

**EFFECTIVENESS OF PALLIATIVE CARE FOR PATIENTS LIVING WITH HIV IN
MUKONO GENERAL HOSPITAL**

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**UGANDA CHRISTIAN
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DECLARATION

I Kagwisagye Sabrina, hereby declare that this dissertation was written entirely by me under the supervision of my advisor and has never been submitted to another organization for consideration for any award.

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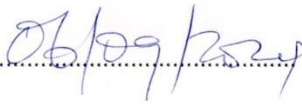
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APPROVAL

This dissertation was produced under my supervision and now due for submission to the School of Social Sciences, Uganda Christian University. "Effectiveness of palliative care for patients living with HIV in Mukono General Hospital .

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Dr. NAREEBA PETER

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DEDICATION

I dedicate this study to my parents who guided, helped, and mentored me throughout my schooling up to the collegiate level. Above all, I give thanks to Almighty God for his direction and assistance in helping me finish this dissertation.

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The study has been a good journey and I am grateful to those who have helped me to make it a success. I thank God for His grace, mercy and protection throughout my research period. I thank my supervisor DrNareeba Peter for his guidance, supervision and suggestions, during my research process.

I extend my acknowledgement to my fellow students in research for providing me with relevant information to enable me completethe study.

Table of Contents

| | |
|--|----------|
| DECLARATION | 1 |
| APPROVAL..... | ii |
| DEDICATION | iii |
| ACKNOWLEDGEMENT | iv |
| ABSTRACT | viii |
| CHAPTER ONE | 9 |
| 1.0 Introduction | 9 |
| 1.1 Background of the Study..... | 9 |
| 1.2 Problem statement..... | 3 |
| 1.3 Purpose of the study..... | 4 |
| 1.4 Objectives of the study | 4 |
| 1.5 Research questions..... | 5 |
| 1.6 Scope of the study | 5 |
| 1.6.1 Content scope..... | 5 |
| 1.6.2 Geographical scope..... | 5 |
| 1.6.3 Time scope | 5 |
| 1.7 Justification of the study..... | 5 |
| 1.8 Significance of the study | 6 |
| 1.9 Conceptual framework | 7 |
| CHAPTER TWO | 8 |
| LITERATURE REVIEW..... | 8 |
| 2.0 Introduction | 8 |
| 2.1 Concept of Palliative Care | 8 |
| 2.2 Concept of HIV..... | 8 |
| 2.3 The current availability and accessibility of palliative care services for PLWHIV..... | 9 |
| 2.4 Effectiveness of palliative care services available and accessible in hospitals in improving the lives of PLWHIV | 11 |

| | |
|---|-----------|
| 2.5 Barriers and facilitators to the effectiveness of palliative care for PLWHIV | 12 |
| 2.6 Literature gap | 15 |
| | |
| CHAPTER THREE | 16 |
| METHODOLOGY | 16 |
| 3.0 Introduction | 16 |
| 3.1 Research design..... | 16 |
| 3.2 Study area and population | 17 |
| 3.3 Sample size determination..... | 17 |
| 3.3.1 Selection of Participants for qualitative data collection | 18 |
| 3.4 Sampling techniques and procedure | 19 |
| 3.5 Data collection methods | 19 |
| 3.5.1 Questionnaire survey..... | 19 |
| 3.5.2 Key Informant Interviews..... | 19 |
| 3.6 Data collection tools | 20 |
| 3.6.1 Questionnaire | 20 |
| 3.6.2 Key informant interview (KII) guide | 20 |
| 3.7 Validity and reliability | 20 |
| 3.7.1 Validity and reliability of quantitative research | 21 |
| 3.7.2 Validity and reliability of qualitative research..... | 22 |
| 3.8 Data analysis..... | 22 |
| 3.10 Anticipated limitations of the study | 22 |
| CHAPTER FOUR | 23 |
| DATA PRESENTATION, INTERPRETATION AND DISCUSSION..... | 23 |
| 4.0 Introduction | 23 |
| 4.1 Findings on demographic characteristics of respondents | 23 |
| 4.2 The current availability and accessibility of palliative care services for patients living with HIV in Mukono General Hospital..... | 25 |
| 4.3 How these palliative care services that are available and accessible in Mukono General Hospital have been effective in improving the lives of people living with HIV..... | 29 |

| | |
|--|-----------|
| 4.4 Barriers and facilitators to the effectiveness of palliative care for patients living with HIV in Mukono General Hospital..... | 32 |
| CHAPTER FIVE | 38 |
| SUMMARY OF FINDINGS, CONCLUSION AND RECOMMENDATIONS..... | 38 |
| 5.0 Introduction | 38 |
| 5.1 Summary of findings | 38 |
| 5.2 Conclusions | 39 |
| 5.3 Recommendations..... | 40 |
| 5.4 Areas for further research..... | 41 |
| REFERENCES | 42 |
| AppendixInterview Guide | 46 |
| Letter from the agency /university | 48 |

ABSTRACT

The study aimed at out airing the effectiveness of palliative care for patients living with HIV in Mukono general hospital. It specifically focused on investigating the current availability, accessibility, barriers in HIV palliative care services.

The study was carried out using descriptive survey research design where both qualitative and quantitative research approaches were also used. The data was collected using interview guide and questionnaires during data collection, both purposive and simple random sampling methods were used. The sample size of 44 patients as included in the study.

According to the study findings, the palliative care provided is effective to the HIV respondents and is effective for them, although there are defined barriers like limited availability of essential medications, stigma and discrimination.

Finally, the study therefore recommends a strong need to address the barriers to medication availability at Mukono General Hospital and the need to enhance follow-ups and monitoring procedures forHIV patients receiving palliative care.

CHAPTER ONE

1.0 Introduction

This study is about examining the effectiveness of palliative care for patients living with HIV in Mukono General Hospital. The study's background, problem statement, purpose, aims, research questions, justification, and conceptual framework are all presented in this chapter.

1.1 Background of the Study

Palliative care for patients living with HIV/AIDS has been stated as a critical component in addressing the needs of individuals affected by this chronic illness (Spencer et al., 2019). HIV/AIDS, once considered a positive, has to be sent into a manageable chronic illness with advancements in antiretroviral therapy (ART). However, despite these medical availability, HIV/AIDS remains a significant global health problem, particularly in regions with limited access to healthcare resources and infrastructure (Croxford et al., 2019). Who defines palliative care as an approach that improves the quality of life for patients and their families facing the problems associated with life-threatening illness, through the prevention and reduce in suffering. This is done through early identification, good assessment, and managing of pain and other problems, whether they are physical and psychological (Watson et al., 2019). Palliative care aims to enhance the quality of life for patients by addressing their physical, psychological, social, and spiritual needs.

In the past years, there has been growing recognition of the need of integrating this care into the management of HIV/AIDS (Li et al., 2021). This holistic approach not only improves symptom management and pain relief but also supports patients and their families in coping with the emotional and existential challenges associated with the disease (Kall et al., 2020). Furthermore, palliative care facilitates discussions around advance care planning and end-of-life care preferences, empowering patients to make informed decisions about their treatment and care.

The effectiveness of palliative care for HIV patients has been increasingly recognized in recent years. Advancements in antiretroviral therapy (ART) have significantly improved lifespans for people with HIV. However, many still experience a range of physical and emotional challenges(El-Jawahri et al., 2021).

Around the world in 2020, only 7 million people – approximately 12% of the 56.8 million people in need of palliative care- received it(Dipio et al., 2022). In Europe and North America, where healthcare systems are relatively well-developed, access to palliative care services for HIV/AIDS patients is more widespread. However, disparities still exist within these regions, with marginalized populations facing barriers to accessing quality care. In Asia, the availability of palliative care for HIV/AIDS patients is limited, particularly in low- and middle-income countries where resources are scarce(Kagarmanova et al., 2022). Low- and middle-income countries especially those in Africa account for 76% of the global need in palliative care(Laabar et al., 2023). For countries to meet this demand for essential care, it is recommended to integrate palliative care services into existing healthcare systems and track them with proper data and indicators to ensure quality of services(Spencer et al., 2019).

In Africa, where HIV/AIDS is most found, access to palliative care remains a significant problem. Countries like Nigeria and South Africa, which have some of the highest HIV rates in the world, struggle to provide effective palliative care services due to limited funding, understaffing, and low infrastructure (Laabar et al., 2023). In Sub-Saharan Africa, where the majority of HIV/AIDS cases are concentrated, the need for palliative care is particularly acute, yet services are often hard to meet (Mah et al., 2023).

Palliative care was introduced in Uganda in 1993 by HAU, a non-governmental organization (NGO) that initiated three community-based palliative care programs in rural and urban communities in Kampala, Hoima, and Mbarara (Luyirika et al., 2022). These organizations primarily focused on supporting clients and their families with counseling, improving attitudes, and approaches to living with the disease. These organizations provided an excellent means of improving patient care while decreasing the stigma associated with HIV/AIDS in Uganda. Yet, they lacked and still lack modern methods of pain and symptom control crucial to strong palliative care(Namukwaya et al., 2021).

In Uganda, the need for palliative care has been estimated mainly through morbidity and mortality data. The World Health Organisation estimates that 1% of the population needs palliative care; therefore, as the current population of Uganda is 40,308,000, an estimated 403,080 Ugandans need palliative care (Laabar et al., 2023). The need for palliative care in Uganda is increasing due to an increasingly ageing population and the relatively high prevalence of HIV/AIDS.

Uganda has made significant progress in providing palliative care services that are integrated into the health system. By 2006, Uganda was one of the 20 countries in the world ranked amongst those in the advanced integration category in palliative care (Namukwaya et al., 2021). The 2011 mapping of global palliative care developments undertaken by the Worldwide Palliative Care Alliance reported that in Africa, only Uganda had achieved advanced integration of palliative care into its health system. Uganda is the second highest ranking African country and 35th country worldwide in the Quality of Death Index of 2020 in terms of quality and availability of palliative care services for adult populations in the world (Laabar et al., 2023). It is estimated that there are 5.87 PC services per million people in Uganda, and this is second only to Swaziland in Africa which has the largest number of PC services per population (Rangaraj et al., 2023). However, there are no studies that have been conducted to ascertain the effectiveness of these palliative care services for patients living with HIV in Uganda and specifically in Mukono General Hospital which forms the basis for this study.

1.2 Problem statement

Uganda's healthcare system aims at providing comprehensive care for people living with HIV (PLWHIV). This includes not only access to life-extending antiretroviral therapy (ART) but also integrated palliative care services (Li et al., 2021). Palliative care focuses on helping with the pain, other symptoms and the psychological burdens that are associated with HIV, improving quality of life (Croxford et al., 2019). However, the reality in Uganda paints a different picture. Despite the recognized benefits of palliative care, access for PLWHIV remains limited. According to a report by the Uganda AIDS Commission (2021), an estimated 70% of Ugandans living with advanced HIV lack access to essential palliative care services although Uganda is the second highest ranked African country and 35th country worldwide in terms of quality and availability of palliative care services for adult populations in the world (Laabar et al., 2023).

This could be attributed to limited funding and resources allocated to palliative care services, a shortage of trained healthcare professionals specializing in palliative care, stigma and discrimination surrounding HIV/AIDS and insufficient integration of palliative care into existing HIV/AIDS treatment programs (Luyirika et al., 2022).

Patients living with HIV in Uganda experience a range of negative outcomes, including increased pain and symptoms, poor quality of life, and high emotional distress (Namukwaya et al., 2021). If this problem is not addressed, it is likely to perpetuate the cycle of suffering and exacerbate the already significant challenges faced by individuals living with HIV in the country. Moreover, the lack of effective palliative care may lead to increased healthcare costs associated with managing uncontrolled symptoms and preventable hospitalizations, further straining the already burdened healthcare system (Mah et al., 2023). Furthermore, the existing literature by (Kagarmanova et al., 2022; Algaralleh et al., 2020) on palliative care for HIV patients in Uganda has predominantly focused on the availability and accessibility of palliative care services, as well as their impact on patient outcomes.

1.3 Purpose of the study

The purpose of the study is to find out the effectiveness of palliative care for patients living with HIV in Mukono General Hospital.

1.4 Objectives of the study

- i. To assess the current availability and accessibility of palliative care services for patients living with HIV in Mukono General Hospital.
- ii. To establish how these palliative care services that are available and accessible in Mukono General Hospital have been effective in improving the lives of people living with HIV.
- iii. To identify barriers and facilitators to the effectiveness of palliative care for patients living with HIV in Mukono General Hospital.

1.5 Research questions

- i. What are the current availability and accessibility of palliative care services for patients living with HIV in Mukono General Hospital?
- ii. How effective have these palliative care services that are available and accessible in Mukono General Hospital been in improving the lives of people living with HIV?
- iii. What are the barriers and facilitators to the effectiveness of palliative care for patients living with HIV in Mukono General Hospital?

1.6 Scope of the study

The scope of the study has covered three dimensions that is; content, geographical and time and these are discussed in detail below.

1.6.1 Content scope

This study has specifically focused on; assessing the current availability and accessibility of palliative care services for patients living with HIV in Mukono General Hospital, establishing how these palliative care services that are available and accessible in Mukono General Hospital have been effective in improving the lives of people living with HIV and identifying barriers and facilitators to the effectiveness of palliative care for patients living with HIV in Mukono General Hospital.

1.6.2 Geographical scope

Geographically, this study has been conducted in Mukono General Hospital located in Nsube-Kauga Parish, Mukono Municipality, Mukono district. Mukono General Hospital is chosen because it is the biggest government hospital where most of the people living with HIV get their medication including palliative care services from.

1.6.3 Time scope

The study has focused on scholarly material from the period 2019 to 2024. It has also been carried out for a period of three months from July to September, 2024.

1.7 Justification of the study

The justification for this study lies in the urgent need to comprehensively understand the effectiveness of palliative care for patients living with HIV in Uganda, particularly in the specific context of Mukono General Hospital. While existing literature by (Kagarmanova et al., 2022;

Algaralleh et al., 2020) on palliative care for HIV patients in Uganda has predominantly focused on the availability and accessibility of palliative care services, as well as their impact on patient outcomes, there is a notable research gap concerning the effectiveness of palliative care interventions for patients living with HIV particularly those receiving treatment from Mukono General Hospital. Previous studies have often overlooked the perspectives of healthcare providers, patients, and their families, as well as the organizational and structural barriers to delivering high-quality palliative care. Therefore, this study aims to address this gap by exploring the effectiveness of palliative care for patients living with HIV in Mukono General Hospital, thereby contributing to the evidence base for enhancing palliative care services in resource-limited settings.

1.8 Significance of the study

For policymakers and government officials, this research holds significance in informing health policies and resource allocation strategies. By understanding the current gaps in palliative care provision, policymakers will be able to prioritize funding and infrastructure development to improve access to these vital services across the country.

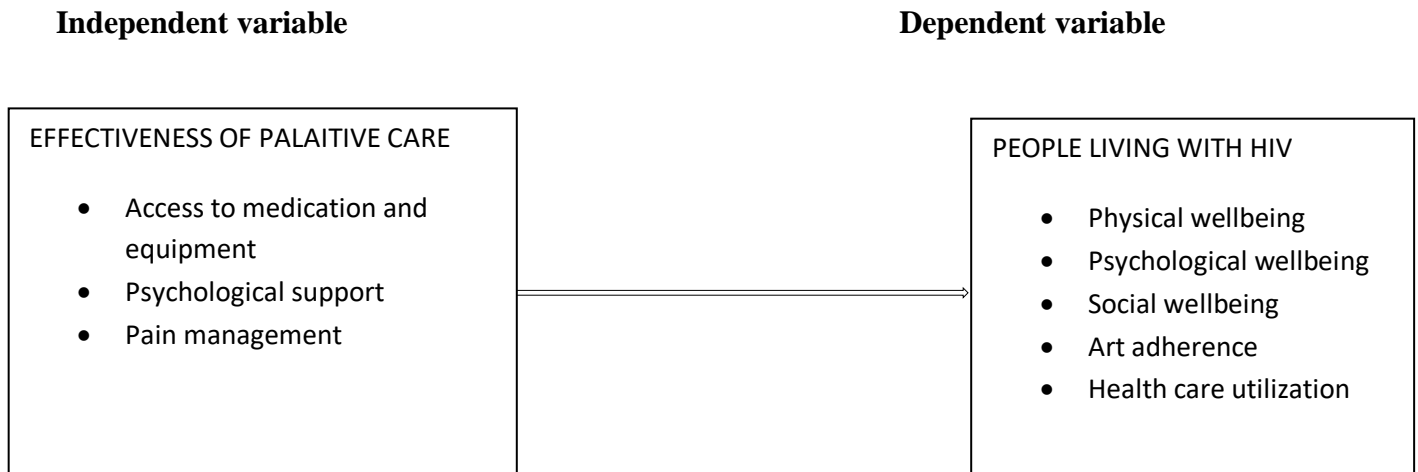
Healthcare providers stand to benefit significantly from the insights gleaned from this study. By gaining a deeper understanding of the challenges and barriers faced by HIV patients in accessing palliative care, providers will be able to tailor their services to better meet the needs of their patients.

For patients living with HIV, the study offers the promise of improved quality of life and enhanced care. By identifying areas for improvement in palliative care services, such as accessibility, affordability, and quality, this research will pave the way for tangible changes that directly benefit patients. Moreover, the study will raise awareness among patients about the importance of palliative care in managing their symptoms, addressing their psychosocial needs, and improving their overall well-being.

Finally, the study has valuable resource for future researchers interested in palliative care for patients living with HIV/AIDS in Uganda. By documenting the current state of palliative care services and identifying areas for improvement, this research will provide a solid foundation for further investigation and inquiry.

1.9 Conceptual framework

Figure 1: Conceptual Framework



Source: *Adopted from, Dipio et al. (2022) and modified by the researcher (2024)*

The above conceptual framework shows the relationship between the independent variable (effectiveness of palliative care) and the dependent variable (people living with HIV). The dimensions under effectiveness of palliative care in this study are; access to medications & equipment, psychosocial support services, pain management strategies and spiritual care. On the other hand, the dimensions of people living with HIV in this study are; physical well-being, psychological well-being, social well-being, ART adherence, healthcare utilization and spiritual well-being. This implies that the effectiveness of these palliative care services will have a huge positive impact on the overall quality of life of the people living with HIV.

CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

This chapter provides an analysis of relevant literature by several scholars as well as what other researchers have to say about the role of medical social workers in improving HIV treatment outcomes in children. Finding out what has been done and what has been omitted in this field of study is the main goal of this literature. Therefore, sources like newspaper articles, magazines, encyclopedia and books related to the people will be used.

2.1 Concept of Palliative Care

Palliative care is a specialized medical approach focused on improving the quality of life for individuals living with serious illnesses, including HIV/AIDS. It goes beyond simply treating the disease itself and instead aims to manage the physical, emotional, psychological, and spiritual symptoms and burdens associated with the illness. This holistic approach recognizes that a person's well-being encompasses various aspects, and addressing all of them is crucial for a dignified and comfortable life(Nevin et al., 2019).

The main concept of palliative care lies in symptom management and prevention. Pain, fatigue and difficulty breathing are some of the physical symptoms that palliative care specialists work to alleviate through medication, non-invasive therapies, and other techniques(Goni-Fuste et al., 2021). Beyond physical symptoms, palliative care also addresses the emotional and psychological distress that often accompanies serious illnesses. Anxiety, depression and fear are common experiences and palliative care teams provide counseling and support groups to help patients cope with these challenges.

2.2 Concept of HIV

HIV is a virus that causes AIDS. Normally, our body has immune system that attack viruses and bacteria. Immune system has white blood cells which protect us from infections. White blood cells contain CD4+ cells which is also known as helper cells or T cells. A person who is infected will be able to develop(Vidal, 2019). These infections take advantage of body's immune system. These infections cause several health problems and even lead to death of a person. HIV has inability to protect against diseases and count of CD4 cells also decreases in HIV. There is no

cure of AIDS but there are certain medicines which are used to slow down the diseases so you stay healthier for long time. There is no medicine to get rid of diseases(Eisinger et al., 2019).

HIV is spread by sexual contact with an infected person, by sharing needles and/or syringes (primarily for drug injection) with someone who is infected, or less commonly (and now very rarely in countries where blood is screened for HIV antibodies), through transfusions of infected blood or blood clotting factors(Dharan& Campbell, 2022). Babies born to HIV-infected women may become infected before or during birth or through breast-feeding after birth. These body fluids have been proven to spread HIV: blood, semen, vaginal fluid, breast milk, cerebrospinal fluid surrounding the brain and the spinal cord, synovial fluid surrounding bone joints; and amniotic fluid surrounding a fetus(Vidal, 2019).

Some people in the early stages of acute HIV infection present with flu-like symptoms within 2-4 weeks after infection. Possible symptoms include fever, chills, rash, night sweats, muscle aches, sore throat, fatigue, swollen lymph nodes and mouth ulcers that may last for a few days to weeks(Eisinger et al., 2019). But some people may not feel sick during acute HIV infection. As the disease gradually progresses to Stage 3, a person may develop yeast infections in their mouth and throats and opportunistic infections can take advantage of the body's weakened immune system associated with the progression of the disease. With the advances in treatment, progression to Stage 3 is less common(Dharan& Campbell, 2022).

2.3 The current availability and accessibility of palliative care services for PLWHIV

Despite significant advancements in antiretroviral therapy (ART) extending lifespans for people living with HIV (PLWHIV), the need for palliative care remains substantial. This specialized care approach aims to manage the physical, psychological, and spiritual burdens associated with HIV, improving quality of life(Islam et al., 2022). However, a significant gap exists between the need for palliative care and its current availability and accessibility for PLWHIV globally. Studies from developed regions like Europe and the United States paint a relatively positive picture. Research shows that integrating palliative care alongside ART significantly improves symptom control and overall well-being for PLWHIV. However, the picture darkens considerably in many developing nations, particularly in Sub-Saharan Africa, which carries a disproportionate burden of HIV(Nair et al., 2020).

Limited resources and a shortage of trained healthcare workers pose significant barriers to palliative care access in Sub-Saharan Africa. Countries like Nigeria struggle to integrate palliative care services into existing HIV treatment programs(Ahmed et al., 2023). Weak referral systems between ART clinics and palliative care providers further exacerbate the problem. Beyond healthcare infrastructure limitations, sociocultural factors also play a role in accessibility. Stigma associated with HIV can lead to delayed help-seeking for palliative care services. Additionally, a lack of awareness about the benefits of palliative care among both patients and healthcare professionals can hinder access(Rangaraj et al., 2023).

Uganda serves as a specific example within Sub-Saharan Africa. Despite a large population living with HIV, access to palliative care remains limited. A 2021 report by the Uganda AIDS Commission highlights that an estimated 70% of Ugandans with advanced HIV lack access to essential palliative care services(Ahmed et al., 2023). This limited access to palliative care has severe consequences for PLWHIV. Uncontrolled pain, distressing symptoms like nausea and fatigue, and emotional burdens significantly decrease quality of life. This can lead to poorer adherence to ART, increased healthcare utilization due to complications, and potentially faster disease progression(Limardi et al., 2019).

Efforts to bridge the gap involve advocating for the integration of palliative care services within existing ART programs. Additionally, exploring alternative service delivery models, such as task-shifting to train nurses and community health workers in basic palliative care skills, holds promise in resource-limited settings. Telehealth and mobile health technologies offer emerging solutions. Tele-palliative care consultations can connect patients in remote areas with specialists, while mobile apps can provide symptom management tools and educational resources for PLWHIV and their caregivers(Nguyen et al., 2021).

Advocacy at the national and international level is crucial. Policies promoting the development and integration of palliative care services within national health plans are essential. Additionally, international funding bodies can play a vital role in supporting capacity building and resource allocation for palliative care in resource-limited settings(Nkandu et al., 2020). While research exists on the effectiveness of palliative care for PLWHIV globally, further studies are needed to understand its effectiveness within specific contexts. Culturally sensitive research designs can

explore the unique needs, barriers, and facilitators of palliative care access for PLWHIV in different regions. Research on implementation science is crucial. Studies exploring the most effective strategies for integrating palliative care services into existing healthcare systems in resource-limited settings can provide valuable insights for policymakers and healthcare providers (Islam et al., 2022).

2.4 Effectiveness of palliative care services available and accessible in hospitals in improving the lives of PLWHIV

Palliative care services play a crucial role in improving the lives of people living with HIV by addressing their physical, psychosocial, and spiritual needs. Several empirical studies have investigated the effectiveness of palliative care services available and accessible in hospitals, focusing on various aspects such as symptom management, quality of life, and healthcare utilization among HIV patients (Algaralleh et al., 2020). One notable study by Kagarmanova et al. (2022) conducted in South Africa examined the impact of a palliative care intervention on HIV patients' quality of life and symptom burden. Similarly, a study by Selman et al. (2014) conducted in Uganda explored the role of palliative care in improving the lives of HIV patients in resource-limited settings. The researchers found that patients who had access to palliative care services reported better symptom control, reduced psychological distress, and improved social support compared to those who did not receive such care. This study highlights the potential of palliative care interventions to address the complex needs of HIV patients in low-resource settings. In addition to improving symptom management and quality of life, palliative care services have been shown to reduce healthcare utilization among HIV patients. A study by Croxford et al. (2019) conducted in Kenya found that patients enrolled in a palliative care program had fewer hospital admissions and emergency room visits compared to those who did not receive palliative care. This suggests that palliative care interventions not only benefit patients but also contribute to more efficient use of healthcare resources.

Research has also demonstrated the cost-effectiveness of palliative care services for people living with HIV. A study by El-Jawahri et al. (2021) conducted in Malawi evaluated the economic impact of integrating palliative care into HIV treatment programs. The researchers found that while the initial investment in palliative care services was significant, the long-term cost savings associated with reduced hospitalizations and healthcare utilization outweighed the initial costs.

This highlights the economic value of investing in palliative care as part of HIV care delivery. Moreover, palliative care services have been shown to improve patient satisfaction and adherence to treatment among HIV patients. A study by Kall et al. (2020) conducted in Zambia assessed patient perceptions of palliative care services and found that patients who received palliative care reported higher levels of satisfaction with their care and were more likely to adhere to their treatment regimens compared to those who did not receive such care.

Despite the growing evidence supporting the effectiveness of palliative care services for people living with HIV, several challenges remain in ensuring access to these services for all patients in need. Limited funding and resources, stigma surrounding HIV/AIDS and palliative care, and a lack of trained healthcare professionals are among the barriers that hinder the widespread implementation of palliative care programs in many settings (Laabar et al., 2023). Empirical research has consistently demonstrated the effectiveness of palliative care services available and accessible in hospitals in improving the lives of people living with HIV. These services not only help manage symptoms and improve quality of life but also reduce healthcare utilization, enhance patient satisfaction, and promote treatment adherence. However, addressing the barriers to access and ensuring the integration of palliative care into HIV treatment programs are essential steps toward realizing the full potential of palliative care in improving outcomes for people living with HIV (Mah et al., 2023).

2.5 Barriers and facilitators to the effectiveness of palliative care for PLWHIV

Stigma and discrimination: Fear of discrimination or judgment might prevent PLWHIV from seeking palliative care services. Additionally, a lack of awareness about the benefits of palliative care, among both patients and healthcare professionals, can hinder access and utilization (Li et al., 2021). Numerous empirical studies have identified stigma and discrimination as significant barriers to the effectiveness of palliative care for patients living with HIV. Research by Mak et al. (2017) in Malaysia found that stigma associated with HIV/AIDS often leads to reluctance among patients to seek palliative care services due to fear of judgment and social ostracization. Similarly, a study by Moens et al. (2014) in Belgium highlighted how healthcare providers' stigmatizing attitudes toward HIV patients can create barriers to accessing palliative care and hinder effective communication between patients and providers.

Limited access to palliative care services: Access to palliative care services remains a considerable challenge for many HIV patients, particularly in resource-limited settings. A study by Namukwaya et al. (2021) in Uganda identified geographic barriers, such as the lack of palliative care facilities in rural areas, as a significant impediment to accessing care. Furthermore, research by Higginson et al. (2017) across several African countries highlighted the scarcity of trained palliative care professionals and limited availability of essential medications as key barriers to accessing palliative care services.

Healthcare provider training and knowledge: The lack of training and knowledge among healthcare providers regarding palliative care for HIV patients is another barrier identified in empirical research. A study by Nkandu et al. (2020) in Kenya found that healthcare providers often lacked the necessary skills and knowledge to deliver palliative care effectively, leading to suboptimal symptom management and patient outcomes. Similarly, research by Harding et al. (2019) in South Africa highlighted the need for ongoing education and training programs to enhance healthcare providers' understanding of palliative care principles and practices.

Limited access and resource constraints: A significant barrier is the limited availability of palliative care services, particularly in resource-limited settings. Shortages of trained healthcare professionals specializing in palliative care create a service gap, hindering access for many PLWHIV. Furthermore, limited financial resources can restrict access to essential medications, equipment, and infrastructure needed to deliver effective palliative care (Dipio et al., 2022).

Cultural considerations: Cultural beliefs and practices regarding death and dying can influence the effectiveness of palliative care. A mismatch between healthcare providers' approaches and patients' cultural expectations can create barriers. Culturally sensitive communication and service delivery models are crucial for ensuring effective palliative care for PLWHIV from diverse backgrounds (Algaralleh et al., 2020).

Integration into existing healthcare systems: Integration of palliative care into existing healthcare systems is crucial for ensuring its effectiveness for HIV patients. However, empirical studies have shown that this integration often faces significant challenges. A study by Selman et al. (2013) in Uganda found that fragmented healthcare systems and lack of coordination between HIV and palliative care services hindered the seamless delivery of integrated care. Similarly,

research by Dzingirai et al. (2018) in Zimbabwe highlighted the need for policy-level interventions to promote the integration of palliative care into national HIV/AIDS programs.

Patient and family preferences: Understanding patient and family preferences is essential for delivering patient-centered palliative care. Research by Harding et al. (2016) in South Africa found that cultural beliefs and preferences often influence patients' decisions regarding palliative care utilization. Moreover, a study by Zimmermann et al. (2014) in Canada emphasized the importance of involving patients and their families in care planning and decision-making processes to ensure that care aligns with their values and preferences.

Psychosocial and spiritual support: Empirical studies have highlighted the importance of providing psychosocial and spiritual support as integral components of palliative care for HIV patients. Research by Kaida et al. (2017) in sub-Saharan Africa demonstrated the significant impact of psychosocial support programs on patients' mental health and emotional well-being. Additionally, a study by Sawatzky et al. (2016) in Canada emphasized the need for addressing patients' spiritual needs as part of comprehensive palliative care, particularly among HIV patients facing existential concerns.

Healthcare financing and resource allocation: Adequate financing and resource allocation are essential facilitators of effective palliative care for HIV patients. However, empirical research has shown that limited healthcare budgets and competing priorities often pose challenges to funding palliative care services. A study by Lynch et al. (2018) in Ireland highlighted the need for sustainable funding mechanisms and resource allocation strategies to ensure the long-term viability of palliative care programs. Similarly, research by Heyland et al. (2015) in Australia emphasized the importance of advocating for increased investment in palliative care to address the growing needs of HIV patients.

Community support networks: The presence of robust community support networks can facilitate access to palliative care and enhance its effectiveness for HIV patients. Research by Broom et al. (2018) in Australia demonstrated the positive impact of community-based palliative care initiatives on patients' social support networks and overall well-being. Additionally, a study by Kikule et al. (2020) in Uganda emphasized the role of community health workers in bridging the

gap between healthcare facilities and patients' homes, thereby improving access to palliative care services.

Patient education and empowerment: Educating and empowering patients about palliative care can help overcome barriers and enhance its effectiveness. Research by Gwyther et al. (2016) in South Africa emphasized the importance of patient education in dispelling myths and misconceptions about palliative care and HIV/AIDS. Moreover, a study by Mwangi-Powell et al. (2018) in Kenya highlighted the need for targeted educational interventions to raise awareness about the benefits of palliative care and empower patients to advocate for their rights to quality care.

Policy and advocacy efforts: Policy and advocacy efforts play a crucial role in addressing barriers and promoting the effectiveness of palliative care for HIV patients. Advocacy at the national and international level is crucial. Policies promoting the development and integration of palliative care services within national health plans are essential. Additionally, international funding bodies can play a vital role in supporting capacity building and resource allocation for palliative care in resource-limited settings. Research by Sleeman et al. (2019) in the United Kingdom emphasized the importance of advocating for policy changes to improve access to palliative care services and address systemic barriers. Similarly, a study by Namisango et al. (2017) in Uganda highlighted the role of civil society organizations in advocating for policy reforms and mobilizing resources to support palliative care initiatives.

2.6 Literature gap

The literature review highlights the significance of palliative care in improving the lives of people living with HIV by addressing their physical, psychosocial, and spiritual needs. Empirical evidence underscores the effectiveness of palliative care interventions in symptom management, enhancing quality of life, reducing healthcare utilization, and promoting treatment adherence among HIV patients. However, significant barriers such as stigma, limited access to services, healthcare provider training gaps, resource constraints, and cultural considerations hinder the effective delivery of palliative care. While existing research offers insights into these challenges and facilitators, there is a notable gap in understanding the specific needs and experiences of pediatric HIV patients and the role of medical social workers in palliative care for this population. Further research focusing on pediatric HIV populations and the contributions of

medical social workers could fill this gap and inform tailored interventions to improve treatment outcomes in children living with HIV.

CHAPTER THREE

METHODOLOGY

3.0 Introduction

This chapter consists of the methodology that is used in conducting the research. It describes how this study will be conducted. It includes the study design, the study setting, sources of data, study population and sample size determination. It also describes the sampling procedures, study variables, data collection methods and tools, validity and reliability of data collection tools, data processing, quality control measures, data analysis, ethical considerations, plan for dissemination of results and limitations of the study.

3.1 Research design

This study employs the use of a descriptive survey research design, employing mixed methods research, which combines both quantitative and qualitative approaches. This research design which involves collecting data to describe the characteristics of a population or phenomenon being studied (Aquino et al., 2018). In this case, the design utilizes to gather information on the

effectiveness of palliative care for patients living with HIV in Mukono General Hospital. Through questionnaires and interviews, data gathered from the patients living with HIV that get their medication from the ART Clinic of Mukono General Hospital and the medical doctors from the ART clinic that offer palliative care to these HIV patients regarding the topic under study (Okonta&Rossouw, 2014). This design is chosen for its ability to provide a comprehensive understanding of the effectiveness of palliative care for patients living with HIV, hence allowing for informed decision-making and targeted interventions to improve palliative care services for HIV patients in the hospital (Jann&Hinz, 2016).

3.2 Study area and population

The study has been conducted in Mukono General Hospital located in Nsuube-Kauga Parish, Mukono Municipality, Mukono district. Mukono General Hospital (MGH) is chosen because it is the biggest government hospital where most of the people living with HIV get their medication including palliative care services from. The study population is therefore include patients living with HIV that get their medication from the ART Clinic of Mukono General Hospital. According to Mukono General Hospital Medical Records (2024), there are a total of 100 HIV patients currently receiving treatment from the hospital in the past six months and these are included in the study as the study population. The study population also includes key informants who will be the medical doctors from the ART clinic that offer palliative care to these HIV patients totaling to 5 key informants.

3.3 Sample size determination

According to Katamba&Nsubuga (2014) sample size is the portion or subset of the total population. The sample size will be determined by the sample calculation formula by Taro Yamane's (1970) formula as follows;

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

“n” is sample size, “N” is population, “e” is error (0.05) or level of confidence 95%

“N” (population) = 100 HIV patients receiving treatment from the ART Clinic in MGH

$$n = \frac{100}{1 + 100(0.05)^2}$$

$$n = \frac{100}{1 + 100(0.0025)}$$

$$n = \frac{100}{1 + (0.25)}$$

$$n = \frac{100}{1.25}$$

n = 80HIV patients receiving treatment from the ART Clinic in MGH

Therefore from the sample size calculation above, the sample size is 80 respondents who are HIV patients currently receiving treatment from the hospital in the past six months. The population and sample size for the HIV patients and the key informants are further divided in the table below.

Table 1: Population, sample size and sampling methods

| Departments | Population | Sample size | Sampling method |
|-------------------------------------|-------------------|--------------------|------------------------|
| HIV Patients from MGH | 100 | 80 | Simple random sampling |
| Medical doctors from the ART Clinic | 5 | 5 | Purposive sampling |
| TOTAL | 105 | 85 | |

Source: *Mukono General Hospital-Art Clinic (2022)*

3.3.1 Selection of Participants for qualitative data collection

A total of 5 key informants who are; medical doctors from the ART clinic that offer palliative care to these HIV patients will be purposively selected since they are the ones that offer palliative care to these HIV patients and also monitor the effectiveness of this kind of treatment given to the patients.

3.4 Sampling techniques and procedure

A total of 80 HIV patients currently receiving treatment from the hospital in the past six months will be selected using simple random sampling where samples will be randomly selected from the HIV patients. These will be determined and selected randomly by use of records from the ART Clinic in Mukono General Hospital and later contacted for their consent. This method will be used because it ensures fairness and minimizes bias in the selection process, allowing for a representative sample of HIV patients to participate in the study (Noor et al., 2022).

On the other hand, a total of 5 medical doctors from the ART clinic that offer palliative care to these HIV patients will be purposively selected. The key informants will be chosen basing on the fact that they are the ones that offer palliative care to these HIV patients and also monitor the effectiveness of this kind of treatment given to the patients. This method will be used to select this category of people because they are few in number and they have the expertise and the knowledge concerning the topic under study.

3.5 Data collection methods

3.5.1 Questionnaire survey

According to Katamba & Nsubuga (2014) a questionnaire survey is a set of questions designed by the researcher for purpose of collecting data. The questionnaire includes open ended questions which require the respondent to give more details about the subject matter and because they give the respondents opportunity to express their opinion in free flowing manner giving them time to think before answering questions since it avoids personal contact. Semi structured or closed ended questions where answers are provided are also be used and the respondents are only be required to tick the best suitable answer about the subject matter. Since the researcher is using questionnaires, I am involved in the process of guiding the respondents in ensuring that the right information is collected from the university students.

3.5.2 Key Informant Interviews

Key informant interviews are used to conduct face to face interviews with key informants who are the medical doctors from the ART clinic that offer palliative care to these HIV patients. An unstructured informant interview guide are used as a tool for collecting in depth information from the key informants. The interview guide is having a list of topical issues and questions which were explored in the course of conducting the interviews. The guide has drawn with the

questions soliciting for the perception on the effectiveness of palliative care for patients living with HIV. The key informant interviews are used because they provide in-depth data which may not be possible to obtain when using a questionnaire.

3.6 Data collection tools

Two types of data collection tools are used in the study. These include questionnaire and interview guides which are briefly explained in the following subsection.

3.6.1 Questionnaire

The data collection tool here will be a questionnaire guide. Questionnaire guides will be used to collect quantitative data from the selected HIV patients currently receiving treatment from the hospital in the past six months. Questionnaire guides will be used for this category of respondents to save on time because their number is big to interview. The standard questionnaire contains a list of possible alternatives from which respondents selected the answer that best suits the situation. The questionnaire will include closed-ended questions for each of the four objectives where the answers will be provided and the respondents requested to tick their preferred option.

3.6.2 Key informant interview (KII) guide

This tool is used to collect information that cannot be directly observed and it is good for the research problem which will only depend on respondents' opinions. It is also good because it gives the research control over the line of questioning hence time saving. Data obtained during the interview will supplement that obtained through the questionnaire. Interviews conducted with 5 key informants who are medical doctors from the ART clinic that offer palliative care to these HIV patients since they are the ones that offer palliative care to these HIV patients and also monitor the effectiveness of this kind of treatment given to the patients.

3.7 Validity and reliability

The principles of validity and reliability are fundamental cornerstones of the scientific method (Kent, 2001). In order for assessments to be sound, they must be free of bias and distortion. Reliability and validity are two concepts that are important for defining and measuring bias and distortion. The following subsections explain how validity and reliability will be determined in this study.

3.7.1 Validity and reliability of quantitative research

Validity is done in order to find out whether the questions are capable of capturing the intended data (Cohen et al., 2007). Experts in research will review the questions to see whether they were capable of capturing the intended response. A Content Validity Index (CVI) is calculated in order to establish the validity of the research instrument. The researcher is using the following formula to establish validity of the research instruments as seen below.

Content validity Index (CVI) = $\frac{\text{Relevant items by all judges as suitable}}{\text{Total number of items judged.}}$

Total number of items judged.

If the CVI is equal to or greater than the recommended 0.70 (Kent, 2001), this will imply that the questionnaire is valid for data collection.

Reliability of the questionnaire instrument is assessed using Cronbach's coefficient alpha (Mugenda and Mugenda, 2003). A pilot study is carried out on 10 respondents and the reliability results are computed using the Statistical Package for the Social Sciences (SPSS). The following formula is used to calculate the Cronbach's coefficient alpha

$$\alpha = \frac{k}{K-1} \left(\frac{1 - \sum SD_i^2}{\sum SD_t^2} \right)$$

Where α = coefficient alpha

$\sum SD_i^2$ = sum variance of items

$\sum SD_t^2$ = sum variance of scale

If the coefficient is equal to or above the recommended .70 (Amin, 2005), it implies that the questionnaire is suitable for data collection.

3.7.2 Validity and reliability of qualitative research

Validity: In qualitative research, the researcher's poor memory can affect the validity of the study. Therefore to avoid this problem as much as possible, the researcher is taking notes during the interviews. Directly after the interviews the researcher is compile data from interviews and transform it into precious information. The researcher is also presenting her results for the respondents to see if she has interpreted their answers correctly. Furthermore, the validity of the result is discussed with the researcher's supervisor with valuable feedback.

Reliability: This will be measured by conducting the study again in order to see if the same results are obtained. Because of the lack of time, the researcher might not have a possibility of conduct the study more than once. Therefore it is likely to be difficult to draw any conclusions on the reliability of this study.

3.8 Data analysis

Data analysis is the process of transforming raw data into usable information, often presented in the form of a published analytical article, in order to add value to the statistical output (Amin, 2005). Two types of analyses are conducted and these included quantitative and qualitative analyses. The following subsections explain the analyses in detail.

3.10 Anticipated limitations of the study

Inadequate finances. The researcher is likely to face a challenge of lacking enough funds to meet the transport costs, printing, binding and facilitation which need a large sum of money to be satisfied.

The researcher is also likely to face the challenge of meeting the reactant respondents who may be tough when consulted for information and this affects the accuracy of the data to be collected

In most cases the researcher is likely to fail to gather information from the respondents since at time they are not cooperating at all. They will usually lack interest because they find no justifications in giving out the information they think that it will be misused by the researcher.

The other challenge will be on designing a questionnaire that will attract respondents to give in their information.

CHAPTER FOUR

DATA PRESENTATION, INTERPRETATION AND DISCUSSION

4.0 Introduction

This chapter presents and discusses the results of analysis that has been done to look at the specific objectives of the study and in relation to the reviewed literature with the help of tables. The study was carried out using interviews with selected HIV patients receiving treatment from the ART Clinic in MGH and key informants who are the medical doctors from the ART clinic that offer palliative care to these HIV patients.

4.1 Findings on demographic characteristics of respondents

This section presents the general background information about the respondents who are HIV patients receiving treatment from the ART Clinic in Mukono General Hospital (MGH) in relation to their gender, age, level of education and marital status as shown in the table below;

Table 1: Background Information about the respondents

| Item | Description | Frequency | Percentage (%) |
|--------------------|--------------------|------------------|-----------------------|
| Gender | Male | 19 | 43.2 |
| | Female | 25 | 56.8 |
| | Total | 44 | 100.0 |
| Age bracket | 21-30 years | 15 | 34.1 |
| | 31-40 years | 18 | 40.9 |
| | 41-50 years | 11 | 25.0 |
| | Total | 44 | 100.0 |
| Level of education | Primary | 10 | 22.7 |
| | Secondary | 14 | 31.8 |
| | Tertiary | 20 | 45.5 |
| | Total | 44 | 100.0 |
| Marital status | Single | 24 | 54.5 |
| | Married | 20 | 45.5 |
| | Total | 44 | 100.0 |

Source: *Primary data 2024*

According to table 1 above, it is observed that the majority of the respondents are female represented by 56.8%, whereas male respondents made up the minority represented by 43.2%. This indicates that more females than males are receiving treatment at the ART Clinic in Mukono General Hospital.

In terms of age distribution, most respondents fall within the 31-40years age bracket, represented by 40.9%. This is followed by the 21-30years age group, which makes up 34.1%. The 41-50years age group constitutes 25.0%, making it the smallest proportion of the age groups surveyed. These findings suggest that the majority of the HIV patients at the ART Clinic are in the middle-age categories of 31-40 and 21-30 years.

Regarding education levels, the largest percentage of respondents, 45.5%, have attained tertiary education. Those with secondary education make up 31.8%, while 22.7% have a primary level of

education. These results suggest that the majority of respondents have relatively higher levels of education, with a significant portion having completed tertiary education.

Lastly, in terms of marital status, a higher percentage of the respondents are single, making up 54.5% of the total sample size, while the married respondents constitute 45.5% of the total sample size. This indicates that single individuals represent the majority of HIV patients receiving treatment at the ART Clinic in Mukono General Hospital.

4.2 The current availability and accessibility of palliative care services for patients living with HIV in Mukono General Hospital

Table 2: Palliative care services accessed at Mukono General Hospital

| Palliative care services | Frequency | Percent (%) |
|-------------------------------------|------------------|--------------------|
| Pain management and symptom control | 12 | 27.3 |
| Counseling and emotional support | 10 | 22.7 |
| Nutritional support | 8 | 18.2 |
| Home-based care visits | 6 | 13.6 |
| Medication adherence support | 5 | 11.4 |
| Social and community support | 3 | 6.8 |
| Total | 44 | 100.0 |

Source: *Primary data 2024*

From the interviews conducted with the selected HIV patients receiving treatment from the ART Clinic in MGH and key informants who are the medical doctors from the ART clinic that offer palliative care to these HIV patients, they were asked to describe the palliative care services accessed by HIV patients at Mukono General Hospital and their responses were as follows;

Pain management and symptom control: The largest group of respondents represented by 27.3% reported that they primarily accessed pain management and symptom control services at Mukono General Hospital. Many patients emphasized that the hospital provided medication and treatments to help manage their HIV-related symptoms, particularly pain associated with their condition. These services were seen as critical for maintaining their quality of life, allowing them to manage pain effectively while undergoing antiretroviral therapy (ART).

Counseling and emotional support: Counseling and emotional support was the second most common service, with 22.7% of respondents mentioning it. Patients noted that they received regular psychological counseling from healthcare providers at the ART clinic. This counseling was critical for dealing with the emotional and mental challenges of living with HIV, reducing feelings of isolation, and helping them cope with stigma from the community.

Nutritional support: Nutritional support services were mentioned by 18.2% of respondents. These patients described receiving guidance on proper nutrition to maintain a healthy immune system while on ART. In some cases, the hospital provided food supplements to those with severe nutritional deficiencies, which they found helpful in managing their overall health.

Home-based care visits: Home-based care visits were highlighted by 13.6% of respondents. They appreciated that healthcare workers would occasionally visit their homes to check on their progress, especially when they were too ill to visit the hospital. These visits provided both medical care and moral support, which they felt was an essential part of the palliative care service.

Medication adherence support: 11.4% of respondents emphasized the importance of medication adherence support provided by the clinic. Patients explained that healthcare providers regularly followed up with them to ensure that they were adhering to their ART regimen, which helped to improve their treatment outcomes and maintain viral suppression.

Social and community support: The smallest proportion of respondents represented by 6.8% mentioned accessing social and community support services. They noted that the clinic occasionally facilitated connections with local community organizations that could provide additional assistance, such as financial support or social services, to help them manage their condition and social challenges. Some of the selected respondent was asked how the palliative care services help him to manage symptoms and side effects related to HIV and this was his response,

*“.....The hospital provides me with pain killers which help me a lot in managing the joint pain and headaches I get from time to time. Without this, I wouldn't be able to manage my daily activities.....”***Respondent 1**

*“.....I provide regular counseling sessions to help patients cope with the psychological and emotional challenges of living with HIV. Many patients find this support invaluable.....”***Medical personal**

Table 3: Ease of access to palliative care services at Mukono General Hospital

| Ease of access to palliative care services | Frequency | Percent (%) |
|---|------------------|--------------------|
| Easily accessible | 18 | 40.9 |
| Somewhat accessible, but with challenges | 12 | 27.3 |
| Difficult to access | 9 | 20.5 |
| Very difficult to access | 5 | 11.3 |
| Total | 44 | 100.0 |

Source:*Primary data 2024*

From the interviews conducted with the selected HIV patients receiving treatment from the ART Clinic in MGH and key informants who are the medical doctors from the ART clinic that offer

palliative care to these HIV patients, they were asked to give their views on the ease or difficulty in accessing these palliative care services when these HIV patients need them and their responses were as follows;

Easily accessible: The largest proportion of respondents represented by 40.9%, reported that palliative care services at Mukono General Hospital are easily accessible. These patients explained that they have been able to receive timely care, with minimal delays, and they found the system relatively smooth and supportive. Most of them highlighted that the hospital's appointment system works efficiently, and the healthcare providers are prompt and attentive in addressing their needs.

Somewhat accessible, but with challenges: The second most common response, from 27.3% of respondents, was that the services are somewhat accessible but come with challenges. These challenges primarily included occasional long waiting times, issues with scheduling, and availability of key resources. Although they could access the services, the journey was sometimes frustrating due to systemic inefficiencies.

Difficult to access: About 20.5% of respondents reported finding it difficult to access palliative care services at MGH. These individuals noted that transportation costs, long distances, and overcrowded facilities created significant barriers to accessing care. In particular, rural-based patients mentioned traveling long distances only to face extended waits upon arrival. For them, accessing services involved additional financial and logistical burdens.

Very difficult to access: A small percentage, 11.3%, indicated that it is very difficult for them to access the palliative care services. These respondents described their experience as frustrating due to the combination of financial limitations, overcrowded services, and inconsistent communication between staff and patients. For them, accessing the necessary care was a significant challenge and often led to missed appointments or delays in treatment. Some of the selected respondent reported that,

“.....I live quite far from the hospital, but I still try to make it here when I can. The services are good, but the distance and waiting times are a challenge.....” **Respondent 2**

“.....*We as service providers try to make services as accessible as possible, but we know that there are times when the system is overstretched, and patients may face delays.....*”

Medical personal

4.3 How these palliative care services that are available and accessible in Mukono General Hospital have been effective in improving the lives of people living with HIV

Table 4: Impact of palliative care on well-being and quality of life

| Impact of palliative care | Frequency | Percent (%) |
|---|------------------|--------------------|
| Improved physical health and reduced pain | 20 | 45.5 |
| Enhanced emotional and mental well-being | 12 | 27.3 |
| Increased ability to manage daily activities | 8 | 18.2 |
| Better understanding of treatment and self-care | 4 | 9.1 |
| Total | 44 | 100.0 |

Source: *Primary data 2024*

From the interviews conducted with the selected HIV patients receiving treatment from the ART Clinic in MGH and key informants who are the medical doctors from the ART clinic that offer palliative care to these HIV patients, they were asked for their views on how the palliative care services received have impacted their overall well-being and quality of life and their responses were as follows;

Improved physical health and reduced pain: A significant number of respondents represented by 45.5% reported that palliative care services have greatly improved their physical health by helping them manage pain more effectively. Patients described the relief they experienced through pain management therapies and medications provided at the clinic. The timely administration of these treatments has allowed them to live with less discomfort and improve their ability to carry out daily tasks.

Enhanced emotional and mental well-being: 27.3% of the respondents also highlighted how palliative care has contributed to their emotional and mental well-being. They noted the support

they received from counselors and healthcare providers, which helped them cope with the stress of living with HIV. Emotional support, especially from regular counseling sessions, was a key factor in improving their mental health, giving them hope and a more positive outlook on life.

Increased ability to manage daily activities: 18.2% of the respondents pointed out that the palliative care services have enhanced their ability to manage daily activities by improving their overall physical stamina and emotional resilience. This has allowed them to engage more in their community, work, and family life. The ability to regain control of their routine activities has been a major source of satisfaction for these patients.

Better understanding of treatment and self-care: A few respondents represented by 9.1% mentioned that palliative care services have provided them with a better understanding of their treatment and how to care for themselves. Through educational sessions and personalized guidance, patients have learned about managing their condition, which has empowered them to take an active role in their healthcare decisions. Some of the selected respondents reported that,

“.....Before I started receiving care, I was in constant pain. The medication has really helped me reduce the pain, and I can now sleep better.....” **Respondent 3**

“.....The treatment has really made a difference in my ability to cope with the emotional challenges. The counseling and support makes me feel much better.....” **Respondent 4**

“....I focus on holistic care, not just physical but also emotional support, which has helped many of our patients improve their overall quality of life.....” **Medical personal**

Table 5: Managing HIV symptoms and side effects

| Managing HIV symptoms and side effects | Frequency | Percent (%) |
|---|------------------|--------------------|
| Alleviated physical pain and discomfort | 18 | 40.9 |
| Improved mental and emotional well-being | 12 | 27.3 |
| Provided guidance on managing medication side effects | 8 | 18.2 |
| Helped with adherence to medication and treatment plans | 6 | 13.6 |

| | | |
|--------------|-----------|--------------|
| Total | 44 | 100.0 |
|--------------|-----------|--------------|

Source: *Primary data 2024*

From the interviews conducted with the selected HIV patients receiving treatment from the ART Clinic in MGH and key informants who are the medical doctors from the ART clinic that offer palliative care to these HIV patients, they were asked for their views on the ways the palliative care services have helped HIV patients to manage symptoms and side effects related to HIV and their responses were as follows;

Alleviated physical pain and discomfort: The majority of the respondents, 40.9%, reported that palliative care services significantly helped in managing physical pain and discomfort caused by HIV symptoms and treatment side effects. Many patients noted that the pain management techniques, including access to appropriate pain relief medication and regular check-ups, made it easier for them to go about their daily lives. For instance, one patient mentioned that before accessing palliative care, they had difficulty moving and performing daily tasks, but after receiving consistent care, their pain has reduced, improving their mobility.

Improved mental and emotional well-being: A significant number of respondents, 27.3%, highlighted the role of palliative care in improving their mental and emotional well-being. The services provided, such as counseling and emotional support helped them cope with the psychological stress associated with living with HIV. Many patients appreciated the compassionate care and counseling that addressed their fears and anxieties about their condition, allowing them to better manage their emotional health.

Guidance on managing medication side effects: About 18.2% of respondents stated that palliative care services offered them valuable advice on how to deal with the side effects of antiretroviral drugs. This guidance ranged from adjusting medication schedules to reduce nausea, to lifestyle changes that minimized dizziness and fatigue. Patients who were initially struggling with the side effects expressed that this professional support made the treatment journey much more bearable.

Helped with adherence to medication and treatment plans; A smaller portion of respondents, 13.6%, emphasized that palliative care had been instrumental in ensuring that they adhered to

their medication and treatment plans. Regular check-ups, reminders, and support from the healthcare staff motivated them to stick to their treatment routines, which improved their overall health outcomes. Some of the selected respondents reported that,

“.....I used to feel tired and weak after taking my medication, but the doctors guided me on how to maintain my diet, and now I feel better.....” **Respondent 5**

“.....The follow-up and support I get from the staff has kept me going with my medication. It’s one of the reasons I’m still strong today.....” **Respondent 6**

“.....Our focus is on ensuring that patients are not only physically comfortable but emotionally supported throughout their treatment. We work closely with them to address all aspects of their care.....” **Medical personal 3**

4.4 Barriers and facilitators to the effectiveness of palliative care for patients living with HIV in Mukono General Hospital

Table 6: Barriers to effective palliative care

| Barriers to effective palliative care | Frequency | Percent (%) |
|--|------------------|--------------------|
| Limited availability of medications | 14 | 31.8 |
| Inadequate follow-up and monitoring | 10 | 22.7 |
| Stigma and discrimination | 8 | 18.2 |
| Insufficient patient education | 6 | 13.6 |
| Financial constraints | 4 | 9.1 |
| Poor communication with healthcare providers | 2 | 4.5 |
| Total | 44 | 100.0 |

Source: *Primary data 2024*

From the interviews conducted with the selected HIV patients receiving treatment from the ART Clinic in MGH and key informants who are the medical doctors from the ART clinic that offer

palliative care to these HIV patients, they were asked for their views on the barriers they have encountered that hinder the effectiveness of the palliative care they receive and their responses were as follows;

Limited availability of medications: From the findings, 31.8% of the respondents reported that a significant barrier to effective palliative care was the limited availability of essential medications. Patients frequently mentioned that certain critical drugs were either not in stock or were difficult to obtain, impacting their ability to manage symptoms effectively.

Inadequate follow-up and monitoring: The findings also revealed that 22.7% revealed that another common barrier identified was inadequate follow-up and monitoring. Patients expressed frustration over the lack of regular check-ups and ongoing assessments, which they felt were necessary for adjusting treatment plans and ensuring comprehensive care.

Stigma and discrimination: The findings established that 18.2% established that stigma and discrimination related to HIV were significant barriers cited by both patients and doctors. Patients often felt judged or marginalized which not only impacted their mental well-being but also affected their willingness to seek care consistently.

Insufficient patient education: The findings pointed out that 13.6% of the respondents noted that a lack of adequate patient education hindered their ability to manage their condition effectively. Patients reported that they did not receive enough information about their illness or how to handle side effects, affecting their self-management.

Financial constraints: The findings revealed that 9.1% of the respondents revealed that financial issues are barriers, with some patients struggling to afford additional treatments or supportive care services. This financial strain often led to skipped appointments or the inability to purchase necessary items.

Poor communication with healthcare providers: A few patients represented by 4.5% mentioned difficulties with communication, including not feeling heard or understood by healthcare providers. This issue often led to misunderstandings and dissatisfaction with the care received. Some of the selected respondents reported that,

“.....Sometimes, the medicines I need aren't available at the clinic. This makes it really hard to control my pain and other symptoms.....” **Respondent 7**

“.....I feel like I am looked down on by some hospital staff because of my HIV status. This makes it hard to ask for help or even talk about my treatment.....” **Respondent 8**

“.....Improving communication skills among staff are an ongoing goal to ensure better patient-provider interactions.....” **Medical personal 4**

Table 7: Facilitators of effective palliative care

| Facilitators of effective palliative care | Frequency | Percent (%) |
|--|------------------|--------------------|
| Availability of specialized staff | 17 | 38.6 |
| Accessible medication and treatments | 14 | 31.8 |
| Supportive family and community | 8 | 18.2 |
| Effective communication with providers | 5 | 11.4 |
| Total | 44 | 100.0 |

Source:Primary data2024

From the interviews conducted with the selected HIV patients receiving treatment from the ART Clinic in MGH and key informants who are the medical doctors from the ART clinic that offer palliative care to these HIV patients, they were asked for their views on the factors or resources that have made it easier for patients to benefit from the palliative care services at the hospital and their responses were as follows;

Availability of specialized staff: The findings revealed that 38.6% of the patients and medical staff highlighted the presence of specialized healthcare professionals as a significant factor that enhances the effectiveness of palliative care. The availability of trained doctors, nurses, and counselors has been crucial in providing tailored support for symptom management and overall

care. Specialized staff offer expertise that improves the quality of care and ensures that patient needs are adequately addressed.

Accessible medication and treatments: Furthermore, 31.8% of the patients reported that easy access to necessary medications and treatments has been a key factor in benefiting from palliative care. The availability of essential drugs and timely treatment helps manage symptoms and side effects effectively. This accessibility reduces the stress of procurement and ensures continuity of care.

Supportive family and community: More so, 18.2% revealed that support from family and community members has been noted as a valuable resource for patients undergoing palliative care. Emotional and practical support from loved ones can alleviate some of the burdens associated with the disease and enhance the effectiveness of the care received.

Effective communication with providers: Finally, 11.4% of the respondents noted that effective communication between patients and healthcare providers is also seen as a facilitator. Clear, open lines of communication help ensure that patients understand their treatment plans, feel comfortable discussing their needs, and receive appropriate guidance and adjustments to their care. Some of the selected respondents reported that,

“.....The doctors and nurses here are very knowledgeable and always available when I need help. Their expertise in managing my condition has made a huge difference in my quality of life.....” Respondent 9

“.....My family and friends have been incredibly supportive, which helps me stay positive and follow through with my treatment plans more effectively.....” **Respondent 10**

“.....Clear communication is essential for effective palliative care. It allows us to address patients' concerns promptly and make necessary adjustments to their care plans.....”

Medical personal 5

Table 8: Suggestions for improving palliative care

| Suggestions for improving palliative care | Frequency | Percent (%) |
|--|------------------|--------------------|
| More accessible facilities | 12 | 27.3 |
| Enhanced staff training | 11 | 25.0 |
| Improved communication | 9 | 20.5 |
| Increased support services | 8 | 18.2 |
| Expanded patient education | 4 | 9.1 |
| Total | 44 | 100.0 |

Source:*Primary data2024*

From the interviews conducted with the selected HIV patients receiving treatment from the ART Clinic in MGH and key informants who are the medical doctors from the ART clinic that offer palliative care to these HIV patients, they were asked for their views on the changes or improvements they would suggest to enhance the effectiveness of palliative care for HIV patients here and their responses were as follows;

More accessible facilities: A common suggestion from respondents was the need for more accessible facilities. Patients and doctors alike expressed a desire for facilities that are easier to reach, particularly for those with mobility issues or who live far from the hospital. The

availability of transportation services or more conveniently located clinics could significantly ease access to care.

Enhanced staff training: Respondents suggested that enhanced training for staff could improve the quality of palliative care. This includes not only medical training but also sensitivity training to better understand and address the unique needs of HIV patients.

Improved communication: Improved communication between patients and healthcare providers was another significant recommendation. Many respondents felt that clearer and more frequent communication about treatment options and care plans could help them feel more involved and informed.

Increased support services: Patients and doctors suggested increasing the availability of support services, such as counseling and social support. This could help address the emotional and psychological aspects of living with HIV.

Expanded patient education: Lastly, expanding patient education on managing HIV and understanding palliative care was recommended. Better education could empower patients to manage their symptoms more effectively and make informed decisions about their care. Some of the selected respondents reported that,

“.....The facilities are sometimes hard to get to, especially when I'm feeling weak. It would be great if there were more accessible locations or transportation options.....”

Respondent 11

“.....I often feel like I'm not fully informed about my treatment options. Better communication would help me feel more inadjusting my care.....” **Respondents12**

“.....Providing comprehensive education to patients can help them make better decisions about their care and improve their overall quality of life.....” **Medical personal 6**

CHAPTER FIVE

SUMMARY OF FINDINGS, CONCLUSION AND RECOMMENDATIONS

5.0 Introduction

This chapter includes the discussion of findings in relation to the literature. It also summarizes all findings reported in chapter four according to questions of the study, draws conclusions, suggests recommendations and also proposes some areas for further study.

5.1 Summary of findings

The findings revealed that at Mukono General Hospital, palliative care services are perceived as accessible to varying degrees by HIV patients and healthcare providers. The most commonly accessed services include pain management and symptom control (27.3%), followed by counseling and emotional support (22.7%). Nutritional support (18.2%) and home-based care visits (13.6%) also play significant roles, while medication adherence support (11.4%) and social and community support (6.8%) are less frequently mentioned. Access to these services is generally reported as easy by 40.9% of respondents, though 27.3% find it somewhat accessible but challenging due to issues like long waiting times and scheduling difficulties. Challenges such as transportation costs and overcrowding make access difficult for 20.5%, with 11.3% finding it very difficult due to financial constraints and inadequate communication.

Furthermore, the study revealed that palliative care services at Mukono General Hospital have significantly enhanced the lives of HIV patients, with 45.5% reporting improved physical health and reduced pain due to effective pain management and symptom control. Emotional and mental well-being has been notably improved for 27.3% of respondents, thanks to counseling and emotional support. Additionally, 18.2% have experienced an increased ability to manage daily

activities, attributing this to improved physical stamina and resilience. A smaller group, 9.1%, noted a better understanding of their treatment and self-care. Furthermore, palliative care has effectively managed HIV symptoms and side effects, with 40.9% benefiting from alleviated physical pain, 27.3% from enhanced mental well-being, 18.2% from guidance on medication side effects, and 13.6% from support with medication adherence.

Lastly, the study findings revealed that there are several barriers to effective palliative care for HIV patients at Mukono General Hospital which include limited medication availability (31.8%), inadequate follow-up and monitoring (22.7%), stigma and discrimination (18.2%), insufficient patient education (13.6%), financial constraints (9.1%), and poor communication with healthcare providers (4.5%). Facilitators of effective care are the presence of specialized staff (38.6%), accessible medications and treatments (31.8%), supportive family and community (18.2%), and effective communication with providers (11.4%). Suggestions for improvement include increasing facility accessibility (27.3%), enhancing staff training (25.0%), improving communication (20.5%), expanding support services (18.2%), and increasing patient education (9.1%).

5.2 Conclusions

The study concludes that palliative care services at Mukono General Hospital are accessible to varying degrees for HIV patients. Key services such as pain management and symptom control, counseling and emotional support, and nutritional support are integral to patient care. Despite the generally positive perception of accessibility, challenges such as transportation costs, overcrowding, and financial constraints affect the ease with which patients access these services. For a portion of patients, these barriers contribute to significant difficulties in obtaining the necessary care.

Furthermore, the study concludes that palliative care at Mukono General Hospital has had a notable positive impact on the lives of HIV patients. The services provided have significantly improved patients' physical health, reduced pain, and enhanced their emotional well-being. Improvements in daily functioning and understanding of treatment are also reported, demonstrating that the palliative care approach effectively addresses both the physical and emotional challenges faced by patients. Additionally, effective management of HIV symptoms and side effects through these services has contributed to overall better health outcomes.

However, the study identifies several barriers to the effectiveness of palliative care, including limited medication availability, inadequate follow-up, stigma, and insufficient patient education. Addressing these barriers is crucial for enhancing the quality of care. Facilitators such as specialized staff and accessible treatments contribute positively, but further improvements are needed. Recommendations include increasing facility accessibility, enhancing staff training, improving communication, expanding support services, and providing more comprehensive patient education to optimize the effectiveness of palliative care services.

5.3 Recommendations

Based on the findings of the study, the following recommendations have been found necessary concerning the effectiveness of palliative care for patients living with HIV in Mukono General Hospital;

The study recommends the need to address the barriers to medication availability at Mukono General Hospital. Ensuring that essential medications are consistently in stock and accessible is crucial for effective palliative care. The hospital should explore strategies to improve the supply chain, collaborate with pharmaceutical suppliers, and establish protocols to manage medication shortages to ensure that patients receive timely and adequate treatment for their symptoms.

The study also recommends the need to enhance follow-up and monitoring procedures for HIV patients receiving palliative care. Regular and comprehensive follow-up is essential for adjusting treatment plans and providing ongoing support. The hospital should implement structured follow-up schedules, increase the frequency of patient assessments, and utilize electronic health records to track patient progress and ensure consistent care delivery.

Furthermore, the study recommends the need to tackle stigma and discrimination associated with HIV. Addressing these social barriers is vital for improving patient outcomes and encouraging consistent care-seeking behavior. The hospital should implement sensitivity training for staff, foster a more inclusive environment, and engage in community education to reduce stigma and create a supportive atmosphere for patients.

In addition, the study recommends the need to expand patient education on managing HIV and palliative care. Providing patients with comprehensive, accessible information about their condition, treatment options, and self-care strategies can empower them to take an active role in

their health management. The hospital should develop educational materials, conduct workshops, and offer one-on-one counseling to improve patient understanding and self-management capabilities.

Lastly, the study recommends the need to increase accessibility to palliative care facilities. Enhancing the convenience of accessing care can reduce patient barriers and improve overall service utilization. The hospital should consider expanding its facilities, improving transportation options for patients, and establishing satellite clinics to reach those who face challenges in accessing care due to distance or mobility issues.

5.4 Areas for further research

Since this study aimed at examining the effectiveness of palliative care for patients living with HIV in Mukono General Hospital, the study recommends that; similar study should be done on other areas concerning this topic and these areas of further research needed include the following:

Future research should focus on exploring the long-term outcomes of palliative care interventions for HIV patients at Mukono General Hospital, focusing on how sustained access to care affects overall quality of life and survival rates.

Additionally, further research should focus on investigating the impact of specific palliative care components, such as pain management and emotional support, on different demographic groups within the HIV patient population could provide insights into optimizing tailored care approaches.

Finally, further research should focus on examining the cost-effectiveness of various palliative care models and their potential for scaling up to improve accessibility and quality of care across similar healthcare settings would be valuable for policy development and resource allocation.

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Appendix

Interview Guide

For the HIV patients receiving treatment from the ART Clinic in Mukono General Hospital

Dear Respondent,

I am Kagwisagye Sabrina a bachelor's student of Social Work and Social Administration from Uganda Christian University-Mukono conducting a research on “the effectiveness of palliative care for patients living with HIV in Mukono General Hospital”. You have been selected to participate in this study because the contribution you make to your organization is central to the kind of information required. The information you provide is solely for academic purposes and will be treated with utmost confidentiality. Please kindly spare some few minutes to respond to the following questions.

Section A: Introductions

1. Tell me about yourself (*gender, age, level of education and marital status*)
2. How long have you been receiving palliative care from this hospital?

Section B: The current availability and accessibility of palliative care services for patients living with HIV in Mukono General Hospital

3. Can you describe the palliative care services you have accessed at Mukono General Hospital?

4. How easy or difficult is it for you to access these palliative care services when you need them?
5. Are there any specific challenges you face when trying to obtain palliative care services at the hospital?

Section C: How these palliative care services that are available and accessible in Mukono General Hospital have been effective in improving the lives of people living with HIV

6. How have the palliative care services you received impacted your overall well-being and quality of life?
7. In what ways have the palliative care services helped you manage symptoms and side effects related to HIV?
8. Can you share any specific examples of how palliative care has improved your daily living or health outcomes?

Section D: Barriers and facilitators to the effectiveness of palliative care for patients living with HIV in Mukono General Hospital

9. What barriers have you encountered that hinder the effectiveness of the palliative care you receive?
10. What factors or resources have made it easier for you to benefit from the palliative care services at the hospital?
11. What changes or improvements would you suggest to enhance the effectiveness of palliative care for HIV patients here?

Thank you for your cooperation

etter from the agency /university



UGANDA CHRISTIAN UNIVERSITY

A Centre of Excellence in the Heart of Africa

July 17th, 2024

ART Manager
PLZ receive the
beared & accord her
the necessary assistance in
her study research.

TO WHOM IT MAY CONCERN

Dear Sir/Madam

Re: INTRODUCTORY LETTER FOR RESEARCH



This is to introduce to you **KAGWISAGYE Sabrina** Registration number **J22B15 118**, a student of Uganda Christian University, pursuing Bachelor's degree in Social Work. She is expected to carry out research in the final year under the guidance of a university supervisor in partial fulfillment for the requirements of the above mentioned award.

Topic: **Effectiveness of Palliative Care for Patients Living with HIV in Mukono General Hospital."**

The purpose of this communication is to request your office to allow her collect data from your organization. Any assistance rendered to her will be highly appreciated.



Doreen Kukugiza
Coordinator, Research & Fieldwork Programmes
Tel: 0773395349
Email: dkukugiza@ucu.ac.ug

Work plan

Appendix I: Work plan

| | | 2024 | | | | | | | |
|--|---------------------------|------|-----|-----|-----|-----|-----|------|-----|
| Task | Person in charge | JAN | FEB | MAR | APR | MAY | JUN | JULY | AUG |
| Formulating the problem | Researcher and supervisor | | | | | | | | |
| Selection of the sample | Researcher | | | | | | | | |
| Formulating the collection instruments | Researcher | | | | | | | | |
| Writing the report and handing it in | Researcher and supervisor | | | | | | | | |
| Data collection | Researcher | | | | | | | | |
| Analysis of the data | Researcher | | | | | | | | |
| Writing of the research report | Researcher | | | | | | | | |
| Submission of the research report | Supervisor | | | | | | | | |