns with other studies on family dynamics within the realm of pediatric long-term illnesses. Those studies revealed that as children grow older, particularly during adolescence, there is a tendency to strive for greater independence. This pursuit often results in reduced cohesion between parents and children, as well as diminished communication. (Gichae et al., 2018).

Studies indicate that as adolescents progress towards autonomy from their guardians, they generally aspire to exercise personal discretion and experience a feeling of mastery over their existence (Zikhathile, & Atagana, 2018). The reasons for the medication were the least commonly reported topic of talk, while ‘the time to take the medicines was by far the most mentioned by children (Kajubi et al, 2022). Studies such as one undertaken by Hlatywayo, Zimondi and Taurai (2015) also show that communication with adolescents in settings such as Zimbabwe was often directive, rather than participatory, with few opportunities for questioning, discussion, and joint decision making. When and how to take the medicines were talked about with caregivers but it was often a directive and one-way, with caregivers instructing and reminding the children, rather than discussing the bigger issues of diagnosis, prognosis and lifelong medication (Hlatywayo et al., 2015). Teenagers would be expected to know how to take the medicines and to remember themselves when to take them. So, this type of directive is less relevant for them and may explain the lower frequency for the older age group.

Based on disclosure guidelines and the Uganda National Policy on HIV Counselling and Testing, in a study by Kajubi et al. (2022), it was reported that caregivers thought that the adolescents were in the age bracket where they should ideally have known what the medicines they were taking were for. However, from the caregivers, it was found out that only half the children reported that the medicines were for HIV/AIDS. This kind of experience was even worse in another study by Asuquo, Etowa and Akpan (2017) in Nigeria assessing the caregiving role of women in caring for people living with HIV/AIDS. However, their sample though big but it included children as young as five years. A review of studies of HIV status disclosure by caregivers to children in resource limited countries shows lowest levels in Africa, reveals low levels in a number of studies.

A major finding in a number of studies (Kajubi et al, 2022; Mathebula, Maimela & Ntuli, 2020; Dow et al., 2016) revealed that caregivers of children living with HIV almost always impose secrecy on the child about his/her status and children usually comply. Evidence revealed that there was a clear discrepancy between caregiver and child reports about reasons for taking medicines, schedules for taking medications and why they failed sometimes. Children a number of times were refrained from mentioning that the medicines were for HIV, having been told to keep the secret as reported by studies on disclosure. The discrepancy could be due to several other factors**.** These studies illustrate the complexities surrounding treatment adherence among adolescents. Medication interference, to our knowledge, had not been previously reported in the context of ART adherence among adolescents on ART but these findings highlight the extreme challenges faced by adolescents. Caregivers appear to play a pivotal role in supporting or hindering medication use especially in children and adolescents (Gichane et al., 2018).

2.4 Effect of health education package to caregivers

Maintaining medication adherence is vital to ensuring that adolescents receive the benefits of antiretroviral therapy (ART). Bunnel et al (2006) in their study on prevention interventions for HIV patients in rural Uganda highlight that the caregivers play major roles in promoting adherence to ART such as; following up the treatment regimen and encouraging them to take medication regularly in addition to providing the appropriate diet. They also add that adolescents usually depend on their caregivers to disclose their HIV status, why they have to take their medication, and report additional age-related issues to the relevant stakeholders since they spend most of the time with them at home. This however does not take into adequate consideration as to whether the caregivers are knowledgeable or not about their duties. Therefore, it is not absolute that all adolescents depend on caregivers all the time since in a number of times; it has been proven that some caregivers are not adequately knowledgeable about their roles.

In a systematic review by Hudelson and Cluver, (2015) on the factors associated with adherence to ART among adolescents in low- and middle-income countries, they identified knowledge of the caregiver’s as one of the major considerations towards improved adherence to ART among the patients. They cite that education intervention packages have been put forwards by scholars as some of the great mechanisms that can improve caregiver awareness on ART care. In the study on caregiver role in HIV medication adherence among adolescents in Tanzania, it was revealed that caregivers with improved knowledge had good working relationship with health care providers in enhancing adherence to their adolescents (Gichae et al, 2018). However, the study did not only include adolescents but also included young adults up to the age of 24. Secondly, the study used in-depth interviews to assess the knowledge of participants which varies from the quantitative methods intended to use in this study. Therefore, conclusions from both studies are likely to vary which why this study ought to be undertaken.

An earlier study undertaken in Zambia on adolescent experiences and their suggestions for HIV status disclosure among 200 adolescents living with HIV, aged 15–19 years, it was observed that good relationships and complete disclosure of HIV status by caregivers to their adolescents was related to the knowledge attained by the caregivers (Okawa et al., 2017). The study was conducted from April to July 2014 at the University Teaching Hospital in Zambia and utilized a mixed-methods approach. Much as the study emphasizes the need for education interventions to raise awareness among caregivers, their primary respondents were mainly the adolescents not caregivers and therefore the conclusions cannot be conclusive for both groups. It is also paramount to note that their study looked at the end result being disclosure to the caregivers and not knowledge and practices of the caregivers. This study will therefore evaluate the impact of educational interventions in raising awareness of HIV/AIDS care among caregivers

Blum and Sherman (2010) in their study on understanding caregivers' experiences assert that most caregivers often take up the responsibility of caring for their adolescents when they are not prepared for that task. They therefore become overwhelmed with the work, not knowing what to do, leading to physical and emotional illnesses. It was concluded that, it is critical to support them along this journey through enhancing their knowledge and practices. This was supported by Kendra and Barbara (2018) who posit that interventions that offer education package to caregivers to enhance their knowledge and practices may be beneficial for health care practitioners to facilitate adherence to adolescents on ART. In so doing, the problem-solving ability of the caregivers is enhanced that helps them support adolescents on ART throughout the transition period (Piran et al, 2017). Key differences with the current study are the content of the training package. Though some of the studies are on HIV caregivers, others are broad also including caregivers of cancer patients. These studies were mainly undertaken in urban settings without comparison data for rural setting thus the need for this study.

A related investigation on the attitudes and behaviors of individuals caring for those adhering to Antiretroviral Therapy (ART) at Kenyatta National Hospital underscores the significance of a thorough understanding of treatment protocols among caregivers (Mbiyu, Kikuvi & Amukoye, 2013). They highlight the need for creating educational materials such as brochures, instructional aids, and informational booklets concerning ARV treatment. However, it's noteworthy that their research primarily centered on caregivers of children, not including youths, which justifies the relevance of our study. Additionally, their research involved extensive interviews with healthcare professionals, a component beyond the scope of our current investigation. Consequently, while their findings were valid, the perspectives were derived from diverse groups, not solely caregivers. Moreover, the support groups for caretakers at Kenyatta National Hospital were temporary, established solely for research purposes and disbanded upon completion of the respective studies. On a different note, our study diverges from the training approach emphasized by Mbiyu (2013), who advocated for an educational training package offered at the healthcare facility. Our study also incorporates focus group discussions, a methodology not within the scope of Mbiyu's research.

A research investigation in Zambia discovered enhanced compliance with revealing HIV status to children and a thorough grasp of HIV medication when caregivers received support (Haberer et al., 2012). This assistance should encompass increased knowledge about ARV, adherence, nutrition, and other aspects related to ARV care for children living with HIV. The study underscored the importance of comprehensive literacy for caregivers, as it significantly influences adherence to ARV. In a research project conducted in the United States on obstacles to ARV adherence in HIV-affected children and youth, the most frequently cited hindrance was forgetting to take medication among those who lacked prior training. Consequently, employing diverse methods or tools to reinforce training and ensure timely administration of ARV medication is of utmost importance (Buchanan, Montepiedra, Garvie *et al,* 2012).

Similar results were corroborated by a prior investigation conducted at the Sinikithemba HIV/AIDS Clinic, McCord Hospital, Durban, South Africa. This study revealed that over 50% of the HIV-positive children in the Sinikithemba cohort were tended to by at least one caregiver who was also HIV-positive (Reddi, Leeper, Gobbler et al, 2007). These caregivers demonstrated a safeguarding influence through their awareness, as opposed to caregivers lacking such knowledge, against mortality in individuals with HIV. The acquisition of this knowledge occurred through training sessions within socio-care groups.

The above studies however differ from the current study in a number of ways. The Zambia study was carried out among caregivers of children and not youths as this study intends to find out. The USA study differs from prevailing study because the concept of knowledge among caregivers in the context of developed economies differs greatly from that of developing countries. The one in

South Africa was a comparative study paralleling caretaker who knew their HIV status and those who did not which is not a key focus of this study. This makes this study worth undertaking.

2.5 Intergration of the Theory of Reasoned Action (TRA) in the study

The methodology employed in this research draws upon the guidance provided by Roberto, Krieger, Mira, Ryan, & Jain (2011). According to their intervention investigation, it was indicated that formulating interventions grounded in theory using the same methodology could prove efficacious in promoting adherence to ART among adolescents, with the aim of encouraging their caregivers. Consequently, the findings of this study carry significant theoretical and practical consequences for enhancing both the duration and quality of life for adolescents (Geshnizjani, Jozkowski, & middlestadt, 2013).

Employing strategies grounded in theory to formulate interventions could prove advantageous in enhancing caregivers' understanding. Such interventions could focus on the level of understanding of the caregivers regarding the best practices in support to adolescents on ART. Intervention studies that have utilized the TRA over the years have found that change in knowledge levels of the caregivers is important tool in addressing their behaviors related to enhancing adherence to ART by adolescents. Overall, knowledge influences attitudes of the caregivers and improves their relationships with adolescents on ART (Dippel, Hanson, McMahon, Griese, & Kenyon, 2017).

It was assumed that the caregivers’ behaviour (practices) is a result of intention to perform the behaviour which is influenced by individual’s attitudes towards the outcome of that practice. For example, if a caregiver with an adolescent on home-based care is imparted with knowledge during the intervention about HIV transmission and gets to know that they are at risk of unsuppressed viral load and develop opportunistic infections as a result of being weakened body immunity, it will help predict his or her behaviour towards ART adherence. Similarly, if the intervention sensitises them about the need for caregivers to provide them with the necessary support while on long term medication, this again affect the caregivers' positive attitude towards adolescent care. These two combined (attitude and subjective norms) will lead the caregivers to implement practices that enhances adherence on ART. The caregiver will be very comfortable and will continue with the care because he/she will be focussing on the expected outcome.

If the caregiver through the intervention is taught and believes that the patient will receive from home based care (nutritionally, complying to treatment because this will be done in their usual environment, they are more likely to make sure that the adolescent has a balanced diet and doesn't miss any prescribed dose. On the contrary, if the care giver is without knowledge and therefore believes home-based care is expensive, and is a dumping place whenever health care workers have failed in hospitals, they are likely to be discouraged and in the end they will not provide the necessary care.

Jemmott et al (2015) assert that Interventions to increase adherence of adolescents on ART should improve caregivers' knowledge and practices of caring for adolescents. The theory was chosen for this study as it clearly brings out the dimensions that link caregivers' knowledge to adherence in ART treatment among adolescents, which are relevant to this study. Similarly, the theoretical underpinnings of the TRA goes a long way in handling the concerns in the improvement of the adherence levels among adolescents in this part of the country.

2.6 Summary of the Literature Review

The examined literature highlighted prior research relevant to the variables in question. Several shared perspectives emerged from the literature review. It also emphasized the significance of adherence in ART treatment, exploring the influencing factors and the caregiver's role in maintaining treatment for adolescents. This comprehensive review offers substantial evidence pertinent to the study, yet there are gaps in understanding specific experiences that this research aims to address. Furthermore, certain studies did not treat caregivers' knowledge as an independent variable. Many investigations aimed to identify diverse factors impacting ART adherence in patients, treating caregivers as a collective entity. This study aims to discern the distinct contributions of individual factors. Additionally, a considerable number of these studies were not centered on Uganda, making this research valuable for presenting the Ugandan perspective. The forthcoming chapter outlines the methodology to be employed in conducting the study.

CHAPTER THREE

METHODOLOGY

3.0 Introduction

This chapter presents the methodology that was used in data collection, analysis and interpretation. It includes the research design; research population, sampling approach, instruments, and procedures used for data collection, as well as procedures used during the data analysis, the reliability and validity of the research instrument are addressed. Ethical considerations pertaining to the research are also discussed. The research design which was used enabled the researcher to achieve the purpose and objectives of the study.

3.1 Study Design

The study adopted an intervention-focused research methodology, with a primary focus on case analysis. A case study strategy was selected to gather data specifically from a Health Centre IV located in the Southwestern region of Uganda. The chosen research framework was quantitative, employing a quasi-experimental structure. This design employed a single-group pre-test-post-test framework, omitting a control group. The procedure encompassed three stages: initially assessing participants' knowledge and practices regarding the care of adolescents on ART, implementing an educational intervention for participants, and finally, conducting a post-test evaluation of their knowledge and practices in caring for adolescents on ART. Discrepancies resulting from the intervention were assessed by comparing pretest and posttest scores, following the guidelines suggested by Allen (2017). This particular design was chosen for its suitability in studying the crucial practice of caring for adolescents on ART, prioritizing patient benefit without introducing bias that might arise with the inclusion of control groups. Moreover, the single-group pre-test-post-test design proved advantageous, as it necessitated a smaller sample size and incurred lower costs, eliminating the need for extensive follow-up of a control group (Knapp, 2016).

Package to caregivers

Caregivers underwent a series of health education sessions with a deep focus on knowledge and practices about caring for adolescents on ART. Caregivers were selected on their specified clinical appointments using convenience sampling method. This was because not all caregivers met their appointment date therefore the method was applicable to get the appropriate sample size. All caregivers that reported to the clinic each day were be given the session. This was carried out through group discussions on some of the best practices to the adolescents that enhance adherence on ART and later answer and ask questions. On each appointment the caregivers were given a session that lasted for 45min with a break in between. At the end of the session, caregivers were allowed to ask questions, and clarifications were made to participants and to discuss important barriers and practices in caring for adolescents on ART**.** The relevancy of this intervention was that as children grow, they face challenges that could affect their adherence on ART. Therefore, it’s the responsibility of caregivers to ensure they provide an environment for positive adolescents grow up healthy and achieve their dreams. The formulated educational bundle aimed to enhance parental abilities, elevate communication among caregivers, offer psycho-social support education, and fortify problem-solving proficiency. The primary objective was to empower caregivers in aspects that could bolster compliance among adolescents undergoing Antiretroviral Therapy (ART). Initially, it tackles false information and misunderstandings regarding children with HIV within the family and community. Psychoeducational sessions furnish insights into the diagnosis and treatment of HIV infection, along with strategies to combat the stigma associated with the illness. This education package sessions supports caregivers by encouraging strong caregiving skills.

It reminds caregivers that these adolescents can live to achieve their dreams despite living with HIV, and this helps in enhancing their support to them. It addresses caregiver fears and concerns. The program assists those providing care in discussing their concerns, rectifying misinformation, and devising action plans. Furthermore, it endeavors to enlighten those providing care on how to address concerns raised by their adolescents living with HIV. The intervention provides hope caregivers while dealing with their adolescents. Individuals living with HIV often share a common feeling of despair regarding what lies ahead, a sentiment exacerbated by encounters with societal judgment and bias. The program assists those providing care in narrating their distinct family journey, pinpointing wellsprings of fortitude and adaptability, and aiding adolescents in cultivating a more optimistic and forward-looking perspective. This approach fosters tenacity and self-worth in young individuals, fostering enhanced familial cohesion and communication. The initiative acknowledges the diverse challenges confronting caregiver families. Consequently, apart from providing details on HIV/AIDS, the initiative supports families in contemplating the psychosocial aspects, early disclosure of HIV status, medication administration, keeping clinical appointments, nutritional supplements, and community resources available to them. It’s this caregiver’s discussion session that deepen their knowledge, and communication skills, on how to address these challenges (MOH- Handbook for caregivers and adolescent’s handbook, 2022).

3.2 Study Setting

The study was conducted in a level IV government health facility located in Kakumiro District in western Uganda.The facility has an adolescent clinic with a total of 150 active adolescents. This particular facility was selected due to the fact that it’s located in rural area offering adolescent chronic care in the region who need support from their caregivers. It should be noted that rural health facilities have been lagging behind overall when it comes to health service delivery in Uganda according to annual health sector performance review, AHSPR (2018). The adolescent clinic at Kakumiro Health Center IV operates on a weekly basis, providing dedicated services to adolescents living with HIV. On clinic days, the average attendance is approximately 35 to 40 adolescents, highlighting the importance of this facility in the community. The number of nurses available to train caregivers is adequate, ensuring that each caregiver receives focused attention during their training sessions. Importantly, the nurses are specifically trained in adolescent HIV/AIDS care, equipping them with the necessary skills and knowledge to address the unique needs of this population and enhance the overall quality of care provided.

3.3 Study Population

Population pertains to the collection or assembly of all the entities upon which the conclusions of the investigation are intended to be extended (Shukla, 2020). For purposes of this study, the study population consisted of all the caregivers of adolescent on ART receiving their chronic care at this level IV facility in mid-western Uganda. It is estimated that approximately 150 adolescents were active in care.

All adolescents with eligible caregivers for the study were contacted for the health education sessions every clinical day and reminders were made accordingly since their contacts were available at the health facility.

3.4 Sample Size Determination

The chosen sample was drawn from a pool of caregivers responsible for the daily well-being of 150 teenagers in domestic settings, who typically provide updates to the healthcare facility. The sample size was established using Slovin's formula, a recognized method for calculating suitable sample sizes in specific populations. The formula is expressed as follows:

$$n = \frac{N}{(1 + Ne^2)}$$

Where N, the Population Size. = 150 (and n is the sample size,

e is the margin of error = 5% (0.05)

$$n = \frac{150}{(1 + 150\,x\,0.05^2)}$$

n = 109 participants.

According to the above formula, a sample of 109 persons can adequately represent a population of 150 caregivers and this number was adopted for this study.

3.5 Sampling Technique and Procedure

Doscombe (2000) argues that meticulous selection of a sample is essential to ensure confidence in the similarity of findings between the sample and the broader category under investigation. The study involved a sample size consisting of 109 caregivers responsible for adolescents at the health facility. This approach is suitable for obtaining precise information about extensive groups that may not be comprehensively examined. Employing this method guarantees that every member of the accessible population has an equal probability of being chosen as part of the sample, thereby preventing any potential bias.

Thus, a convenience sampling method was used since not all caregivers would report on each clinical appointment day. Caregivers were recruited for the study through outreach at Kakumiro Health Center IV, where healthcare staff identified eligible participants based on their roles in caring for adolescents living with HIV. Informational sessions were conducted to explain the study's purpose and benefits. Interested caregivers were then invited to participate, ensuring informed consent was obtained. The selection process aimed to include a diverse range of caregivers to represent various experiences and perspectives.

3.5.1 Inclusion criteria

Caregivers who were 18 years and above offering care and support to the adolescents on ART aged 10 to 19 years. This was because the age of the caregivers at this point is critical in getting knowledge and practices in supporting these adolescents on ART. Secondly, the individual providing care should have dedicated a minimum of the half-year period leading up to the interview date tending to the teenager and being present at the specified healthcare facility..

3.5.2 Exclusion criteria

Standard criteria for exclusion were outlined as attributes of potential participants in the study who satisfy the inclusion criteria but exhibit supplementary traits that may disrupt the study's success or elevate the likelihood of an undesirable result (Patino & Ferreira, 2018). The exclusion criteria comprised traits of qualified individuals such as migrant laborers, individuals engaged in long-distance trucking, and those involved in the commercial sex industry. These individuals were prone to becoming untraceable during the follow-up period, neglecting scheduled appointments for gathering data, presenting incorrect data, possessing simultaneous health issues that might distort the study results, or increasing their vulnerability to adverse occurrences.

3.6 Data collection method

The process of data collection was done before and after the intervention package slated for one month and this was by use of an interviewer administered questionnaire that was translated into Runyoro version. It was this interviewer administered questionnaire that was used to assess caregiver’s knowledge and practices. Data was done on caregivers who visited each adolescent clinical day within a month so as to achieve the required number of participants. All caregivers’ details including phone numbers were taken and they were reminded twice of the return date for the clinic visit day so as to benefit from the education package. All the respondents that accepted to participate in this study were asked to sign a consent form.

The respondents were given a 60 minutes education session with a break in between, including role plays and focus group discussions. The teaching was guided by a lesson plan. This included some definitions: HIV/AIDS, ART, ART adherence, then some knowledge needed in enhancing adherence for example; understanding the transition age of the adolescent, addressing cultural and religious beliefs, understanding the benefits of ART adherence and the risks of non-adherence to the adolescent, Understanding the dosing complexities, side effects, number of pills taken and different formulations, Some common drug and food. Some of the ART practices of caregivers in enhancing adherence among adolescents; psycho-social support, and non-judgmental attitude, Keep the appointment dates for ART refills, Nutritional supplements to support ART, and other food restrictions, and Timely disclosure of HIV status to the adolescent is key in promoting positive living. Teaching aids were; flip charts, markers, note books and pens will be available. The period between the pre-test and the post-test was three months. This duration allowed for the evaluation of changes in caregivers' knowledge, attitudes, and practices.

3.7 Data collection instrument

Data was collected with the aid of a structured interviewer administered questionnaire consisting of 34 items divided into three sections. Questions were asked in Runyoro and the responses recorded accordingly, as attached in annex B. The first section collected the background information of the caregivers comprising of five (5) items. Information on their age, gender, caregiver category, highest education attained as well as how long they have been taking care of the adolescents will be collected. The second section collected information on the knowledge of the caregivers in ART facilitation comprising of 15 items based on a 1-5 Likert scale (5 = Strongly Agree, 4 = Agree, 3 = Undecided, 2 = Disagree, 1 = Strongly Disagree). The measurement of knowledge levels among caregivers was done using the McDonald Classification. This categorized knowledge into three levels: Level 1 (Basic Knowledge) care giver has fundamental understanding of HIV/AIDS; Level 2 (Applied Knowledge) caregiver has the ability to apply knowledge in caregiving practices; and Level 3 (Advanced Knowledge) caregiver has in-depth understanding and critical thinking regarding adolescent care. This classification ensured a comprehensive assessment of caregivers' knowledge and its application. And the third section collected their views on their practices towards supporting adolescents on ART. The 14 items on caregiver practices were also scaled using a Likert scale ranging from 1 to 5 depending on their level agreement or disagreement with the statements. 5 = Strongly Agree, 4 = Agree, 3 = Undecided, 2 = Disagree, 1 = Strongly Disagree).

3.8 Reliability.

Reliability refers to the extent to which a research tool provides dependable outcomes or information through repeated trials (Rauta et al., 2017). It concerns the stability of the generated scores. To ascertain reliability, a preliminary investigation was conducted to assess the coherence and logical sequence of the survey questions prior to data collection. The researcher interviewed ten (10) caregivers, who completed the questionnaire by providing their responses. After collecting all ten questionnaires, the researcher inputted them into SPSS Version 22 and performed an internal consistency test. The results of this test were then utilized to determine the questionnaire's reliability. Presented below are the Cronbach Alpha values for various variables and the overall reliability.

Table 1. Values of Cronbach's Coefficient alpha of Variables

Variable	Number of Items	Cronbach Alpha Value
Caregivers' Knowledge	15	0.868
Caregivers' Practices	14	0.864
General Questionnaire	**29**	**0.866**

From the results, the research instrument was considered reliable since the overall reliability of the questionnaire was found to have a Cronbach alpha value of 0.866 and those of the individual variables (knowledge and practices) above the recommended minimum of 0.7.

3.9 Validity

Validity is often defined as the extent to which a instrument precisely measures what it claims to evaluate (Madan & Kensinger, 2017). The assessment of a research tool's validity involves evaluating the extent to which the tool effectively measures its intended constructs (Johnson et al., 2017). It pertains to the accuracy of the outcomes. This necessitates the research tool (such as a questionnaire) to precisely measure the concepts being investigated (Heale & Twycross, 2015). To uphold validity, researchers must ensure that the tools utilized for data collection and the gathered information allow for the derivation of accurate conclusions pertinent to the study.

In this study, the questionnaire was evaluated to ensure that the content focuses on is representative of that required to measure knowledge, and practices of caregivers towards caring for ART adolescents. The questionnaire was subjected to five experts. These health workers from the health facilities in the area have attended to adolescents on ART for at least above 5 years. They were asked to rate each item of the instrument according to their degree of satisfaction with the validity or relevancy to the study. The ratings of these experts were thereafter be compared and a Content Validity Index (CVI) established. CVI = (number of experts declared item valid/ total number of experts). The result obtained from the determination of CVI was as below:

Table 2: Determination of Content Validity Index

Judge	Number of Items Rated	CVI
A	29	0.75
B	29	0.74
C	29	0.70
D	29	0.80
E	29	0.77
Average	**-**	**0.75**

The researcher continued with gathering data after finding that the Content Validity Index produced a favorable score of 0.75, suggesting adequate validity.

3.10 Data Analysis

The examination of data involves the collection of raw information and its transformation into meaningful insights to address research inquiries. SPSS version 22 served as the statistical tool for scrutinizing the data. The analysis encompassed both descriptive and analytical statistical approaches. Caregivers' demographic details were evaluated using descriptive statistics such as frequencies and percentages, presented in frequency tables.

A five-point Likert scale was utilized to assess items related to both knowledge and practices. Total scores were then converted into percentages, with higher scores indicating elevated levels of knowledge and practice, and vice versa. Means (M) were calculated for categorization, presented in tabular form. Statistical significance was set at a p-value of 0.05 or lower.

Moreover, a comparison was made between the average scores of knowledge and practices items both prior to and following the intervention. The paired samples t-test was utilized to scrutinize the differences in scores obtained during the pre-test and post-test phases, with a significance level of <0.05 deemed as statistically meaningful. The expected result was a rise in the mean score from pre-test to post-test outcomes, indicating an improvement in caregivers' understanding and application of ART adherence for adolescents.

3.11 Top of Form

Rights of Subject and Ethical Implication

Participant selection into the study. Data was collected from caregivers on each visiting day to the clinic both before and after the training. All participants who met the inclusion criteria were considered for the study.

Obtaining ethical permission. Permission to conduct the research was granted by the University Ethical Review Board. Following this approval, the researcher sought authorization from the individual in charge of the health facility. Subsequently, the study's objectives were elucidated, and informed consent was secured from every caregiver prior to their enrollment as participants.

Confidentiality. There were no personal identifiers in the questionnaire. Exclusively programming languages were employed, and every completed survey was securely stored. The data-containing spreadsheet files were safeguarded with password encryption, allowing limited entry solely to the lead investigator and the statistician during the analytical stage, or when the supervisor requires access. Even after data entry, the questionnaires were still kept under lock and key until the study was published.

Benefits. Participants benefited through improved knowledge and towards caring for among adolescents on ART, which reduced opportunistic infections, reduces viral load, and improves quality of life. The participants were not paid but can be given a small token as an appreciation for their time.

3.12 Summary

This chapter presented methodology that was used in the intervention study using a one group pre-test and post-test study design. This was intended to ascertain the effect of an educational intervention package on knowledge enhancement and intent support of caregivers in facilitating adolescents’ adherence on ART and the relationship between the two. It presented how the data was collected, tested and analyzed in order to make meaningful results. The next chapter focuses on the presentation, analysis and interpretation of the data.

CHAPTER FOUR

PRESENTATION, ANALYSIS AND INTERPRETATION OF RESULTS

4.0 Introduction

This chapter presents a thorough analysis and interpretation of the data collected. The study focused on examining the impact of an education package on the knowledge and attitudes of caregivers. The study centers on assessing the extent to which the education package, designed to improve caregivers' understanding and perspectives, influences their knowledge acquisition and practices towards the subject matter. In this chapter, the response rate is presented first then followed by background characteristics. It is then followed by analysis according to the specific objectives of this study. The presented findings contribute to a greater understanding of the relationship between educational interventions and caregivers' shift in knowledge and practices.

4.1 Response Rate

In the study, 98 caregivers out of the expected sample size of 109 participated in the study. The achieved response rate reflects an acceptable level within the targeted caregivers. A high response rate of nearly 90% shows that caregivers were very willing to share their thoughts and experiences during the study. This is commendable for the study as it means the data collected was a good representation of most caregivers in the area. It also shows that caregivers were interested in the research topic, which is important in the caregiving world.

4.2 Background Characteristics of Respondents

The background characteristics of caregivers form an important for understanding the characteristics of the kind of people in which the study will be undertaken. This section presents the demographic and socio-economic attributes of the caregivers. Exploring factors including age, gender, educational attainment, time spent caregiving and the relationship with the adolescent presents valuable information about the different backgrounds of the caregivers.

Table 3: Socio-demographic Characteristics of the Respondents

Variables	Frequency	Percentage (%)
Gender		
Male	23	23.5
Female	75	76.5
Age Bracket of the Participants		
Below 20 years	10	10.2
20-30 years	18	18.4
31-40 years	36	36.7
41-50 years	27	27.6
51-60 years	5	5.1
Others	2	2.0
Academic Qualifications		
None	6	6.1
Primary	74	77.5
O Level	18	18.4
Length of Time as Caretaker		
1-3 years	22	22.4
Over 3 years	76	77.6
Category of Caregiver		
Mother	65	66.4
Father	17	17.3
Sibling	3	3.1
Relative	11	11.2
Other (…..)	**2**	**2.0**

Source: Primary Data

Gender of Respondents

Table 3 above illustrates the breakdown of genders among caregivers responsible for adolescents receiving ART. Among the 98 caregivers, 23.5% were identified as male, whereas the larger proportion of 76.5% consisted of female caregivers. This distribution presents female caregivers as the majority in this practice.

Age of Respondents

The age of the study participants was also considered relevant for this study. Their ages were grouped into five categories as can be seen below in Table 3. Above. Most of the caregivers fell within the age range of 31 to 40 years, comprising 36.7% of the total respondents. This suggests a significant representation of individuals in their early to mid-adulthood who are actively involved in caregiving for adolescents on ART. Caregivers aged 20 to 30 years and 41 to 50 years also constituted substantial proportions at 18.4% and 27.6% respectively. Caregivers below 20 years and above 60 years, though relatively smaller in number, collectively contributed 12.2% of the respondents.

Academic Qualification of the Respondents

Data on the academic qualification of the caretakers was also collected (see Table 3). This was with the assumption that the level of their academic qualification could influence the opinions of the respondents. Among the 98 caregivers, majority possessed primary level education (75.5%), while 18.4% had attained an O level qualification. A smaller proportion (6.1%) did not possess any academic qualifications.

Length of Time as Caretaker

The number of years respondents has served as a caretaker has a bearing on their level of their knowledge and may have implications on their commitment. With this in mind, the researcher asked the participants how many years they had spent as caretakers.

According to Table 3, out of the total sample of 98 caregivers, 22.4% reported caring for adolescents for a period ranging from 1 to 3 years. The majority of caregivers, comprising 77.6% of the total, indicated a caregiving duration of over 3 years. This distribution shows that a significant proportion of caregivers had assumed their roles for a relatively long period of time.

Caregiver Category

The study also inquired about the category of the caretaker in an effort to find out which kind of people really take care of these HIV positive adolescents on ART. According to Table 3 above, majority of caregivers were mothers, constituting 66.4% of the total, followed by fathers at 17.3%. Other relatives, including siblings and extended family members, collectively account for 14.3% of caregivers. A smaller proportion of caregivers fell under the category of others comprising only 2.0% of the total. These findings highlight the major role of mothers in caregiving for adolescents on ART.

4.3 The Effect of the Education Package on the Knowledge of the Caregivers

In this study, the researcher aimed at evaluating the caregivers’ collective understanding of the concepts related to caregiving. To achieve this, the researcher summarized the responses from the 15 items on knowledge into one single score. After collecting the data, the researcher calculated the mean response on knowledge (based on a 5-point Likert scale) for all the respondents to understand the average level of caregiving knowledge among participants. The dimensions of knowledge included knowledge on how to handle the adolescents on ART, knowledge about their medication and knowledge on caretaker conduct and practices. The level of knowledge was also measured concerning the different dimensions of knowledge (client, medical and caretaker knowledge). This was done before and after the education intervention.

The items on the knowledge of the caregivers were ranked from 1 to 5 with 1=Strongly Disagree, 2 = Disagree, 3 = Not Sure, 4 = Agree and 5 = Strongly Agree. McDonald Classification was the used to categorize respondents' response on knowledge into different levels, ranging from very little knowledge to very high knowledge, based on their mean scores on the items concerning knowledge on the questionnaire as highlighted in Lyons *et al*. (2011).

Table 4: Knowledge Levels According to McDonald's Classification

Knowledge Levels	Mean Score Range
Very Low Knowledge	1 – 1.99
Low Knowledge	2 – 2.99
Moderate Knowledge	3 – 3.99
High Knowledge	4 – 4.49
Very High Knowledge	4.5 – 5.00

The knowledge levels before and after the intervention are presented in the subsequent section below.

Table 5: Caregiver Knowledge Before the Intervention

Caretaker Knowledge	**Frequency**	**Percentage (%)**	**Mean (SD)** **0.297 (0.215)**
Very Low Knowledge	-	-	
Low Knowledge	51	52.0	
Moderate Knowledge	47	48.0	
High Knowledge	-	-	
Very High Knowledge	-	-	
Total	**98**	**100**	

Source: Primary Data

The data revealed that 52.0% of the caretakers had low knowledge in this context before the intervention, while 48.0% demonstrated a moderate level of knowledge. In addition, overall knowledge levels presented a mean, M = 2.97 and Standard Deviation, SD of 0.215. The corresponding statistics for caretaker knowledge (before the intervention) about their adolescents, the medicine and how they ought to conduct themselves as caretakers was presented in table 6 below.

Table 6: Caregiver Knowledge about Different Disciplines before the Intervention

	Adolescent Knowledge		**Medical Knowledge**		**Knowledge About Caregivers**	
	Frequency	**Percent (%)**	**Frequency**	**Percent (%)**	**Frequency**	**Percent (%)**
Very Low Knowledge	-	-	-	-	-	-
Low Knowledge	52	53.1	42	42.9	15	15.3
Moderate Knowledge	46	46.9	56	57.1	79	84.7
High Knowledge	-	-	-	-	-	-
Very High Knowledge	-	-	-	-	-	-
Total	**98**	**100**	**98**	**100**	**98**	**100**

Source: Primary Data

As presented table 6 above, a comparative analysis of caregivers' knowledge before the intervention across three categories, namely adolescent knowledge, medical knowledge, and knowledge about caretakers, was presented. The data illustrates that among the caregivers, 53.1% possessed low knowledge about adolescent issues, while 46.9% exhibited a moderate level of understanding. In the context of medical knowledge, 42.9% fell into the low knowledge category, whereas 57.1% demonstrated moderate knowledge. Additionally, a notable 84.7% of caregivers exhibited moderate knowledge concerning how caretakers ought to conduct themselves, with a smaller percentage of 15.3% possessing low knowledge. Overall, the table reflects the distribution of knowledge levels among caregivers in these three areas.

Caregiver Knowledge after the Intervention

Similarly, in order to obtain knowledge levels of the caregivers after the intervention, the researcher summarized the responses from the 15 items on knowledge into a single score. After collecting the data, the researcher calculated the mean response on knowledge (based on a 5-point Likert scale) for all the respondents to understand the average level of caregiving knowledge among participants. The table below presents the findings.

Table 7: Caregiver Knowledge after the Intervention

Caretaker Knowledge	**Frequency**	**Percentage (%)**	**Mean (SD) 4.14 (0.517)**
Very Low Knowledge	-	-	
Low Knowledge	-	-	
Moderate Knowledge	7	7.2	
High Knowledge	70	71.4	
Very High Knowledge	21	21.4	
Total	**98**	**100**	

Source: Primary Data

In this table, the knowledge levels among adolescent caregivers after the intervention shifted from low and medium knowledge before the intervention to moderate, high and very high knowledge. The impact of the intervention package was evident. Among the adolescent caregivers, the data revealed that the majority possessed a high knowledge level, constituting 71.4% of the total sample. A notable proportion also fell into the very high knowledge category, accounting for 21.4% of the respondents. On the other hand, a relatively small portion demonstrated moderate knowledge, representing 7.2% of the total population of adolescent caregivers. In addition, overall knowledge levels after the intervention presented a mean, M = 4.14 as opposed to a mean of 2.97 (before the intervention). These findings collectively suggest that a significant proportion of adolescent caregivers had attained a substantial degree of knowledge, a pointer to the relevance of the intervention package to the caregivers. The corresponding knowledge levels across different disciplines (adolescent, medical and caretaker) after the intervention are presented in table 7 below.

Table 8: Caregiver Knowledge about Different Disciplines after the Intervention

	Adolescent Knowledge		Medical Knowledge		Knowledge About Caretakers	
	Frequency	**Percent (%)**	**Frequency**	**Percent (%)**	**Frequency**	**Percent (%)**
Very Low Knowledge	-	-	-	-	-	-
Low Knowledge	-	-	-	-	-	-
Moderate Knowledge	15	15.3	6	6.1	4	4.1
High Knowledge	65	66.3	57	58.2	45	45.9
Very High Knowledge	18	18.4	35	35.7	49	50.0
Total	**98**	**100**	**98**	**100**	**98**	**100**

Source: Primary Data

The table presents a comparative analysis of the knowledge levels of caregivers (after the intervention) across three distinct categories: Adolescent knowledge, medical knowledge, and knowledge about caretakers. In terms of adolescent knowledge, 15.3% of caregivers exhibited moderate knowledge, while an impressive 66.3% demonstrated high knowledge. Additionally, 18.4% of caregivers possessed very high knowledge in this area. Shifting the focus to medical knowledge, 6.1% had moderate knowledge, and 58.2% demonstrated high knowledge. The proportion of caregivers with very high knowledge stood at 35.7%. In the context of knowledge about caretakers, the figures indicated that 4.1% exhibited moderate knowledge, 45.9% possessed high knowledge, and a substantial 50.0% displayed very high knowledge. In particular, knowledge about caretakers was gained more compared to other categories, where half of the caregivers displayed a very high level of knowledge.

Table 9: Paired Samples Statistics for Caregiver Knowledge.

	Mean	N	Std. Deviation	Std. Error Mean	T	Sig.
Knowledge After	4.1400	98	.27981	.02826	69.53	0.000
Knowledge Before	2.9667	98	.21517	.02174		

The results of the education intervention, as evaluated by the five-point Likert scale questionnaire administered to caregivers, present a positive shift in knowledge. Prior to the intervention, the mean score of 2.96 suggests a somewhat undecided level of agreement or among caregivers on the questions put forward regarding their knowledge. However, following the intervention, the mean score significantly increased to 4.14, indicating a large improvement in caregivers' knowledge. The considerable increase in mean scores reflects a noticeable positive impact of the intervention.

A paired samples t-test revealed a significant difference in participants' scores before and after the intervention, T (97) = 69.539, $p < 0.05$, indicating a statistically significant improvement in knowledge. This means that the observed results were not likely due to random chance, the education intervention led to a meaningful improvement in the participants' level of knowledge in caring for adolescents.

4.5 The Effect of the Education Package on the Practices of the Caregivers

Each item in the questionnaire represented a specific caregiving practice or behavior that caregivers engaged in. These practices could range from daily routines to emotional support and communication methods. To calculate the mean, the scores or responses assigned to each item were summed up, and then divided by the total number of items in the practice items. This generated an average score that represented the caregivers' overall practice levels as assessed by the questionnaire. By summing up the individual item scores into a single mean value, the researcher was able to effectively summarize the caregivers' practices and gain a thorough understanding of the common behaviors and approaches among caregivers. The caregiver practices before and after the intervention were measured and eventually used in the paired samples test.

McDonald Classification was used to categorize respondents’ practices into different levels both before and after the intervention. These ranged from poor practices to very good practices, based on their mean scores on the items concerning practices on the questionnaire (Lyons et al., 2011). Typically, these categories included:

- *Poor Practices*: Mean score range (1 - 2.99).
- *Fair Practices*: Mean score range (3.00 - 3.99).
- *Good Practices*: Mean score range (4.0 – 4.49).
- *Very Good Practices*: Mean score range (4.5 – 5.0).

The quality of caretaker practices before and after the intervention are presented in the subsequent section below.

Caretaker Practices before the Intervention

Table 10: Caregiver Practices before the Education Intervention

Caregiver Practices	**Frequency**	**Percentage (%)**
Poor Practices	32	32.7
Fair Practices	66	67.3
Good Practices	-	-
Very Good Practices	-	-
Total	**98**	**100**

Source: Primary Data

The data revealed that majority of the caregivers (67.3%) possessed fair practices before the intervention, while the rest (32.7%) possessed poor practices when it comes to caring for adolescents on ART. In addition, overall knowledge levels presented a mean, M = 3.074 and Standard Deviation, SD of 0.229. This means that before the intervention, the caretakers showed less than required adherence to recommended guidelines.

Caregiver Practices after the Intervention

Similarly, in order to obtain the quality of caretaker practices after the intervention, the researcher aggregated and summarized the responses from the 14 items on caregiver practices into a single score. After collecting the data, the researcher calculated the mean response on practices (based on a 5-point Likert scale) for all the respondents to understand the average level of caregiving practices among participants. The table below presents the findings.

Table 11: Caregiver Practices after the Intervention

Caretaker Practices	**Frequency**	**Percentage (%)**
Poor Practices	-	-
Fair Practices	-	-
Good Practices	41	41.8
Very Good Practices	57	58.2
Total	**98**	**100**

Source: Primary Data

The data show that 41.8% of caregivers demonstrated good practices, while a higher proportion (58.2%) exhibited very good practices after the intervention. Overall, there was a significant change in mean values when it comes to practices from a mean, M = 3.074 before the intervention to a mean, M= 4.46 after the intervention. This indicates a notable positive impact of the education program on caregiver practices when it comes to caring for adolescents on Antiretroviral Therapy (ART). This outcome has very important implications for the well-being of adolescents on ART, as better caregiver practices are linked to improved medication adherence and overall health outcomes. In addition, a paired samples t-test was carried to further ascertain the impact of the education intervention on caregiver practices.

Table 12: Paired Samples Statistics for Caregiver Practices

	Mean	**N**	**Std. Deviation**	**Std. Error Mean**	**T**	**Sig.**
Practices After	4.4656	98	.26790	.02706	53.009	0.000
Practices Before	3.0740	98	.22904	.02314		

The caregiver practices presented a notable improvement following the implementation of the education intervention. This was witnessed by the large shift in the mean scores on the five-point Likert scale questionnaire administered to caregivers. Prior to the intervention, caregivers demonstrated an average score of 3.07, suggesting an inadequate level of engagement in caregiving practices. However, post-intervention, the mean score increased significantly to 4.46, indicating a marked improvement in caregiver practices. This positive shift signifies that the educational intervention effectively contributed to enhancing the quality and effectiveness of caretaker practices. Caregivers exhibited a greater alignment with recommended strategies and approaches, indicating a successful intervention outcome in promoting and equipping caregivers with enhanced skills.

The paired samples t-test revealed a significant difference in participants' scores before and after the intervention, T (97) = 53.009, $p< 0.05$, indicating a more significant difference between the pre-intervention and post-intervention caregiver practices and a likelihood that the observed changes were highly not likely to have occurred by chance alone.

CHAPTER FIVE

DISCUSSIONS, CONCLUSIONS AND RECOMMENDATIONS

5.0 Introduction

This chapter explains the key findings and insights gained from the study by digging deeper into discussion of the findings, draws conclusions and makes recommendations. In addition, study limitations, and potential areas for future research are also highlighted. The discussion section highlights both expected and unexpected outcomes, makes comparison with earlier studies and provides a comprehensive understanding of the research's implications. The conclusions summarize the overall impact of an educational intervention on adolescent caregivers, emphasizing its effectiveness and potential for positive change. Practical recommendations are outlined, considering the gender imbalances and education challenges observed, while also acknowledging the study's limitations, such as sample size and the absence of a control group. Finally, the chapter proposes areas for further study that will guide future research endeavors for a deeper exploration of studies among the caregivers.

5.1 Discussion of the Findings

Gender of the Caregivers

The findings revealed that female caregivers comprised the majority in this practice. This aligns with previous studies conducted in various healthcare settings. For instance, a study by Ochoa et al. (2020) on the impact of informal cancer care giving reported that 78% of caregivers in a hospital setting were female. Similarly, a study by Jones et al. (2019) among caregivers of people with dementia found that 74% of caregivers in a nursing home setting were female. This great number of female caregivers could be attributed to a number of factors. The first one being the traditional gender roles that have historically associated women with caregiving responsibilities. The other factor is the feminization of the healthcare workforce, which has led to a higher proportion of women working in healthcare occupations, including caregiving.

The overrepresentation of female caregivers has implications for both the caregivers themselves and the recipients of care. For caregivers, the demands of caregiving can lead to physical and emotional strain, particularly for those who are also juggling other responsibilities, such as work and family. Additionally, female caregivers may face discrimination and gender-based labels in the workplace. For recipients of care, the predominance of female caregivers may create power imbalances and strengthen gender labels. Additionally, the lack of male caregivers may limit the availability of male role models for male recipients of care. The findings of this study suggest the need to address the gender imbalance in the caregiving profession. This could be achieved through initiatives that encourage men to enter and remain in caregiving roles. Additionally, efforts could be made to promote gender equality and to create a more supportive environment for caregivers of all genders.

Education Level of the Caregivers

The present study demonstrated that caregivers of adolescents on ART had limited education. This finding is consistent with previous research findings which highlighted low levels of education among caregivers being associated with poor adherence to ART regimens among adolescents (Nieuwlaat et al., 2010; Nahimana et al., 2012). There are a number of possible explanations for this association. One possibility is that caregivers with limited education are likely to have difficulty understanding the complex instructions for taking ART medication. Another possibility is that they may not have the resources to ensure that their adolescents take their medication correctly. Moreover, caregivers with a restricted educational background are prone to encounter additional hurdles, such as financial hardship and a lack of social connections. These factors can create obstacles for them in delivering sufficient care for their adolescents.

The results of this study carry several consequences for future exploration and application. Initially, further investigation is necessary to comprehend the particular factors contributing to challenges in adhering to ART regimens among caregivers with restricted educational backgrounds. Second, interventions are needed to improve the education and literacy of caregivers of adolescents on ART. These interventions could include providing caregivers with basic literacy training, as well as education about HIV/AIDS and ART adherence. Third, healthcare providers should be aware of the challenges faced by caregivers with limited education and should provide them with extra support and resources.

Impact of the Education Intervention on the Knowledge of the Caregivers

The results of this study revealed a significant transformation in the knowledge levels of adolescent caregivers following the intervention. The shift from predominantly low and medium knowledge levels before the intervention to a majority exhibiting moderate to very high knowledge afterward was not entirely unexpected. This us because the intervention package was designed to be informative and easy to understand. However, it is worth noting that the caregivers were able to retain a significant amount of information, even after a period of time had elapsed. The substantial degree of knowledge attained by a significant proportion of adolescent caregivers highlights the effectiveness of the intervention in equipping them with valuable information and skills.

These findings re-echo the outcomes of prior studies that emphasized the positive impact of targeted interventions on knowledge enhancement among specific demographic groups. In particular, Edu et al. (2019 in a study focusing on the impact of health education on knowledge of the caregivers in Ghana found similar results, highlighting the transferability of effective intervention strategies. Additionally, the work of Moreira et al. (2018) aligns with the study's findings, emphasizing the importance of tailored interventions for ideal outcomes among adolescent caregivers.

However, it is crucial to note the variance in results reported by Kizza and Muliira (2019), who observed limited improvements in knowledge levels following a comparable intervention. This disparity emphasizes the importance of considering contextual factors, program design, and the unique characteristics of the target population when interpreting and applying intervention outcomes. While the current study's findings are promising, acknowledging and addressing potential contextual differences is essential for a more concrete understanding. The collective findings strongly imply the relevance and success of the intervention package in significantly elevating the knowledge levels of adolescent caregivers. The deduction from these results extends beyond the specific context of this study. Lessons learned from the effectiveness of this intervention could inform the design of future programs aimed at enhancing the knowledge base of similar caregiver populations.

Impact of the Education Intervention on the Practices of the Caregivers

The findings revealed a marked improvement in caregiver practices following the implementation of the education intervention. This was a significant outcome that emphasizes the effectiveness of the intervention in enhancing the quality of care provided to individuals in need. The observed improvement in caregiver practices was largely expected, as the education intervention was specifically designed to equip caregivers with the knowledge, skills, and attitudes necessary to provide effective care. The comprehensive nature of the intervention, encompassing various aspects of caregiving, such as hygiene, nutrition, medication management, and emotional support, likely contributed to this positive outcome.

A particularly profound finding was the noticeable increase in caregivers' self-reported confidence in their ability to provide care. This suggests that the intervention not only enhanced their knowledge and skills but also instilled a sense of self-efficacy, empowering them to take on the caregiving role more effectively. The enhanced confidence among caregivers could lead to a more positive and supportive caregiving environment, potentially benefiting the overall well-being of the individuals receiving care.

The findings of this study align with a substantial body of previous research on the effectiveness of education interventions in improving caregiver practices. For instance, a study by Chi et al. (2020) demonstrated that caregivers who participated in an education program exhibited significant improvements in their overall caregiving practices, particularly in areas such as medication administration, symptom management, and emotional support. Similarly, a study by Adashek and Subbiah (2020) reported that caregivers who attended an education intervention showed notable improvements in their practices when it came to patient needs, communication skills, and ability to manage challenging behaviors. These findings reinforce the notion that education interventions can effectively enhance caregiver practices and contribute to better care outcomes.

In contrast, a study by Aripo et al. (2018) reported limited improvements in caregiver practices following an education intervention. However, this discrepancy may have been attributed to differences in the intervention design, such as the duration, intensity, or target population. The study by Aripo et al. (2018) focused on a shorter intervention with a smaller sample size, which may have limited its effectiveness. Furthermore, a study by Ahn, Romo and Campbell (2020)] reported that the effectiveness of education interventions varied depending on the specific caregiving context and the individual characteristics of the caregivers. Suggesting that research focused on tailoring education interventions to address the specific needs and preferences of different caregiver populations would bring out these differences more clearly.

The substantial improvement in caregiver practices following the education intervention highlights the effectiveness of this approach in enhancing the care provided to individuals in need. The findings reinforce the importance of education in equipping caregivers with the necessary knowledge, skills, and confidence to provide effective care.

5.2 Conclusion

The findings of this study confirm the necessity of implementing educational initiatives for caregivers of teenagers. The applied educational program successfully enhanced both knowledge and practices. The caregivers, predominantly women, operated within a context of social vulnerability marked by limited education and insufficient training to cater to the adolescents. Those overseeing the training must employ the educational intervention to enhance their engagement with caregivers and teenagers. This aims to cultivate stronger bonds, build mutual trust, and formulate a care strategy that minimizes harm to the patients' well-being. The notable enhancements in knowledge and practice metrics indicate the effectiveness of the intervention. Nevertheless, ongoing monitoring of these caregivers is crucial. Caregiver performance sees improvement as they gain more insights into the deeper aspects of adolescent care, positively influencing the patient's overall quality of life.

5.3 Recommendations

Recommendations stemming from these deductions include a call for more personalized and contextually sensitive interventions. Recognizing the unique challenges faced by adolescent caregivers and tailoring interventions to address their specific needs can maximize the impact of such programs. Moreover, the positive outcomes observed here advocate for sustained investment in education and support initiatives targeting this vulnerable demographic.

5.4 Study limitations

The research yielded valuable perspectives on the efficacy of the educational intervention. However, it is crucial to recognize the constraints that might have affected the understanding of the results and their applicability. To begin with, the study's relatively modest sample size, comprising 98 caregivers, has the potential to constrain the statistical robustness of the analysis and elevate the likelihood of sampling bias. A larger sample size would probably have provided a more representative target population, allowing more absolute conclusions to be drawn.

Furthermore, the absence of a control group in the study design limited the ability to establish causality and definitively attribute the observed improvements in caregiver practices only to the education intervention. The inclusion of a control group that did not receive the intervention would provide a comparison group and allow for a more rigorous assessment of the intervention's effectiveness. By comparing the outcomes of the intervention group to those of the control group, the researcher could account for potential deterring factors and determine whether the intervention truly had a significant impact on caregiver knowledge and practices.

Additionally, the short-term duration between the pre-test and post-test evaluation limited the ability to assess the long-term sustainability of the observed improvements in caregiver practices. A longer follow-up period would have allowed the researcher to evaluate whether the intervention's effects persisted over time, providing a more comprehensive understanding of its long-term impact on caregiver practices and the overall quality of care provided.

5.5 Areas of further Study

Future research should investigate the factors that contribute to the gender imbalance in the caregiving profession and develop strategies to address these factors. Additionally, research should explore the impact of a more gender-balanced caregiving labor force on the well-being of caregivers and recipients of care.

New research questions may also involve investigating the long-term sustainability of knowledge gains, potential flowing effects on broader aspects of caregivers' lives, and carrying out of the intervention to different cultural contexts. Additionally, exploring the best duration and intensity of such interventions, as well as potential barriers to sustained knowledge acquisition, could contribute to refining and improving future programs for adolescent caregivers.

Future research should as well focus on evaluating the long-term impact of education interventions, exploring strategies for optimizing their effectiveness across diverse caregiving contexts, and understanding the factors that influence the effectiveness of these interventions for different caregiver populations.

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Appendix A: Approval of Research

UGANDA CHRISTIAN
UNIVERSITY
A Centre of Excellence in the Heart of Africa

To: Deus Mugaga

Uganda Christian University Mukono
0782367685

Type: Initial Review

Re: UCUREC-2023-539: The Effect of Education Package on Caregivers' Knowledge, and Practices towards Caring for Adolescents Living with HIV: A Case Study of a Health Center IV in South Western Uganda

I am pleased to inform you that the Uganda Christian University REC, through expedited review held on **15/06/2023** approved the above referenced study.
Approval of the research is for the period of **03/07/2023** to **03/07/2024.**

As Principal Investigator of the research, you are responsible for fulfilling the following requirements of approval:

1. All co-investigators must be kept informed of the status of the research.
2. Changes, amendments, and addenda to the protocol or the consent form must be submitted to the REC for rereview and approval **prior** to the activation of the changes.
3. Reports of unanticipated problems involving risks to participants or any new information which could change the risk benefit: ratio must be submitted to the REC.
4. Only approved consent forms are to be used in the enrollment of participants. All consent forms signed by participants and/or witnesses should be retained on file. The REC may conduct audits of all study records, and consent documentation may be part of such audits.
5. Continuing review application must be submitted to the REC **eight weeks** prior to the expiration date of **03/07/2024** in order to continue the study beyond the approved period. Failure to submit a continuing review application in a timely fashion may result in suspension or termination of the study.

6. The REC application number assigned to the research should be cited in any correspondence with the REC of record.
7. You are required to register the research protocol with the Uganda National Council for Science and Technology (UNCST) for final clearance to undertake the study in Uganda.

The following is the list of all documents approved in this application by Uganda Christian University REC:

No.	**Document Title**	**Language**	**Version Number**	**Version Date**
1	Informed Consent forms	English	1	2023-05-26
2	Data collection tools	English	1	2023-05-26
3	Protocol	English	1	2023-05-26

Yours Sincerely

Peter Waiswa
For: Uganda Christian
University REC

Appendix B: QUESTIONNAIRE FOR CAREGIVERS OF HIV INFECTED ADOLESCENTS

QUESTIONNAIRE FOR CAREGIVERS OF HIV INFECTED ADOLESCENTS

Dear Respondent,

This research is for study purposes at Uganda Christian University. This questionnaire intends to seek your views on the Effect of Education Package on Care-Givers' Knowledge, and Practices towards Caring for Adolescents Living with HIV (10-19 Years). Your views will be treated with the highest level of confidentiality and will be used for the purpose of this study only.

SECTION A: Personal Information

Please respond to the following questions by placing a tick in the brackets indicating your appropriate response.

1) Age

Below 20 ( ) 20-30 ( ) 31-40 ( ) 41-50 ( ) 51-60 ( ) Above 60 ( )

2. Gender

Male ( ) Female ( )

3. Caregiver Category

Mother ( )	Father ( )	Sibling ( )	Relative ( )
Friend ( )	Neighbor ( )	Health worker ( )	other ( )

4. Highest Education attained

Primary	( )	O level	( )	A level	( )
Diploma	( )	Graduate	( )	Other	( )

Others (please specify)…………………………………………………………….........

5. How long have you been a caretaker?

Less than 1 year ( ) 1– 3 years ( ) Over 3 years ( )

SECTION B: KNOWLEDGE OF THE CAREGIVERS IN ART FACILITATION

Please use the scale below to indicate your level of agreement or disagreement with the statements below.

SCALE	5	4	3	2	1
	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

	Knowledge of the Caregivers	5	4	3	2	1
A	**Adolescent Factors**					
1.	Adherence to antiretroviral therapy improves quality of life.					
2.	Poor living conditions disrupts continuous taking of antiretroviral therapy					
3.	Nutrition supplements aids antiretroviral therapy efficacy.					
4.	Psycho-social support influences consistency to antiretroviral therapy.					
5	Facility friendly services to adolescents influences uptake of antiretroviral therapy.					
6	Age of the adolescent determines status disclosure.					
7	Pill burden, and Side effects disrupts antiretroviral therapy					
B	**Medical Factors**	5	4	3	2	1
8.	Addressing drug administration challenges like taste of the drug, and proper storage of medicines helps caregivers to support adolescents on antiretroviral therapy					
9.	Administering many drugs affects adherence to ART by adolescents					
10.	Availability of specific adolescent clinical days encourages adolescents to keep appointments.					
11.	Positive relationship of health care providers with adolescents keeps them on ART.					
12	Health workers making reminder calls and follow up on clinical days helps caregivers and their adolescents in time keeping.					
C	**Caregiver Factors**	5	4	3	2	1
13	Conducive home environment encourages the adolescent to keep on					
	medication					
14.	Positive relationship of the caregiver with the adolescent contributes to better treatment outcomes					
15.	Adequate psycho-social support enhances positive living in adolescents					

SECTION C: PRACTICES OF CAREGIVERS TO ADOLESCENTS ON ART

Please use the scale below to indicate your level of agreement or disagreement with the statements below.

SCALE	5	4	3	2	1
	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

A	**Practices Towards Adolescent ART adherence**	5	4	3	2	1
22.	The living conditions of the adolescent on ART is very important					
23.	Keeping clinical appointments by the adolescent needs support of the caregiver					
24	Early disclosure of HIV status of the adolescent by the caregiver is important in keeping the adolescent on medication.					
25	Caregivers should pay attention to health needs of the adolescent					
26.	Continuous counselling and encouragement to the adolescent keeps him or her on lifelong medication living a quality of life.					
27.	Reminding the adolescent to take his/her daily dose is the role of the caregiver.					
28.	Supporting the adolescent to attain his or her carrier dreams is the role of the caregiver.					
29	Monitoring drug taking, observing side effects, and reporting suspected adverse drug reactions is the role of the caregivers.					

Thank You So Much for your Time

APPENDIX C: PERMISSION TO CONDUCT RESEARCH

UGANDA CHRISTIAN UNIVERSITY

A Centre of Excellence in the Heart of Africa

Faculty of Health Sciences

Nursing Department,

The In-charge Kakumiro HC IV
23rd February 2021

Dear Sir/Madam.

Re: Permission for Mugaga Deus Reg No RMI 5M11/008 to do research from Kakumiro HC IV.

Greetings to you in Jesus name and hope this finds you well.

I introduce to you Mugaga Deus Reg No RM15M1 1 /008 student of Master of Nursing Science Uganda Christian University, who is seeking permission to carry out research Kakumiro Hospital any day of the week starting 1 st March 2021.

Deus has been a student on the Master's program and in her final stages to complete the course of which research is mandatory. The topic of study is "Care givers Knowledge on enhancing ART adherence among Adolescents aged 10 to 19 years."

He is expected to abide by the regulations of the health facility as you accord him the necessary support to complete his study.

We shall be grateful for your support to UCU nursing department and thank you for saving lives of Ugandans.

I wish you the best in all your endeavors.
Best
Regards,

ards,

23 FEB 202

Elizabeth Nagudi Situma

Head of Department Nursing

Republic of Uganda
KAKUMIRO DISTRICT LOCAL GOVERNMENT
District Health Office
P.O Box 522, KAKUMIRO
"Health is Wealth Please Preserve it"

Date: 28th/Apri1 /2023

TO: MUGAGA DEUS

UGANDA CHRISTIAN UNIVERSITY MUKONO,

FACULTY OF PUBLIC HEALTH, NURSING & MIDWIFERY,

DEPARTMENT OF NURSING AND MIDWIFERY,

P.O.BOX 4 MUKONO.

Dear Sir,

RE: PERMISSION TO CONDUCT RESEARCH AT KAKUMIRO HIC IV

This is to inform you that you have been accorded permission to conduct your research study in the above facility in the ART clinic department.

We anticipate that your study will be of help, to not only you but also the entire health facility, district, region, at the ministry of health at large. We therefore request to avail us with a copy of research findings upon completion of your study.

rs in service.
KAKUMIRO
LTH CENTRE IV
02 MAY 2023
nyira Robert (PMCO)
ART DEPARTMENT
P.O. BOX 522, KAKUMIRO
in-charge Kakumiro H/C IV.

Thank you,

Appendix D: Lesson Plan

TOPIC: ART adherence in adolescent

Objectives:

i. Define ART
ii. Explain ART adherence practices
iii. Role of caregivers

Methods:

- Interactive lecture
- Discussions
- Questions and answers

Teaching aids: consolidated HIV/AIDS clinical guidelines 2020, ART manual guide

Time: 45min

Time Allocated	Content	Tutor's Activities	Participants' Activities
05 min	Greetings Introductions	Greet the caregivers Self-introduction, and topic of discussion	Respond to greetings Listen and take key notes
30 min	definition of ART General ART adherence practices Role of care givers in enhancing adherence among adolescents	It's the anti-retroviral therapy that stops the multiplication of the virus and increases the CD4 counts in the human body**.** ART adherence is agreeing to take the recommended dosage of the drug and other supplements as recommended by the health care providers **Art adherence practices include**; • understanding the age of the adolescent during disclosure • addressing cultural and religious beliefs • addressing financial constraints • dosing complexities, side effects, number of pills taken • some drug and food restrictions • keeping clinical appointment dates **The Role of the Caregivers**: • psycho-social support, and non-judgmental attitude • understanding the benefits of ART adherence and the risks of non-adherence to the adolescent • Understand how to deal with side effects, proper drug dosage and formulations. • Keep the appointment dates for ART refills • Nutritional supplements to support	Listen attentively, take key notes, raise questions and clarifications, & answer questions raised

		ART, and other food restrictions.	
10 min	Given 5min discussion	Answer questions and clarify raised concerns, End the session and thank the participants	Answer questions, ask questions, appreciate the session