PERSPECTIVES OF PATIENTS AND INFORMAL CAREGIVERS ON CANCER PALLIATIVE CARE AT HOSPICE AFRICA UGANDA

A POSTGRADUATE DISSERTATION

PRESENTED TO

THE FACULTY OF HEALTH SCIENCES
IN PARTIAL FULFILLMENT OF THE REQUIREMENT FOR
THE AWARD OF A DEGREE
MASTERS OF PUBLIC HEALTH–HEALTH PROMOTION

UGANDA MARTYRS UNIVERSITY

NKULANGA ALEX

2014 – M282 – 20023

OCTOBER, 2016

DEDICATION

To all my participants the Cancer patients who endure living with cancer but do not give up hope until the end of life and their Caregivers who dedicate their lives to the care of their loved one either on full time or part time basis.You truly bring out the meaning of life that is keeping up the Hope and transforming lives of others for the best. Your commitment is an inspiration for me to always focus on what I can do for others.

I also dedicate this research to my mother Mrs. Valerie Mugisha Kalimba and Mrs. Jocelyn Rugunda; thank you for bearing and supporting this my vision. I appreciate all your patience with me in pursuit of my dream.

ACKNOWLEDGEMENT

I thank the Almighty God for giving me the courage and grace to do this study and granting me good health throughout this course. Indeed grace has much more abound in me through it all.

I would like to appreciate and acknowledge my Supervisor Dr. Everd Maniple B. who always went out of his way to guide me and respond to my emails in perfect time. For the positive criticism I am grateful and thank God for placing you in the right place at the right time.

I appreciate my classmates of Masters of Public Health-Health Promotion for the drive to perform, encouragement and team spirit. Special thanks to the patients of HAU and their informal caregivers, who provided me with both primary and secondary data without any reservations.

I am also truly grateful to Hospice Africa Uganda Ethics and Research Committee (HAUREC) and all the staff of Hospice Africa Uganda especially within the Institute of Hospice and Palliative Care in Africa (IHPCA): Harriet Nakiganda, Dr. Margaret Tumwebaze, Dr. Olet Adong Dorothy and Sylvia Dive; from the Clinical department: Loyda J Twino, Nurse Roselight, Nurse Sarah and Dr. Stephen Luboyera and finally Milly Nabakooza (CEO) and Grace Nayiga (HR) from the Administration department.

I would also like to express my sincere gratitude to my mother and siblings for their patience and support. I acknowledge the unwavering support and encouragement of Rt. Hon. PM Dr. Ruhakana Rugunda and Mrs. Jocelyn Rugunda, I am forever indebted to you. Thank you for guiding and believing in me throughout this journey.

God richly bless you all!

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LIST OF ABBREVIATIONS AND ACRONYMS

PC	Palliative Care
CA	Cancer
HC	Health Centre
EOL	End of life
HBC	Home Based Care
HAU	Hospice Africa Uganda
UCI	Uganda Cancer Institute
WCRF	World Cancer Relief Fund
WPCA	World Palliative Care Association
HIV/AIDS	Human Immune Deficiency Syndrome
AHSPR	Annual Health Sector Performance Report
PCMHP	Palliative Care Manual for Health Professionals
UPCRH	Uganda Parliamentary Committee Report on Health

OPERATIONAL DEFINITION OF KEY TERMS

The following are the existing definitions of key components basing on various literature of the palliative care specialty.

- **Palliative Care** is the active total care of patients whose disease is not responsive to curative treatment but focus is majorly on control of pain of other symptoms, of psychological, social and spiritual problems.
- **Hospice care** is end-of-life care provided by health professionals and volunteers to help people who are dying have peace, comfort and dignity by giving them medical, psychological and spiritual support.
- **End of Life** refers to preparations for patients' death by all family members and medical personnel.
- **Cancer** is an abnormal growth of cells in one or several body tissues which tend to proliferate (grow) in an uncontrolled way and, in some cases, to metastasize (spread) to other parts of the body.
- **Informal Caregivers** within the context of palliative care are any relative, friend, or partner who has a significant relationship and provides assistance (physical, social, or psychological) to a person with a life threatening incurable illness.
- **Patients** are those individuals (in the context of palliative care) who are diagnosed with a life threatening illness that is incurable.
- **Phenomenology is** the study of events that have occurred in the lives of individuals.
- **Perspectives** refer to the way of seeing things or an understanding of the importance of something.

ABSTRACT

Introduction: The purpose of the study was to examine the phenomenon of cancer palliative care as perceived by patients and informal caregivers who are receiving palliative care at Hospice Africa Uganda. The study shows the views, contentment and expectations of patients and caregivers about the nature of support received in cancer palliative care at HAU. The broad objective of the study was to examine the perspectives of cancer patients and their family caregivers on cancer palliative care so as to improve the delivery of palliative care services offered by HAU. Whereas the specific objectives of the study were: To identify the nature of palliative care support given to patients and their family caregivers; to examine patients and family caregivers' perceptions of palliative care received and to find out whether the mechanisms in place enabled effective feedback from the clients about care received at HAU.

Methodology: A descriptive a phenomenological approach of qualitative data collection was used. Purposive sampling method was used in identification of participants and thereafter in-depth interview were used to collect data by use of an interview guide. Data were collected using an audio recorder and later transcribed. Data analysis was through thematic analysis. Four themes and fifteen sub-themes emerged through data categorization.

Results: The views of caregivers were quite divergent from those of patients experiencing the pain which implies that there is no clear understanding of the care package to the patients and caregivers. Nevertheless, it was recognized that HAU gives medical, financial and food support to patients. However, the financial support at HAU differed from that given by branches of HAU in rural areas like Hoima. The financial support given was found not to be adequate and access to this support was inequitable among cancer and HIV/AIDS patients. It was also found out that palliative care has improved quality and prolonged life of patients. More so, caregivers' anxieties were significantly reduced when their patients started receiving palliative care. However, much as that was the case; there were concerns by some participants that professional caregivers withhold information regarding patients care to both patients and caregivers. The mechanisms of feedback at HAU had gaps and were somehow half hazard implying that the patients were suffering silently because there was no clear feedback mechanisms a negative impact on the quality of care provided.

Conclusion: By listening to the views of patients and caregivers about the nature of support it would help the agency to be relieved of giving what may not be fully required by the patients or what is inadequate because being palliative the patients and caregivers would be able to have a say because a good support should originate from the views of patients. Given the views of the patients and family caregivers therefore, one would conclude that by spreading the support the organization would have better made a more holistic support by emphasizing this to the satisfaction of the patients and their caregiver in line with their views.

Recommendation: I recommend that HAU administration streamlines its operations to include patients and caregivers views for purposes of management of the nature of support efficiently. There may also be dynamic staff interactions with clients, to enable detailed discussions on the care package so as to get a mediated sense of service to the patients and ensure equity in provision of support. Integration of patients and caregivers in Palliative Care at all levels to understand their views would be of advantage to HAU in enabling effective feedback mechanisms.

CHAPTER ONE

GENERAL INTRODUCTION

1.0 Introduction

The researcher's intention was to study the perspectives of patients and caregivers on cancer palliative care received at Hospice Africa Uganda (HAU).This chapter presents the following sections in relation to the topic; background of the study, statement of the problem, major and objectives of the study, research questions, scope of the study, justification of the study, definition of terms and theoretical framework.

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual (WPCA, 2014). According to World Health Organisation, Palliative care can be defined in two categories that is for adults and for children.

Palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care. The care package offers a support system to help patient's live as actively as possible until death (improved quality of life) and offers a support system to help the family cope during the patient's illness. In regards to bereavement; a team approach is used to address the needs of patients and their families, including bereavement counselling (WPCA, 2014).

World Health Organisation defines palliative care for children as the active total care of the child's body, mind and spirit, and also involves giving support to the family. This care begins when the child is diagnosed and continues whether or not a child receives treatment directed at the disease. Therefore health providers must evaluate and alleviate a child’s physical, psychological, and social distress. Notably, effective palliative care requires a broad multidisciplinary approach that involves family, use of available community resources, can be provided in tertiary care facilities, in community health centres and in children’s homes (WPCA, 2014).

Palliative care is applicable early in the course of illness in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy. It includes those investigations needed to better understand and manage distressing clinical complications (WPCA, 2014).

Palliative care is not limited to any one care setting, but provided wherever a person’s care takes place, whether the patients’ own home, a care facility, hospice inpatient unit, hospital, or outpatient service (WPCA, 2014). The main focus of Palliative care is relief of suffering, psychosocial support and closure near the end of life. Therefore, as the disease progresses many patients opt for palliation as the paramount goal of care. Although, palliative care is often inadequate with pain and suffering often unrelieved and yet hospice care is often begun in the last weeks of life in some of the cases (Lo *et al*, 1999).

Hospice care is defined as end-of-life care provided by health professionals and volunteers through giving medical, psychological and spiritual support to help people who are dying to have peace, comfort and dignity. The dignity of patients can be achieved when caregivers try to control pain and other symptoms so that a person can remain as alert and comfortable as possible and also provide services like psychosocial support to a patient’s family (WPCA, 2014).

Palliative medicine is a holistic approach that must include pain and symptom control as well as care for the psychosocial, spiritual and cultural needs of the patient and family. This approach ought to be sensitive to cultural and religious beliefs of the patients so as to be acceptable by all communities (Merriman, 2010). Culture as a whole needs to look at dying not as a medical problem but as a natural part of life that can be meaningful and peaceful. Our lives can be enhanced by knowing that one day we will die and this influences choices at the end of life (Puchalski, 2002).

In Uganda, there are cultural rituals surrounding death and into bereavement to ensure support for the bereaved family for a fixed time. Uganda's multi-tribal society therefore implies that the cultural rituals vary from culture to culture due to the diversity within the multi-cultural society. Bereavement care is support given to people grieving the possible or actual loss of their loved ones. This component of palliative care involves giving psychological, emotional and practical support to people experiencing feelings of loss or grief after losing their loved ones (Merriman, 2010).

Bereavement services in palliative care offer the foundation for determining the types of bereavement services and support offered to caregivers and families, depending on their needs and risk factors. Notably, professional support to all bereaved people is unlikely to be effective and can be counter-productive. Therefore, unnecessary intervention may disrupt the natural course of grieving and the presence of interventions could trigger a loss of social support if friends and family withdraw from the bereaved as a result of their receipt of professional services depending on the cultural settings of the bereaved family (Aoun *et al*, 2012).

The National Institute for Clinical Excellence (NICE) in the United Kingdom proposed a similar three-tiered approach to bereavement in palliative care according to the needs of caregivers and families, which is based on cancer or expected deaths. The model advocates that all the bereaved people should have access to information about bereavement and relevant available supports.

This information ought to be delivered by the palliative care service involved in the care of the patient and family, with much of the support coming from the bereaved person's social networks, including compassionate family and friends (Aoun *et al*, 2012).

Families experiencing the loss of a loved one can also be supported by bereavement mutual-help groups, faith-based and other community groups. While a smaller proportion between 10 to 12 % may need specialist intervention such as counselling, mental health services, bereavement services or psychotherapy to supplement or because these levels of support are not available to them (Aoun *et al*, 2012).

The non-communicable diseases that require palliative care differ between adults and children and account for 66% of deaths worldwide. These include the following; Alzheimer's, dementia, cancer, cardiovascular diseases, cirrhosis of the liver, chronic obstructive pulmonary diseases, diabetes, HIV/AIDS, kidney failure, drug-resistant tuberculosis(TB), rheumatoid arthritis, blood and immune disorders, meningitis, neonatal conditions and congenital anomalies (WHO, 2011).

According to the World Palliative Care Association the estimated number of adults in need of palliative care at end of life is over 19 million. The majority of these are older adults and predominantly male while 6% of people in need of Palliative care are children. The diseases requiring Palliative care at the end of life were categorised into three groups namely; cancer, HIV/AIDS and progressive non-malignant diseases. Hence, the proportion of adults in need of Palliative care for cancer is relatively important for all regions and it ranges from 19.6% in the African Region and 41.5% Western Pacific Region (WPCA, 2014).

More so, a great majority (78%) of adults in need of PC at end of life belong to low and middle-income countries although the highest rates of adults in need of cancer palliative care are found in European and western Pacific Regions (WPCA, 2014). Patients diagnosed with cancer and their family caregivers experience shock and before long their lives are altered. Whereby, some family members decide to either adjust their work plans or completely decide to become full time caregivers to their loved ones and thereby help them to overcome the shock that comes with the diagnosis and also provide care throughout the illness until end of life.

Support given to cancer patients by their family caregivers helps them feel loved, accepted and cared for while caregivers report a sense of accomplishment in fulfilling the final wishes of the patient and a belief that they are able to give something back to the person for whom they are caring (Stajduhar, 2013).

Cancer is an abnormal growth of cells in one or several body tissues which tend to proliferate (grow) in an uncontrolled way and in some cases, to metastasize (spread) to other parts of the body. It is one of the leading causes of intractable death, associated with pain and emotional distress for both the patient and family or close caregivers. Additionally, cancer is a group of more than 100 different and distinctive diseases that affects different body tissues and organs. For example; breast cancer, colon cancer, skin cancer, leukemia, lymphoma, multiple myeloma, bone cancer and many more (Bancroft, 2011).

The incidence of cancer is high globally, with estimates of 14.1 million people affected. Of these 7.4 million cases were in men while 6.7 million cases were in women. Above all, this number was projected to increase to 24 million by 2035 (WCRF 2012). In Uganda, it is common practice for people not to go for routine screening or medical checkup therefore many seek medical attention when they are weakened by the illness. This is due to the fact that we do not have a universal health insurance policy in Uganda and hence a lack of financial support contributes to failures to seek medical care in time when the cancer can be treated and cured.

Notably, cultural beliefs also influence treatment of cancer patients and their caregivers who may end up attributing their illness to witchcraft. Hence, a vast amount of money is channeled in seeking traditional healer’s services. So that by the time they are diagnosed with cancer in its later stages and are referred for palliative care their resources are exhausted hence many patients and informal caregivers fail to access funds to facilitate movements intended to seek care hence most patients opt to stay in their home districts as the disease progresses while others endure the pain until death and a few of these patients are able to access palliative care.

In Africa today, less than 5% of cancer patients reach surgery or treatment services and its further estimated that up to 50% of cancer and other patients also have AIDS. Therefore, in 1994 palliative Care was extended to HIV/AIDS following research into the control of pain and other symptoms. Most patients in Africa and beyond prefer to be at home when very ill and hence they are discharged to home care as soon as possible. In recent years, community volunteers have been referring patients who are in need from their villages, many of whom have never seen a health worker unlike before when patients where referred by hospitals (HAU, 2016).

Majority of people in developing countries do not access health services easily but they too can access palliative care through their trained community volunteer and referral systems within their community health services. However, although 74% of Districts have a palliative care service, palliative care is still not even reaching 10% of those in need (HAU, 2006).

According to the Uganda Cancer Institute Annual Report, a total of 60,000 cases are registered annually. The report further notes that the risk of cancer before the age of 75 is 17.8 per cent and predicted 80,000 cases by 2015. Notably, the Uganda Cancer Institute Handles 4 per cent of all cancer cases in Uganda because it is centrally located and difficult to access for the majority of the cancer patients in the country (UCI, 2010).

In 2012, the Uganda Cancer Institute was able to provide a range of services which included; 12,096 outpatients; 2,652 inpatients; 2,652 Physiotherapy patients and Medical social support to 14,748 patients. In addition, the institute also carried out: 69,156 Laboratory investigations and: 9,870 imaging investigations. Notably, the majority of these cases are diagnosed with cancer after it has progressed to later stages while a few cases are identified in time for treatment (AHSPR, 2013).

Evidence found suggests that patients do not receive the full benefit of palliative care services since health care professional perspectives like; attributes of respect, approachability, genuineness, empathy, connectedness, compassion, sensitivity, an ability to listen, good communication, provision of information, empowerment, and timeliness are often documented as priority. Notably, less focus is put on patients' perspectives of end-of-life care which are often limited to the state of disease like cancer than the care received (Ciemins *et al*, 2014).

Terminally ill patients are often referred to hospice and palliative care services late if at all. The same study further observed that only 11.5% of hospice patients utilized the full six month benefit. Thus, increased palliative care and hospice use is needed to help the millions of people who die each year without any end-of-life care services. Timely receipt of clear and consistent information regarding the patient's health status is essential to the decision to move from curative to comfort care. (Ciemins *et al*,2014).

Cancer family caregiving experience has unifying features endorsed by a broad spectrum of diverse caregivers. For some caregivers the experience is largely gratifying and positive, while for others it is stultifying if not crushing. This crushing experience could be due to the fact that caregivers are never prepared for the shock that comes with diagnosis of their loved ones with cancer and their perspectives may possibly never be considered through the care-giving process (Williams & Bakitas, 2012).

The development of home based palliative care services emphasizes the need and importance for caregivers to understand the nature of patient's illness, scope of service provision and their own role and competencies in palliation due to the fact that informal caregivers usually close family relatives frequently play a vital role in the provision of palliative care (Docherty *et al*, 2008).

The perspectives of patients need to be acknowledged and clearly understood in case reviews or multidisciplinary meetings by specialists in treatment discussion of the prognosis and treatment of patients due to the insight these views provide on the patient's feelings and effect of the care received (Taylor *et al*, 2014).

Perspectives of informal caregivers and professional caregivers on other diseases differ from those of formal or informal caregivers in such a way that health care professionals' (HCPs). Notably, perspectives on end-of life-care have been well-documented but less focus has been placed on patients' and families' perceptions and experiences. Focus on patients' perspectives has often been limited to specific disease states, for example, cancer, with emphasis on the illness itself, rather than the care received (Ciemins *et al*, 2014).

There is a great need for palliative care knowledge to be spread globally so that all people are knowledgeable about the different services under palliative care like training and sensitization of caregivers regarding routine screenings, which help identify cancer in time for curative care. The major reason for this study therefore was to highlight the importance of knowing the perspectives of patients and informal caregivers on cancer palliative care at HAU so as to better understand their experiences with the care received at the end of life, including barriers and facilitators to a positive experience.

Feedback from beneficiaries of palliative care who are patients and family caregivers may in turn provide health care professionals with insight into how to improve palliative care at HAU and in Africa by integrating or inclusion of these aspects into the palliative care package. The major focus of the study was on the various components of palliative care such as prolonging life, relieving pain, symptom control and finally psychosocial support of patients and their family caregivers.

1.1 Background of Study Area

This study was conducted at Hospice Africa Uganda, the first agency to introduce and provide Palliative care in Uganda. Hospice Africa Uganda (HAU) introduced Palliative Care in Uganda in September 1993 through the efforts of Dr. Anne Merriman with some of her colleagues in partnership with the Ministry of Health to provide medications for pain and symptom control. These included powdered morphine from which oral morphine is produced, which allowed patients to be free of pain, leading to a peaceful and more dignified death in the care of their families at home or any other setting according to patient’s preference (Merriman,2010).

Due to the gaps that existed in the Palliative care services in Africa, Hospice Africa Uganda was established and Uganda was chosen as the first model to offer service, education, research and promoting excellent but affordable clinical care appropriate to the cultures in Africa. Uganda therefore became the third country in sub-Saharan Africa to avail pain control services to cancer patients after Zimbabwe and Kenya. Freedom from pain is a basic human right and palliative care provides this freedom by use of morphine (Merriman, 2010).

The first Hospice in Uganda started in a two bed roomed house offered by the Sisters (Religious Nuns) in residential section of Nsambya Hospital between the nursing school and the hospital. Patients begun to come in, some referred by the Hospital and during that time palliative care was offered to all patients who came. In 1994, the constitution was written and a board was formed thereby leading to the formation and registration of Hospice Africa Uganda as a Non-Government Organization (NGO) in Uganda and was registered as a company limited by guarantee (Merriman, 2010).

Additionally, the Hospice was set up to be affordable, culturally acceptable and adaptable to other conditions in Africa. Thereby, emphasizing training as one of the ways of reaching that goal. In Uganda medical students of Makerere University were being trained in palliative care since 1993. The greater need for palliative care to reach all rural settings made it possible to start teaching medical students from Mbarara University of Science and Technology (MUST).Thus, leading to the birth of Mobile Hospice Mbarara in Southwestern Uganda and Little Hospice Hoima in Western Uganda (Merriman, 2010).

These centers were established hoping to target patients in low density areas but they currently act as models for Africa. Since the founding Hospice in Kampala is more of a center for excellence and training although, palliative care is still provided at the Kampala Hospice (Merriman, 2010). Notably, Hoima and Mbarara palliative care centers are unevenly distributed compared to different regions in Uganda and most importantly the great need for palliative care. Thus, implying that many people who require cancer care may have to travel to other regions to access Palliative care and spend a lot of resources in the process.

The term Palliative comes from a Latin word “pall” which means blanket or covering denoting the comfort given through palliative care. Dr. Balfour Mount recognized as the founder of palliative care used the word palliative in 1970’s in introducing this mode of care in Canada. Since Hospice was associated with a death house. In Africa, palliative care came in with the rise of the AIDS epidemic and although some countries have a rise in HIV/AIDS others are reducing.

Cancer is on a rise and is estimated at 10% by 2020 in Africa thus representing one million deaths a year from cancer (Merriman, 2010).

In 1994, palliative care was extended to HIV/AIDS patients following research indicating a great need to control pain and symptoms of the disease while other non-communicable diseases among hospice patient’s and others need specific palliative care since 50% do not reach health services or palliative care services are not yet available from their health providers (HAU factsheet, 2015).

Palliative care can be delivered to patients in various ways (models) and the factors that determine the appropriate model include; cost of service, national policy, available resources, and acceptance by local leaders, sustainability and availability of adequate palliative care support systems. The models include, facility based palliative care which involves delivery of care at health centers, hospitals, outpatient clinics and hospices thus ensuring appropriate health care and referral of patient from initial visit with thorough holistic assessment to diagnosis and treatments (PCMHP, 2008).

Home based care which involves delivery of a comprehensive package to the patient and the family at home. HBC includes pain and symptom management, psychosocial care, spiritual care and support in daily living activities. Another model is the Facility Outreach palliative care model is provided by specialist palliative care health professionals who travel from the health facilities to other centers to provide palliative care services closer to the community especially walk–in patients. Palliative care providers also plan road side clinics as a model of care by arranging stops overs at different locations like trading centers, schools or under a tree so as to meet with patients and family members (PCMHP, 2008).

Day care model is intended to give the patient’s time away from home every Tuesday to interact with other patients and health care givers in a community environment and also receive complementary therapies plus allowing family care givers to a break for a day as well, hence this model also targets the psychosocial aspects of both patients and informal caregivers (PCMHP, 2008).

Notably, the models of palliative care provided by Hospice Africa Uganda involves respecting the spiritual values of the patients regardless of their faith. It is vital to establish a strong and reliable communication base with family caregivers and equip them with basic skills of administering medication and knowledge of the right dosage and its purposes. Therefore, the study was carried out HAU because this agency is the pioneer in providing palliative care in Uganda and helped spread it in East and Central Africa through education services plus the fact that the agency serves a bigger number of patients.

1.2 Statement of the Problem

There is a shortage of hospice and other palliative care services in Uganda and as a result, most of the palliative care takes place at home in the hands of informal caregivers. However, the perspectives of informal caregivers on cancer palliative care and the support they receive from Hospice Africa Uganda are not known.

Being equipped with knowledge of the perspectives of patient’s and informal caregiver’s on Palliative care received at Hospice Africa Uganda would greatly contribute to improvement of the quality of care and address the needs of informal caregivers as well. Addressing informal or family caregivers needs in palliative care through provision of care and research would give feedback to the agency regarding the views of informal caregivers as well thereby contributing to their inclusion among concerns discussed in case review meetings.

There is need therefore, to explore palliative care services by understanding patients and family caregiver's perceptions so as to integrate their views into improving palliative care as a more comprehensive mode of care addressing needs of all individuals with chronic illnesses and their families. More so, the perceptions of patients ought to be acknowledged and clearly understood in multidisciplinary meetings by specialists in treatment discussion of the progress of disease and treatment of patients. Appropriate analysis of this vital information may be adopted into the body of knowledge in the palliative care specialty.

1.3 Research Question

- How do cancer patients and their caregivers perceive palliative care received at Hospice Africa Uganda?

1.4 Objectives of the Study

1.4.1 Major Objective of the Study

The main objective of this study was to examine the perspectives of cancer patients and their family care givers so as to improve the delivery of palliative care services offered by HAU.

1.4.2 Specific Objectives

- To identify the nature of palliative care support given to patients and their family caregivers at HAU.
- To examine patients and family care givers perceptions of palliative care they receive at HAU.
- To find out whether the mechanisms in place at the agency enabled effective feedback from the clients about the care received.

1.5 Scope of the Study

The researcher used Hospice Africa Uganda located in Makindye division in Kampala along Mobutu Road opposite the American Club as a case study. The major focus of the study was Palliative care to cancer patients and their informal caregivers hence all other patients who may be receiving palliative care like HIV patients without cancer were excluded. Notably, cancer patients with other co-morbidities (other diseases) were included while all non-cancer patients on palliative care were excluded.

The inclusion criterion for this study was only those cancer patients attending Hospice Africa Uganda and their selection was carried out at the agency. Patients staying in the community beyond the catchment area of Kampala were not tracked there. The study also included Informal caregivers who would come to the agency with the patients and were immediate family members of the patients such as relatives, spouse, and children. The study excluded professional caregivers like Palliative care nurses, clinicians, social workers and doctors at HAU who were not directly related to the patients apart from the professional care they provided to the patients.

1.6 Significance of the Study

With cancer cases on the rise in Uganda characterized by late diagnosis of most of these cases whereby only pain relief and symptom control can be provided. It is crucial that palliative care is available for all cancer patients and their families. This study therefore intended to strengthen awareness creation about palliative care in Uganda, adequate management of risk factors that expose people to cancer plus guiding policy formulation, implementation and review on control and treatment of chronic illnesses like cancer in Uganda.

Development partners, Government, Non-governmental organization (NGO's) may use findings from the study to improve planning, coordination and evaluation of projects and programs targeting cancer treatment and palliative care. The study greatly contribute to adequate utilization of palliative care service country wide and hence limit the inequitable access to this care specialty that is more of a human right for every human being not to die in pain. Ugandans will therefore be knowledgeable about the care and gradually reduce the high number of cancer patients who endure extreme pain without knowledge of or access to palliative care and thereby reducing the burden of disease on the government.

The study was intended to further contribute comprehensive knowledge for future researchers and academicians on palliative care model for chronic illnesses and greatly contribute to quality improvement due to the direct feedback from the beneficiaries of palliative care. Lastly the study was key to the fulfillment of requirements of the university.

Despite the several efforts globally to spread Palliative care to all people with chronic illnesses, there are still misconceptions about palliative care in many countries and Uganda in particular especially addressing the perceptions of patients and their family caregivers and integrating them in improvement of the palliative care model they receive.

The World Health Organization estimates that there are 0·5 million deaths per year from cancer in Africa, and that by 2020, 70% of new cancer cases will be in the developing world. Cancer rates in Africa are expected to grow by 400% over the next 50 years (Harding & Higginson, 2005). The general public does not have adequate knowledge about palliative care concepts. For example, only 34% of the general population knows about palliative care units in Japan, whereas the rate of knowledge in the United Kingdom is 70%. This indicates clearly a lack of health related information to many people even in developed countries (Hirai *et al*, 2011).

More so, 32% of the Japanese general public believes that palliative care units are places where patients simply wait for death, and these misperceptions are decreased after individuals actually use a specialized palliative care service. Thus, the lack of knowledge and general misperceptions regarding palliative care are considerable barriers to palliative care and appropriate pain control, and hence further education of the general public would be of great value (Hirai *et al*, 2011).

The study will therefore provide more knowledge about palliative care services in Uganda and be a form of feedback to professional caregivers thereby helping to improve this palliative care provided to people with chronic illnesses. Furthermore, it was anticipated that the results generated will guide the review of policies in the Ugandan health and education system and enlighten future researchers on palliative care given the rising concerns and numbers of people with chronic illnesses in developing countries like Uganda.

1.8 Theoretical framework

Theoretical framework is an analysis of the relationship between different theories that may inform and influence my idea of the research study. There are a number of theories which match well with the study like the grounded theory in which a researcher derives a general abstract of theory of a process, action or interaction grounded in views of participants but may not be suitable for the study since grounded theory explores processes, activities and events yet the main focus of the intended study is individuals' lived perspectives (Creswell, 2009 pg13&177).

This study intends to use phenomenology, which is considered as a process as well as a method, but is more of a theoretical perspective and involves studying a small number of subjects through extensive and prolonged engagement to develop patterns and relationships of meaning. In this process the researcher sets aside (brackets) his own prior experiences and understanding of the phenomenon under study in order to understand those of the participants in the study (Creswell, 2009).

Work is not considered to be phenomenological if some sense of the reduction is not articulated and utilized. Referring to phenomenology as a research approach alone is not enough. Therefore, it is important to clarify how the principles of phenomenological philosophy are implemented in the particular study. Published empirical studies based on phenomenology should include a minimum of scientific criteria such as articulation of methodological keywords, articulation of the investigated phenomenon, and description of how an open attitude was adopted throughout the research process (Norlyk & Harder, 2010).

Phenomenology arose as a philosophy before World War 1 and has continued to exist prominently in modern society as a challenge to the dominant views on the origin and nature of truth (Dowling, 2007). There are several approaches to doing phenomenological inquiry namely the transcendental phenomenology, an original form of phenomenological philosophy advanced by Edmund Husserl. This approach advocates for applying the phenomenological attitude over natural attitude with the main interest being to discover and discuss the lived world. Husserl's theory aims to identify the structure of experiences as described by the research participants and hence its descriptive nature (Kafle, 2011).

The original descriptive phenomenological method does acknowledge the grounded and embodied nature of the researcher and his or her situated position, which demands bracketing and reduction to abstain from the researcher's natural attitude and presuppositions (Davidsen, 2013).

The second type of phenomenology is the existential phenomenology introduced by Heidegger and aims at understanding existence and stresses the description of everyday experiences as they are perceived by the individuals (Kafle, 2011). Phenomenological research majorly focuses on what the person experiences and its expression in language that is as loyal to lived experiences as possible hence phenomenological inquiry attempts to describe and explain the meanings of human experience beneath how people describe them from the structures that underlie consciousness to the essential nature of ideas (Rudestam, 2007).

Hermeneutic phenomenology advanced by Martin Heidegger is concerned with life world or human experience as it is lived with a focus toward illuminating details and seemingly trivial aspects within experience that may be taken for granted in our lives, with a goal of creating meaning and achieving a sense of understanding of the phenomenon (Kafle, 2011).

Husserl focused on rich description of narratives while Heidegger added the hermeneutic perspective with the importance of the interpretation of stories hence narratives have been acknowledged to be important throughout the phenomenological journey (Davidsen, 2013). Phenomenological research characteristically starts with concrete descriptions of lived situations, often first-hand accounts, set down in everyday language and avoiding generalizations thus enabling the researcher to reflectively analyze these descriptions by offering a synthesized account and thereby identifying general themes about the essence of the phenomenon (Finlay, 2009).

Husserl defines the idea of putting oneself philosophically in a position to hear and understand what is said and a calls the phenomenological standpoint, the attitude of epoché. Therefore, the difference between the Husserlian and the hermeneutic position may not be so great and researchers who advocate an interpretive approach also acknowledge the need for thorough description of the phenomenon (Davidsen, 2012).

The theoretical orientation within the qualitative study in which theory becomes the end point is an inductive process of building from the data to broad themes to a generalized model or theory. The researcher begun by gathering detailed information from participants and then formed this information into categories or themes and sub-themes. These themes were developed into broad patterns, theories, or generalizations that were then compared with personal experiences or with existing literature on the topic. Therefore, the researcher explored the individual lived experiences through in-depth interviews and observations of cancer patients and informal caregivers' perspectives on cancer palliative care as lived experiences and basic knowledge of the care package.

The descriptive phenomenological design was most appropriate because the responses of the cancer patients and informal caregivers were shared and used in the development of messages for improving palliative care in Uganda and Africa. This study therefore used a descriptive phenomenological theory of perception which was best suited for this study to fully obtain patients' and informal caregivers' account of their experiences as it relates to the phenomena in question.

CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

This chapter reviews the existing literature on the palliative care services available to cancer patients in different parts of the world, Sub Saharan Africa and Uganda in particular Kampala district. The focus was on the various components of palliative care such as prolonging life, reducing pain, symptom control and finally psychosocial support of patients and family or informal caregivers.

The literature review in line with key themes which formed the basis of this research and depict the nature of support in palliative care. These included; prolonging life of patients, psychosocial support and care services and family care givers in palliative care among others. The following are existing definitions of key components basing on various literature of the palliative care specialty.

The principles of palliative care are consistent around the world. However, some aspects such as, socioeconomic environments, prevailing diseases, health-care systems, technology, and drug availability differ enormously, meaning that palliative care has different characteristics in different regions over the world. Palliative care in African countries is designed to fit within the cultural, spiritual and social contexts within Africa. The palliative care needs in Africa include home and respite care, pain and symptom control, financial, emotional and spiritual support, and also food, shelter, legal help, and school fees (Harding &Higginson, 2005).

Palliative care for children is the active total care of the child’s body, mind and spirit, and also involves giving support to the family. This care begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease (WHO, 2002).

According to HAU (2006), palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patient's illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counseling.

Palliative care is offered by different organizations, such as specialist palliative care providers like Hospices, or by public, private and not for profit care and support organizations trained in palliative care, such as (TASO) The AIDS Support Organization, health centers, and hospitals. Organizations are encouraged to work together with other organizations that can provide the missing components, by making appropriate referrals (HAU, 2006).

Palliative care is required throughout the course of illness, from onset of diagnosis, as patients may experience recurrent infections and painful conditions. For example, a patient with HIV may require short-term palliative care for management of pain or symptoms. Once these are managed and treated, the patient no longer complain of symptoms and may not require palliative care until the next episode of pain or symptom but may require supportive care such as spiritual care, social support, and counseling. The need for palliative care, especially pain and symptom control increases as the disease progresses (HAU, 2006).

Care for patients in a palliative acute care setting is primarily concerned with symptom relief. At times, specific treatment aimed at an acute condition is appropriate. Pain is the most common symptom of patients with cancer who are in palliative care and seeking acute care. Other patients in palliative care may also experience continuous or intermittent pain, and the principles of treatment are the same (Krause, 2010).

A patient in later stages of cancer or patients who no longer responds to treatment will need increasing palliative care. End stage care does not focus on prolonging life, but on easing symptoms and improving the quality of life remaining. The family and patient will also need support to prepare for the patient's death. After the death, bereavement support will continue as the family will need to be followed as they grieve (HAU, 2006).

World Health Organization, disseminated a 3-step "stepladder" outlining an approach to treating pain in patients. The scheme is clearly applicable for all patients in palliative care because it is a relatively inexpensive yet effective method for relieving cancer pain in about 90% of patients. This 3-step ladder for cancer pain relief can be summarized in five phrases: the first step in the ladder is a non-opioid, typified by aspirin. If this does not relieve the pain, an opioid for mild to moderate pain, typified by codeine, should be added as the second step of the ladder. If this fails to relieve the pain, an opioid for moderate to severe pain, typified by morphine, should be used as the third step of the ladder (WHO, 2002).

Additional drugs, called adjuvants, are used under certain conditions. The "right" dose is the dose that relieves the patient's pain and lastly the need for regular administration of pain- relief drugs should be emphasized. Ideally, the patient's drug regimen should be written out in full for the patient and family to work from. Surgical intervention on appropriate nerves may provide further pain relief if drugs are not wholly effective. Holistic care treats the patient as a whole person, not just as a medical case. This approach focuses not only on physical care, but also psychological (emotional), social and spiritual care. This psychological and emotional support and care should be available for the caregivers as well as the patient. Family members, community volunteers, professional care and support workers (health workers, counselors, social workers), work together before, during and after periods of care giving (WHO, 2002

2.1 Care Services

Care services are more about provision of care to both patients and their care givers. Care services involve: physical, emotional and spiritual care, but in many cases the spiritual aspects are rejected. Yet, spirituality contributes a great deal to the palliative care package. Emphasis is majorly on how palliative care is provided in all its components plus other aspects so as to ensure that the care package maintains the dignity of the patients and their families. The majority of cancer cases are usually diagnosed when the disease is in its later stages and this discovery affects the lives of patients and their families negatively. This implies that patients on knowing their status may be withdrawn, they lose meaning of life. Therefore, there is more need for care services among terminally ill patients to maintain their personal dignity as human beings despite the weak health status they are experiencing (Vilalta *et al*, 2014).

Engaging in doctor-patient communication may have similarly important effects on end of life care for white and Latino advanced cancer patients. This observation was after studying the relationship of patients and communication based factors in the prediction of end of life care for self-reported Hispanic and white advanced cancer patients (Loggers *et al*, 2013).

Patients receiving palliative care wish to live for the present with as much normality as possible and show only minor concern for their past and future. For patients, what is important is the present experience or condition considering spiritual aspects of treatment in the clinical management in palliative care (Vilalta *et al*, 2014).

Dependence and weakness require that patients receive help from others, hence patients become recipients mainly of services from health professionals and feel supported by their care and attention. More so, physicians need to develop a reflective attitude and a patient approach which truly enables the terminally ill to participate in shared decision making. Physicians should transfer their reflective attitude into practice by framing options in a way that facilitates patients' participation through early assessment of patients' expectations (Siebel *et al*, 2014).

Palliative care services also involves competence of the health care professionals who ought to be sensitive to the needs of patients, but also be able to manage their own psychosocial issues that may arise in the process of caring for many patients with chronic illnesses who are dying. The mental health of the caregivers is important if they are to remain empathic and effective in the giving of care and support to the patients in palliative care (HAU, 2006).

Experience of care received at the end of life or during serious illness, including barriers and facilitators to a positive experience bring insight into understanding patient and family perspectives of a positive palliative care. Knowledge of this experience is essential in providing high-quality palliative care. Palliative care services involves care given by family members (Ciemins *et al*, 2014).

Hudson and Payne argued that, there should be substantial and sustained commitments to improve services and resources for family caregivers, by governments, health authorities, and research councils in order for palliative care to deliver upon its core function of adequately supporting the patient along with the family (Hudson and Payne, 2011).

Coordination and provision of palliative home care by a Specialized Out-Patient Care team (SOPC) appears to provide a pivotal contribution to the quality of care in a patient's palliative and dying phase. The team significantly improved the perceived quality of life of patients and caregivers and lowered the caregivers' burden of care as well as their levels of anxiety and depression (Groh *et al*, (2013).

Public health approaches for families are warranted so that death and dying can be viewed once again as a part of life (rather than, for example, as a medical failure). The above public health approaches should also focus on addressing the lack of support for caregivers in impoverished regions and for minority caregiver groups (Hudson & Payne, 2011).

From a social and policy perspective, caregivers need to be supported by care systems that actually lessen rather than increase the burden of caregiving. For example, poor communication, lack of information, inflexible health care appointments (often at different hospital clinics and requiring repeated time off work), and slow response to request for services all add to caregiver frustration. To alleviate some of these burdens, periods of relief might be found in physical rest, social interaction, education, recreation, or employment outside the home. The term palliative care ought to be widely understood by all care givers simply because of diverse myths about palliative care specialty (Hudson &Payne, 2011).

The cost of treatment of cancer is high and patients with serious illness and functional impairment account for a rapidly increasing share of medical expenditures in the United States and other high-income countries. There is a clear pattern of specialist inpatient palliative care consultation teams reducing hospital costs and this is based on the findings from the study on the economic impact of Hospital inpatient palliative care (May *et al*, 2014).

The Institute of Medicine’s Report notes that creation of learning health care information technology (IT) systems for cancer is important to palliative care because it could facilitate the integration of palliative care into oncology care. Knowing how to best treat symptoms, address psychosocial and spiritual needs, provide bereavement support and other aspects of care could provide direction for evolving models of care. This system could provide palliative care clinicians with feedback about how well they are managing patients' pain and other symptoms while administering treatment (Ferrell *et al*, 2014).

According to Ferrell, US tax payers will not willingly embrace new models of care without rigorous demonstration of at least cost-neutrality and better quality of care. Governments are unlikely to have additional revenue to spend on cancer in the near future. The good news is that palliative care can help address these issues by providing the type of care that patients and families want at an affordable cost. The Institute of Medicine (IOM) Report establishes a solid foundation to support better incorporation of palliative care and hospice care into the cancer care delivery system, but also presents a challenge to extend this care to the more than 12 million Americans living with a cancer diagnosis and to the 570,000 who die each year of cancer. Ultimately, high-quality cancer care requires the provision of palliative care from the time of diagnosis and timely referral to hospice care at the end of life (Ferrell *et al*, 2014).

The incidence of certain cancers is rising in African countries including cancers that may run in some families such as breast cancer (increased risk in a daughter if a mother, sisters or cousins have had breast cancer, ovarian cancer, bowel or colon cancer; increased risk if parent or siblings have had bowel cancer at young age), hepatitis B may also cause primary liver cancer while people with HIV/AIDS are at greatly increased risk for certain cancers, including KS- Kaposi's sarcoma, NHL-non-Hodgkin's lymphoma, Invasive cervical cancer, Hodgkin's lymphoma, and squamous cell cancers (HAU, 2006).

Palliative care is ultimately the last opportunity to identify the affected individuals where storing DNA-Deoxyribonucleic Acid (substance carrying genetic information) would help to clarify risk for family members. In some families, genetic counseling about familial cancer risk is beneficial and reassuring. For most people who are diagnosed with cancer, there is no family link while others may have an increased risk of certain cancers for example a person may have been born with some of their body cells already damaged. Damaged cells increase the risk of cancer, but the strength of a person's immune system plays an important role in the development of these cancers (Lakhani *et al*, 2013).

Hospice Africa Uganda, notes that cancer often presents late. Eighty percent (80%) of cancer patients in Africa are thought to present with advanced, incurable disease. Prognosis even for those who reach the cancer institute (estimated at 5% of cancer patients), is extremely poor, because of late presentation and limited treatment options. Notably, late presentation is usually after the patient and their caregivers have spent a lot of their resources on alternative treatments without knowledge of what they are treating exactly. The implication of late presentation on the patient is that the disease is usually in its later stages whereby only pain relief and symptom management can be provided (HAU, 2006).

Perspectives of informal caregivers and professional caregivers on other diseases differ from those of formal or informal caregivers in such a way that health care professionals' (HCPs) perspectives on end-of life-care have been well-documented but less focus has been placed on patients' and families' perceptions and experiences. Focus on patients' perspectives has often been limited to specific disease states, for example, cancer, with emphasis on the illness itself, rather than the care received (Ciemins *et al*, 2014).

Additionally, to informal caregivers, late presentation and incurability of disease for their loved ones implies that they may have to overcome the initial shock and repress the pain they feel when their loved ones are diagnosed with cancer but instead be stronger for the patient, adjust their work schedules or some discontinue work to be full time caregivers. Informal caregivers also start bracing themselves to starting a new journey of spending much more of their incomes and time on treatment for their loved ones. Research is ongoing all the time into cancer and its causes to understand more, promote routine screening and therefore be able to treat it and prevent it in the future.

2.2 Prolonged life

Prolonging life in relation to palliative care refers to improving the quality of life or ability for palliative care to extend life for a patient with chronic illness to another level thus granting them more abilities and helps them to die in dignity. The benefits of palliative care are not even restricted to end of life care. Early integration of palliative care has been proven to improve quality of life and reduce the need for burdensome aggressive treatments. Access to palliative care is limited or nonexistent in many countries, it is mostly in developed countries that palliative care is included in healthcare systems while most developing countries have few or no palliative care services available. There is need for governments especially in developing countries to ensure the integration of palliative care into health care systems at all levels (Radbruch *et al*, 2013).

Integration of palliative care with standard cancer treatment early results in prolonged and meaningful improvements in quality of life. In addition, palliative care also leads to less aggressive end-of-life care, including reduced chemotherapy and longer hospice care. Therefore, timely introduction of palliative care may serve to mitigate unnecessary and burdensome personal and societal costs (Temel, 2010).

End of life care for a patient includes preparations for patient’s death by all family members and medical personnel although the patient’s lives may be prolonged due to palliative care (Moran, 2014). Early palliative care provides better quality of life, increased prognostic awareness, and even improved survival for patients with advanced cancer thereby contributing to prolonged life (Back *et al*, 2014).

Healthcare professionals providing medical care to patients with serious illnesses ought to consider that the roles they play in meeting patients' religious and spiritual needs may increase the comfort and meaning in the process of dying. Human dignity as well is acknowledged by addressing spiritual needs of patients by granting them their freedoms of worship and decision making power (Mackinlay, 2007).

Palliative care can effectively relieve pain or suffering and can be provided at relative low cost, access to palliative care has to be considered as a human right. In cases of particularly severe suffering, failure to provide palliative care may constitute cruel, inhuman, or degrading treatment. (Radbruch *et al*, 2013). Timely palliative care service consultations are associated with earlier and more frequent hospice referrals avoiding aggressive life-prolonging cancer care. Patients receiving palliative care consult irrespective of time to consultation were more likely to access hospice care than those who never had a palliative care consult. Therefore, if consulted in a timely fashion, palliative care consults may potentially decrease the extent of aggressive cancer care near the end of life. This implies that patients who are informed about palliative care and consult in time may benefit from the available service. This is manifested in their response to treatment and prolonged life (Gonsalves *et al*, 2011).

2.3 Psychosocial support in palliative care

Formal or professional care providers often find it difficult to discuss prognosis and end of life issues with patients. Previous studies document that many physicians do not discuss advance directives or prognosis with terminally ill patients while the patient still feels well but instead wait for the exhaustion of therapies or onset of symptom for these discussions. There is need for additional developments necessary to ensure adequate education and support of cancer patients and their oncology teams to facilitate timely referral (O'Connor *et al*, 2014).

Religion and spirituality frequently play a fundamental role in maintaining patient well-being in the face of terminal illness like cancer. Therefore, future spiritual care models must balance supportive caregiver attitudes with substantive engagement of patients' spiritual resources, struggles, and practices (Alcorn *et al*, 2010).

Palliative care has emerged as a priority in medical education. Yet, it remains inadequate, for example half of graduating seniors feel unprepared for end-of-life issues; 19%–33% feel that inadequate time was devoted to instruction and 67% of deans agree. There is need to integrate palliative care into medical education worldwide (Billings *et al*, 2010).

For many years, palliative care was not offered to pediatric patients and, even today, only a small percentage of children with incurable disease in Europe can actually benefit from palliative care services. Many of these children die in unsuitable conditions, without relief from distressing symptoms, usually in hospital (and often in an intensive care unit), not in their own home. Children with life-limiting and life-threatening illnesses that lead to death or a life of severe disability deserve a profound cultural and organizational reappraisal of how we care for them when treatment is aimed not at recovery but at offering the best possible quality of life and health (Benini *et al*, 2010).

Caregivers are typically prone to physical and psychological morbidity, are responsible for many tasks like symptom management and are financially disadvantaged. More so, 50% of caregivers are below population norms on physical health, and rates of depression and anxiety in up to 44% of care givers have been reported, while complicated grief where debilitating grief is experienced for an extended period is noted at approximately 10% to 20% of family caregivers (Hudson *et al*, 2012).

Rumination is defined as involving repetitive focus on personal difficulties and feelings, and thinking about their causes, meanings, and consequences. Rumination focused on depressed symptoms, is implicated in the onset and maintenance of psychological distress. It is thought to be triggered by unresolved and unattainable goals and in response to discrepancies between actual reality and ideal outcomes and aspirations (Gaflin *et al*, 2010).

The symptom burden is typically high and underestimated relative to patient and family perception in patients with advanced disease and that end-of-life discussions do not take place in a timely manner, if at all, for many patients (O'Connor *et al*, 2014). Psychological distress and rumination in palliative care confirmed existential concerns are elevated in patients and caregivers. These concerns are associated with distressing rumination, and associated with increased anxiety and depression (Gaflin *et al*, 2010).

Mental health of parents can influence family function as well as affect patient and sibling quality of life and physical health; hence efforts to reduce parent distress are critical. Hence, the Institute of Medicine recommended that cancer care include the provision of appropriate integrated services to optimize psychosocial outcomes. This care for the whole patient must include care for parents and family members in particular, in the setting of pediatric cancer (Rosenberg *et al*, 2013).

2.4 Family Caregivers in Palliative Care

In the context of palliative care, care givers refer to the professional health care providers and family care givers. Family care givers within the context of palliative care are any relative, friend, or partner who has a significant relationship and provides assistance (physical, social, or psychological) to a person with a life threatening, incurable illness (Hudson *et al*, 2012).

A caregiver is an individual who provide ongoing care and assistance, without pay, for family members and friends in need of support due to physical, cognitive, or mental health conditions. Informal caregivers are sometimes called family caregivers or unpaid caregiver to differentiate from other health care professionals who provide care (CCC, 2009).

A meta-analysis of 23 studies comparing health indicators of caregivers for people with dementia with non-caregivers found stress hormones in caregivers were 23% higher and that their antibody responses were 15% lower than those of non-caregivers hence implying that care-giving may influence the physical health of caregivers (Vitaliano *et al*, 2003). During times of sickness of any condition, it is the role of family care givers to provide support to patients through careful initiation of discussion in regards to advanced care planning incase patients refuse therefore caregivers can be conduits through which hospitals can assist patients to approach care and sensitively help in initiation of care with patients (Michael *et al*, 2013).

Family caregivers have consistently expressed their need for the following: education to prepare them for their role: about how to respond to the challenges (physical, social, spiritual, and psychological) of their role, and about how to access resources (internal and external) to assist them to maintain optimal psychosocial well-being. This implies that care givers at family level are never prepared in all aspects for the chronic illnesses that their family members experience. Therefore unless the need to build capacity of family caregivers is met with appropriate training and psychosocial support by all stakeholders, the purpose of palliative care of providing care to patients and their families may never be fully achieved (Hudson &Payne, 2011).

Estimates of bereaved family members of patients with cancer who had home care also hoped for home care at the end of life lie at 60% and approximately 70% hoped for death at home but only 7.3% of patients with cancer die at home in Japan. Previously, patients who hoped to stay at home were unwillingly admitted to a hospital because their symptoms were out of control at home and their families were anxious and the care burden was excessive. The continuity of home care for patients with cancer at the end of life is likely to be attributed to the family caregiver's attitude and empowerment (Ishii *et al*, 2012).

Palliative care specialty is very crucial in medical training for physicians, but it is inadequate due to a number of reasons like faculty lacking confidence in their skills and ability to teach palliative care. For example, less than 50% of residency programs in United States have faculty expertise in end-of-life care. Therefore, institutional support may be lacking but if faculty and residents articulate and exemplify the merits of providing high quality end-of-life care, students may be more likely to have the confidence, experience and enthusiasm to carry this high-quality care into their professional lives (Billings *et al*, 2010). The development of curricula to be used in oncology settings, online resources, train the trainer programs, and other educational approaches could make an important contribution to quality cancer care (Ferrell *et al*, 2014).

In addition, there is a need for on-going research or information seeking by caregivers regarding cancer so as to be equipped with the latest knowledge and skills which in turn will benefit both of them and the patients receiving the care. More so, the required package of care for cancer patients will be provided by the caregivers to both patients and their families equipped with basic care giving skills in case of home care (Ferrell *et al*, 2014).

The challenge of research in palliative care amplifies several aspects of informed consent, given the nature of the populations and the studies that can inform better quality of care, the legal issues, the knowledge, attitudes, and beliefs of patients or participants, their families, and health care providers influence informed consent (Agar *et al*, 2013).

The treatment plan should be individualized and based on the patient's overall prognosis, potential to regain function, and desire and motivation to participate in the program. Several interventions can be used in supportive and palliative care rehabilitation programs, such as physical, occupational, and speech-language therapy (Javier and Montagnini, 2011).

There have been cases that caregivers make video and audio recordings of patients that are to be used in documentaries for study purposes without consent of the patient which is absolutely unethical in palliative care. In palliative care, there may be a perception that a clinical trial brings hope for improved health, which may be an unrealistic expectation. Despite these difficulties, a participant's own informed consent remains the gold standard to improve the quality of palliative care services given to terminally ill patients and their families (Agar *et al*, 2013).

There are some family caregivers whose experience is largely gratifying and positive, while for others it is stultifying if not crushing. The study implicates several intervention components to be developed and tested as favorably supporting caregivers, namely, reinforcing positive aspects of caregiving, cultivating open communication, and acknowledging the prior experiences and social foundation of the caregiver's life that can be supportive or burdensome (Williams & Bakitas, 2012).

Family or informal caregivers providing hospice palliative care at home are undertaking a wider range of tasks like psychological, social and spiritual care; personal care; medical care like administration of medications and injections; advocacy and care-coordination in an environment where they have less support from professional caregivers (Voice in Health Policy, 2004).

Participants’ consent at the time of enrollment, advance consent by participant, and ‘‘proxy’’ consent all meet the ethical requirements of informed consent and can be used in palliative care clinical trials. Obtaining informed consent for participation in hospice and palliative care clinical trials is an ongoing challenge faced by researchers and caregivers. This is because caregivers are sometimes called upon to be present when researchers are explaining terms of the consent form to a patient who may not be able to sign the form or when a client is a minor where in both cases the signature of the caregivers may apply (Agar *et al*, 2013).

In Sub-Saharan Africa and in particular Uganda, people are gradually appreciating palliative care and the advantages it brings for those with chronic pain. Nonetheless, many people continue to relate palliative care to mercy killing while others are totally unaware of its existence let alone its benefits. Additionally, throughout the course of illness palliative care gives compassionate care that leads to either cure or death. However, it is noted that this mode of care, grants an opportunity to patients and their family caregivers to share the last moments of their lives together. This enables the patients to die in the comfort of their homes or other locations of choice to the families thus helping them through the bereavement process (Bona *et al*, 2011).

Notably, the gaps identified like misconceptions or low levels of knowledge about palliative care, lack of access or low access to palliative care and the fact that this specialty of care is still inadequate too many people that desperately need it in developing countries like Uganda implies that there is great need to address the urgent need for palliative care in Africa because pain relief is a human right that all people with chronic illnesses ought to access. Denial or lack of access to palliative care is equivalent to in humane treatment.

2.5 Conclusion

Conclusively therefore, the study examined the perspectives of patients and caregivers on cancer palliative care received at HAU. The gap identified was that the general populations and more so many Ugandans still do not know or lack appropriate knowledge about palliative care let alone its availability in Uganda. Family or informal caregivers are ill equipped for their roles and this is manifested in the quality of care provided to patients where some components of palliative care are not included in the care package for example the spiritual aspect of patients' life is rarely acknowledged. Plus, caregivers psychological needs are not addressed to enable them fully focus on the patient needs hence inclusion of both patients and family caregivers will greatly contribute to achieving the ultimate goal of palliative care.

CHAPTER THREE

RESEARCH METHODOLOGY

3.0 Introduction

This chapter presents the study area, study design, study population, sampling procedure, methods of how data was collected and analyzed, trustworthiness and ethical considerations which were considered and adhered to during and after data collection. It also presents how the findings of the study are to be disseminated.

3.1 Study Area

The study was conducted in Kampala city and it focused on patients receiving palliative care within the Kampala catchment area of Hospice Africa Uganda. The study was conducted in these areas and population so as to provide adequate knowledge and information to the research.

3.2 Research Design

The study employed a descriptive phenomenological approach of qualitative data collection and the findings were used to appropriately understand the diverse views of cancer patients and their family caregivers on cancer palliative care service.

3.3 Study Population

The study population from which participants were selected included patients receiving cancer palliative care and informal or family caregivers residing in Kampala district within the HAU catchment area. The participants in the study were found at the agency when they come for day care every Tuesday and for review while other participants and caregivers were accessed through various home visits that the researcher participated in with the different Hospice teams, which guided entry into the lives of the participants.

All participants were accessed at Hospice Africa Uganda with help of the agency list of current patients' from the data base. The researcher contacted the Clinical and Data Management Departments in charge of patient's database to request access to potential participants for the purpose of this study and was guided on the right procedure of selecting participants. Informed consent forms were issued to clients following clarification on what the study was about using a participant information sheet in accordance with the language preference of potential participants.

3.4. Study Unit

This study included cancer patients and family (informal) caregivers receiving palliative care and have had an experience using palliative medicine. The participants selected were those living within Kampala District and had clear understanding of the benefits of palliative care.

3.5. Sample Size

Patients receiving palliative care from Hospice Africa Uganda within Kampala current catchment area were the primary focus for interviews. Patients were selected with assistance of the clinical department palliative care teams and data base department to help in identifying patients and informal caregivers who were able and willing to participate in the study and able to fulfill the inclusion criteria.

Purposeful sampling strategy was used in identification of participants that is the target of 10 patients and 6 caregivers for in-depth interviews. This helped to explore the experiences of patients and informal caregivers regarding palliative care received and also give the researcher in-depth knowledge of the research question.

The researcher intended to hold focus group discussions (FGD's) to acquire views and opinions from the informal or family caregivers who provide care to patients at their homes most of the time, but this method was found to be inappropriate given the setting of data collection and nature of participants who come to the agency at different time intervals. Basically, it was not possible to access the required number of informal caregivers at the same time for a focus group discussion.

3.5.1 The specific inclusion and exclusion criteria for participating in the study

The following criterion was used to locate participants who provided the most accurate representation of their lived experiences. The sample size selected was based on the nature of the study as well as limitations of time and logistical constraints. The participants were purposively selected with help and guidance from Agency's Clinical and Data Team.

3.5.2 Inclusion Criteria

All participants considered were those who are experiencing or have experienced life while receiving cancer palliative care and were able to reflect on and provide detailed information about a phenomenon. Although experience alone may not appropriately depict the desired information hence potential participants were selected purposively and only those who met the inclusion criteria below were considered to be involved in this study.

The inclusion criteria therefore involved;

- Patients and informal caregivers who have received cancer palliative care within a period of one month or above 1 year.
- Patients receiving Cancer palliative care from HAU,
- Patients and informal caregivers willing to reflect on their lived experiences while receiving cancer palliative care at HAU,
- Patients and informal caregivers who are able to speak either Luganda or English.

- Informal caregivers whose patients died or are unable to talk because their experiences or perspectives are also valuable.
- Participants who are able to participate in face to face audio-tape interview lasting between 45-90 minutes.

The sample size was therefore determined by saturation (a point at which repetition of information occurs with no evidence of new knowledge coming up) of emerging themes and categories from the interviews held with the participants. Generally, participants for qualitative phenomenological studies are small in number compared to other types of research like mixed and quantitative studies.

3.5.3 Exclusion Criteria

The exclusion criteria involve all patients at HAU receiving palliative care for other conditions that are not cancer and caregivers who are professional caregivers and are not family members to the patient.

3.5.4 Sampling Technique

Purposive sampling technique was used in this phenomenological study due to the fact that it was to best help the researcher understand the problem and the research question (Creswell, 2009 pg.178). This sampling technique only permits selection of only those participants who have the attributes needed to be in a position or qualify as participants to provide the necessary data.

Purposive sampling or selection of data sources involves choosing people or documents from which the researcher can substantially learn about the experience. The major concern in purposive sampling is whether the data collected are sufficiently rich to bring refinement and clarity to understanding an experience (Pilkinghorne, 2005).

3.6 Data Collection Methods

Gathering data in qualitative research is intended to provide evidence for the experience being investigated and evidence is in form of people's accounts of the given experience (Pilkinghorne, 2005). The researcher used qualitative methods of data collection like; observations, semi-structured in-depth interviews with open-ended questions, documents and audio materials.

Data was collected directly from participants through interviews by listening, writing brief notes and recording and follow up questions came from their answers. The researcher analyzed evidence to produce a description of the experience being investigated and data collected served as ground on which findings were based.

Most patients and informal caregivers were accessed from the agency when they come for Day-care and review while other patients and informal caregivers were found in their homes when the researcher joined the clinical teams for home visits. The researcher selected 10 patients and 6 caregivers resulting into 16 interviews following the above mentioned inclusion criteria.

3.6.1 In-depth Interviews

Interviews involving semi-structured and generally open-ended questions that are few in number were carried out and were intended to elicit views and opinions from the participants. This was based on the use of an interview guide

3.6.2 Direct Observation of Participants

Observation refers to a technique of gathering data through direct contact with an object usually a participant. This method is used to supplement and clarify data derived from participant interviews (Pilkinghorne, 2005). Observation tool also provides information about actual behavior of participants. Direct observation is useful because some behavior involves routines of which the participants are hardly aware of and hence this tool allowed the researcher to put behavior in context and thereby understand behavioral patterns better.

3.7 Data Analysis and Presentation Methods

The aim of this study was to unveil the perceptions of cancer patients and their caregivers on palliative care received at Hospice Africa Uganda. The focus was on the various components of palliative care such as prolonging life, reducing pain, symptom control and finally psychosocial support of patients and their family caregivers.

Phenomenological research uses the analysis of significant statements, the generation of meaning units and development of an essence description (Creswell, 2009)**.** Qualitative content analysis is data-derived that is, codes generated from the data themselves are systematically applied in the course of the study (Sandelowski, 2000).

The researcher developed an interview guide to elicit detailed descriptions of participants' perceptions of their experiences of cancer palliative care at HAU. Interviews were conducted at HAU and patients' homes. The collected data was analyzed by coding and categorizing, focusing on meaning of what is said and expressed by participants. Coding and classifying of data was carried out so as to reduce statements classified under a code into meanings. Thereafter, comparisons were made between themes and context; similarities and differences between participants and related findings with the research question.

The Major questions included the following: How long have you received palliative care? How did you know about the existence of palliative care? How is life while receiving palliative care different from life before while you are sick? How has palliative care impacted the way society views you? How has Palliative care contributed the care received as a patient? What other mode of care do you receive apart from palliative care? Why? This was achieved by use of Edmund

Husserl transcendental phenomenology theoretical framework because it is the most appropriate in answering the research question; “How do cancer patients and their caregivers perceive palliative care received at Hospice Africa Uganda?

3.7.1 Data Analysis

Data analysis applied Creswell’s recommended six steps for qualitative data analysis from specific to general involving multiple levels of analysis (Creswell, 2009). The data was organized and prepared for analysis by transcribing the interviews and optically scanning the materials. All filed notes were typed and the data was sorted and arranged into different types depending on the sources of information. Thereafter, all the data was read through so as to obtain a general sense of what the participants had said and their tone of voice by reflecting on its overall meaning, depth, credibility and use of the information. Any thoughts about the data were written as well at this stage.

The description and themes were represented in a form of a narrative passage to convey findings of the analysis for example a detailed discussion of the several themes, subthemes, illustrations, multiple perspectives of individuals and quotation (Agar *et al*, 2013). Finally, data analysis involved making an interpretation or meaning of data by describing the lessons learned. In this case lessons learned refer to the researcher’s personal interpretation or understanding derived from the findings with information from literature or theories.

3.7.2 Quality Control

Qualitative data was collected using an interview guide and observations. The interview guide was developed in English and later translated into the local language (Luganda) and then back translated to English with help of a professional language expert to find out the consistency in meaning.

3.7.3 Reliability

Reliability of this interview-based phenomenological design was ensured by the researcher being the only one to design, implement, and analyze this study. Questions and adjustments made thereafter enhanced clarity and led to increased reliability. The rapport created through in-depth interviews with the participants increased the reliability of the information research participants provided. The interview guide in English was translated into Luganda and then back into English to ensure consistency. Reliability was tested by asking the same question within the same interview. The collected data was systematically recorded and coded according to themes so that the result could be reproducible by any other person with a similar conclusion.

3.7.4 Validity

Validating an argument or research process basically means showing that it is well founded and sound (Rudestam and Newton, 2007 pg.112). Qualitative studies reflect the reality as perceived by the participants. The validity and accuracy of the data collected was achieved by the sustained engagement with the participants while in the field and continuous consultations with the supervisor during analysis.

3.8 Ethics, Consent and Confidentiality

3.8.1 Ethical Considerations

The entire research process was conducted with due respect to ethical considerations under guidance from Uganda Martyrs University. Participation in the study was strictly on voluntary basis. Informed consent is an important aspect of ethical principles in research. The Uganda Martyrs University Institutional Review Board reviewed the proposal, the informed consent form, and the interview guide and thereafter granted approval in form of the letter granting permission to start data collection.

The introduction letter from the University was attached to the amended copy of the proposal and presented to Hospice Africa Uganda Research and Ethics Committee (HAUREC). The approval letter from HAUREC was granted thereafter and the researcher further got clearance from both the Human Resource Department and the Clinical Department of the agency (HAU) in order to start data collection the following week.

In the process of conducting the study, care was taken to respect human dignity and secure informed consent from the participants. Additionally, the principle of academic integrity which involved acknowledgment of sources of both primary and secondary information was used in the study.

The information acquired was kept confidential and the identities of the participants were protected. Confidentiality of participants was ensured for their comfort and it was important to inform them that their private information is protected.

Informed Consent forms were issued to all participants for signing and thereafter signed copies plus audio recordings were protected and kept safely at the researcher’s residence. Manual notes were recorded and stored electronically. Transcribed data was kept in a password-protected personal computer and all information provided by the participants was kept confidential and was not shared with a third party.

Participants were free to withdraw from the study if they so wished. Prior to interview, each participant was given a written informed consent form according to their language preference that is either English or Luganda.

3.8.2 Informed Consent

Prior to seeking informed consent, participants were provided with a participant information sheet indicating details about the study, the purpose of the study, methods of information gathering , level of participant involvement, assurance of confidentiality and anonymity, level of risk and their right to withdraw from the study without prejudice. If the participant selected was too sick or unable to talk, an impartial witness or caregiver was to be present during the informed consent discussion.

After the written informed consent form was read and explained to the participant, and after they have orally consented to their participation in the study, and have either signed the consent form or provided their fingerprint. The witness signed and personally dated the consent form. By signing the consent form, the witness attested that the information in the consent form and any other written information was accurately explained to them, apparently understood and that informed consent was freely given by the participant.

3.8.3 Anonymity

Anonymity refers to measures that were taken to protect the identity of participants in the study. Before any interview was carried out, participants were asked to select a pseudonym for confidentiality purposes. The original transcripts were in the hands of the researcher and kept in a secure place.

3.8.4 Storage of Information

The researcher was the only person with access to the collected information together with his supervisor, thesis committee and HAUREC. Signed consent forms were kept at the researchers' place securely at the time of the research, and will be kept for five year period following completion of the study after which they will be destroyed.

3.8.5 Plans for dissemination of findings

The copies of this report shall be submitted to the Faculty of Health Sciences of Uganda Martyrs University for the academic award of Master of Public Health-Health Promotion of Uganda Martyrs University.

The findings from this study may be published in a recognized medical journal or university's intra-web which may help to promote research and further justify the need for both local and international support in cancer palliative care.

A copy of the report shall be given to Hospice Africa Uganda which will in turn help the agency in evaluating its service provision, may also be used to raise donor support and to build on the body of knowledge in the care package that is appropriate for the Ugandan context and any developing country.

CHAPTER FOUR

PRESENTATION OF RESULTS

4.0 Introduction

This chapter presents the results or findings of the study in order to answer the study questions and meet objectives of the study. It begins with an overview of the perspectives of participants in this study through participant interviews. The study was guided by the three specific research objectives namely: To identify the nature of palliative care support given to patients and their family caregivers at HAU; to examine patients' and family caregivers' perceptions of palliative care they receive at HAU and; to find out whether the mechanisms in place enabled effective receiving of feedback from the clients.

4.1 Demographic Characteristics of Participants

4.1.1 Table 1: Demographic characteristics of Participants (Source: Field Findings)

Categories	Male	Female	Total
Patients	4	6	10
Caregivers	4	2	6
	8	8	16

Table 1 shows the context of the participants interviewed; 8 of whom were male while 8 were female. Of all the participants 10 were Patients while 6 caregivers totaling to 16 participants. Notably, patients included 6 female patients and four male patients while caregivers included 4 male caregivers and 2 female caregivers. Among the 10 patients who participated 5 of them had cancer only while the other 5 had both cancer and HIV/AIDS. Of the five patients with co-morbidities; 3 were male while 2 were female representing half of the total number of patients.

Some of the participants interviewed represented those currently employed, unemployed and those dependent the on support of various agencies like Mild May and Hospice Africa Uganda (HAU) for basic needs.

4.2 Perspectives as seen through significant statements

Significant statements in this case refer to participants' narratives during the interviews that are related to the phenomenon under study and are considered to be of significance. Analysis involved extraction of significant statements from each of the participants' narratives. Five major themes that emerged on perspectives of patients and their caregivers of cancer palliative care at Hospice Africa Uganda. The broad themes that emerged were: Nature of support in palliative care, Patients' Perceptions of Cancer Palliative Care, Caregivers' Perceptions of Cancer Palliative Care, Roles in Health Care and finally Quality of Care in Palliative care at HAU.

In addition, each of the 18 sub-themes in their categories namely: Financial, Medical and Food support, Inequitable access to care, Adequacy of financial support and Support in urban and rural; Scope of Care services, Knowledge of Palliative Care, Improved quality of life; prolonged life, Empathy and Compassion in Palliative Care, Anxieties of Caregivers; Roles of Government, Roles of Individuals, Long waiting time, Client Feedback and communication, Patient-Centered Care and Formal and Informal caregivers.

4.3 Nature of Support in Palliative Care

The scope of support can be defined as the kind of help or care package given to cancer patients at Hospice Africa Uganda. Basically, the care package involves mostly medical care that is provision of medicines and reviews by professional caregivers, financial support, food provision and psychosocial support.

In line with the nature of support given to patients, several viewpoints were given for instance support given was found not to be adequate given the needs of the patients, access to financial support was viewed as inequitable between cancer and HIV/AIDS patients. Additionally, financial support given was found to be differing between rural and urban centres of the agency like Hoima, Mbarara and Kampala.

These findings summed up the perspectives of patients regarding the nature of support although most the majority of participants revealed that medical support is vital and thus over riding all other kinds of support given by Hospice Africa Uganda.

4.3.1 Financial Support

According to the participants, Palliative care provided by Hospice Africa Uganda has an element of financial help given only to needy patients to help them address basic needs like medicines acquired out of the agency for other conditions, school fees for their children, scholastic materials like books and transport facilitation. The agency has social worker and palliative care teams that are equipped with skills to make appropriate assessment on who qualifies for the financial support given the fact that resources are not readily available for all patients in need.

The majority of Patients at Hospice Africa Uganda receive medical care including medicines and reviews free of charge. The patients who have a lot of need and are the majority do not have to pay any money. While those who are financially stable are requested to make a contribution of ten thousand shillings (10,000) towards the service they receive. Some of these patients get care from multiple sources as revealed by one of the participants' statements:

> ["…*Ng'ogyeko obujjanjabi bwenfuna ku hosipisi, nfuna obujjanjabi obulala okuva muddwaliro lya Mild May era ndimumativu nnyo n'obujjanjabi bwa hosipisi. Banfaako nga bwenetaaga ate nga byabwerere*…"] **Participant 7**

> ["…Apart from the palliative care, I also receive cancer treatment from Mild May centre but I am very contented with Hospice care because they provide care that I require and yet it is free of charge…"] (**Participant 7-Male Patient)**

Due to the fact that many participants categorically mentioned a need for the agency to support them financially. This is because some of some of them are financially supported while others do not access financial help. However, there was a general need for financial support as well:

> ["…*Bw'ofuna obulwadde bwa kookolo ebiseera ebisinga okitegela luvanyuma ng'omaze okusasanya sente mukwejjanjaba, n'olwensonga eyo nzendowooza nti singakisoboka ekitongole kino okutekawo ensawo yo'kuyamba abalwadde abatesobola mu by'entambula*…"] **Male Participant 1**

> ["…When you get cancer you usually get diagnosed after getting drained of all financial resources, so if it is possible for the agency to set up some kind of fund to help facilitate patients with transport especially those patients who cannot facilitate themselves to access care…"] (**Participant 1-Male Participant)**

The agency goes an extra mile in buying medicines for other conditions that may not be readily available at the agency or the agency buy assigning individuals staff members to purchase the required medicine and distributes it to the patient in need:

> ["…*Bwewabawo endwadde endala yonna ng'omutwe, omusujja oba obulumi obulala nfuna eddagala wano ku'hosipisi ate bwelitabawo ba mpa sente nendigula ebweru oba nebalingulira*…"] **Participant 2**

> ["…In case of any other conditions like headache, malaria or some other pain I get the medicine from HAU and if it is not available they give me money to buy it out of here or they buy it for me…"] (**Participant 2-Female Patient)**

Dependence on the financial assistance from Hospice Africa Uganda was found to be high among participants and there was high expectations of this assistance whenever they come to the agency for review:

> ["…*I haven't received cancer treatment because I was told to get an x-ray that could show the progress of the disease but I do not have the money. I told the team at Hospice to help me with finances to do the x-ray and I am now waiting for their feedback*…"] **(Participant 6-Male Patient)**

Some clients of the agency expressed the fact that they experience major challenges like a lack of transport, which at times leads to failure to collect their medication. They emphasised the need for transport facilitation in order to keep up with the set appointments:

> [“…*The first time I came to Hospice, I was given transport facilitation like twice and it varied between 5000 and 10,000 shillings but that was about it. We all face the same challenge of transport because some times I fail to raise the means of transport to come for review and medication*…”] **(Participant 10-Female Patient**)

4.3.2 Support in Urban and Rural areas

Hospice Africa Uganda’s support also varies or differs between rural and urban areas. It is believed that patients and informal caregivers in rural settings have more social needs than those in an urban setting. The arrangement of financial facilitation to patients at HAU differs from that followed by rural branches of the agency. It is believed that social and medical needs of patients in rural areas are higher than those of patients in urban settings. With reduction of donor support, the agency downsized its operations by ensuring that only the main needs (medical) of patients are met except in extreme cases:

> [“…*When I remember in Little Hospice Hoima, the team used to give us some little money to sustain us through the week. This money ranged from 5000 to 10,000 or 20,000 shillings and it could help us buy soap, food and sugar but when I came at Hospice in Makindye it was different, with no financial facilitation for patients*...”] **(Participant 6-Male Patient)**

4.3.3 Inequitable Access to Care

Patient’s access care but differently for example there was a concern by a female participant about inequity in financial support. According to her, patients with HIV/AIDS are facilitated with a small allowance for upkeep or transport unlike cancer patients:

> [“…*I am very contented with the care I receive at Hospice but maybe my concern is the fact that our colleagues with HIV/AIDS are given certain transport facilitation yet people like me with cancer are not given transport*…”] **(Participant 10-Female Patient)**

4.3.4 Adequacy of Financial Support

The financial support provided to patients was recognized to be inadequate given the social needs they face on day to day basis. Some of the participants mentioned using the little money they get to transport them while others emphasised using it to buy food, sugar and soap throughout the week.

There are instances whereby caregivers experience lack of transport fare to come to the agency to collect medicine for their loved ones who are not be strong enough to come physically to the agency. This may be due many factors hence the funds set for transport are diverted to the urgent needs of the caregiver. However, the team at Hospice may sometimes facilitates needy family caregivers with transport back home all in effort to ensure that the patient the patient can access medicine and live pain free:

> [“... *It is challenging when medicine runs out at the same time my child falls sick and the transport fare intended for Hospice is then diverted to treating the child yet the patient needs medicine to relieve their pain. There are times I just come over to collect her medicine and the Hospice team here gives me transport back home*...”] **(Participant 15-Male Caregiver)**

4.3.5 Medical Support

Patients also receive medical care from HAU and this includes; reviews or assessment by medical personnel, provision of medicines like liquid morphine, pain killers and other forms of support that cannot be easily accessed by the patients elsewhere.

Bureaucratic tendencies affect access to cancer treatment in Uganda and thereby hinders completion of the cycle of cancer treatment. However, the care at Hospice which is accessed without bureaucracy, stabilizes the patient and helps them live pain free and is thereby outstanding, compared to other cancer treatments in Uganda:

> ["*…Nzikiriza nti singa eddagala lya'kookolo* (cancer) *lyali lifunika nalibadde namalayo dda doozi. Ndowooza obujjanjabi bwenfuna wano bunzikkakanya kubanga bwemba nga siri mu bulumi, kitegeeza nti n'ebilowoozo byange bibeera bilungi…*"] **Participant 1**

> ["…I believe that if that cancer medication was accessible, I would have completed the dose a long time ago. The treatment I get here is what stabilizes me because if I do not have pain, even my thoughts are good..."] **(Participant 1-Male Patient)**

The views aired out by participants revealed that the medicine given by hospice does not only relieve the pain but also manages the symptoms of the disease. For example, the patients used hospice medicine to dry up her wound:

> ["*…Mubutuufu, obulamu bwange bwadda engulu ku hosipisi kubanga muddwaliro eMulago namalayo dozi ye'ddagala naye ekiwundu kyange tekyawonela ddala. Naye oluvanyuma lwokusindikibwa wano nafuna eddagala elyakalizaddala ekiwundu kubeere lyange…*"] **Participant 3**

> ["…Actually, my life was revived at Hospice because at Mulago Hospital I completed the dose but my wound was not fully healed. It is only after I was referred to Hospice that I got medicine which completely healed the wound on my breast…*"*] (**Participant 3-Female Patient**)

Patients freely make consultations, assessments or reviews from medical personnel and medicine for cancer that enables them to live pain free. Notably, palliative care at Hospice Africa Uganda is packaged in a context that is fitting to the context of Uganda:

> ["*…The treatment I've been getting at Hospice is great and actually I've come for review but to also ask the doctor if there is other form of treatment that can help to dry up the wound because getting other medicines at Mulago Hospital is tedious…*"] **(Participant 4-Female Patient)**

Due to the challenges experienced by patients in accessing cancer treatment and medication in other health facilities like Mulago Hospital and Uganda Cancer Institute, some of the participants interviewed suggested that more supervision of cancer medication and equipment should be strengthened to avoid misallocation of drugs and breakdown of equipment:

> ["*…Singa hospice etekebwamu obusobozi bwonna obujjanjaba kookolo, kyandi tusanyudde nnyo. Walina okubawo obukuumi obwongeddwamu kuddagala lya kookolo nebikozesebwa okusobola okukendeza obubbibwe'ddagala mu basawo…*"]
> **Participant 4**

> ["…If Hospice could be equipped with all forms of cancer treatment, we would be the happiest. There should be improved supervision of cancer medication and equipment to control possibility of misallocation by some health workers…"]
> **(Participant 4-Female Patient)**

In addition to medical support, the statement below literally means that participant 4 suggested that the agency empowers patients as a form of support. Empowerment support to those patient's involved in small income generating activities (IGAs) is an effort to ensure self-sustenance of patients:

> ["*…Hosipisi esobola okugaba eddagala lya kookolo lyona naddala eri'abalwadde abatesobola n'okuyamba abo abakolayo emirimu emitono egyigendeleddwa okwongela kunfuna yabwe mubuli ngeli yona okusobola okukendeza kubuzibu bwebayitamu…*"] **Participant 4**

> ["...Hospice Africa Uganda can help to provide all cancer medicines especially for patients who are needy and support those others who are carrying out income generating activities in any way so as to address the major psychosocial needs..."]
> **(Participant 4-Female Patient)**

Every time that the liquid morphine is taken by patients; the pain disappears completely hence enabling patients to live pain free and sleep comfortably as long as they have the medicine to relieve the pain and take it as prescribed by professional caregivers:

> [“…*Obulamu bukyukila ddala bwenywa eddagala lya hosipisi kubanga obulumi bugendela ddala*…”] **Participant 6**

> [“…Life changes completely for the better whenever I take medicine from Hospice in that the pain goes away…”] **(Participant 6-Male Patient)**

> [“…*Eddagala lyetufuna wano lituyamba okubeera mubulamu obutalimu bulumi no’kwebaka obulungi n’olwekyo omuntu alina okutambula nalyo buli walaga. Obulumi bukomawo eddagala lya’mazzi (morphine) bweligwawo*…”] **Participant 8**

> [“…The medicine we get here helps us to live a pain free life and sleep so comfortably and so one has to move with that medicine everywhere. Pain only re-occurs when the liquid morphine is finished. I was given medicine to put on my wound to keep it dry...”] **(Participant 8-Male Patient)**

The medicine that HAU provides does not only relieve pain but also manages the symptoms of the disease as mentioned in the significant statement by participant 8 who was given medicine to help dry up his wound.

The Patients at HAU have a sense of security and certainty in receiving cancer palliative care whenever they come to the agency unlike in other cancer treatment centres. When patients fail to raise funds for cancer treatment or access medicine at other centres they console themselves in the fact that Hospice Africa Uganda will help with pain relief medication that is free from any payments:

> [“…*Treatment has helped me a lot especially the medicine we get at Hospice. I get more medicine at Hospice and it has really worked a lot. There was a time when I failed to raise money for chemotherapy (100,000 shillings) but I knew that I would get other medicine from Hospice* …”] **(Participant 9-Female Patient)**

Noticeably, cancer medicines are very expensive for the common man but the majority of patients interviewed for example participant 10; revealed that the medicine provided by HAU is free of charge with exception of those clients who are in position to make a contribution of 10,000 shillings every time they come to the agency to collect medicine:

> ["…*Cancer medicine is very expensive but at hospice we get medicine free of charge*…"] **(Participant 10-Female Patient)**

In this statement, the caregiver expresses his contentment for palliative care package at Hospice Africa Uganda and goes on to highlight the fact that the patient also receives other forms of treatment due to her advanced age:

> ["…*There are other kinds of treatment that my mother receives especially with her advancing age but that doesn't stop her from getting palliative care. I am very contented with the palliative care package at Hospice Africa Uganda*…"] **(Participant 11-Male Caregiver)**

The caregivers acknowledged the positive effect palliative care on their patients' lives in the expressed views. There was a caregiver in particular who stated that her patients' life would be worse if she had not found out about palliative care service available at Hospice Africa Uganda:

> ["…*Palliative care has reduced her pain so much and the swelling on her hand has reduced except for the lower part of the hand. She was diagnosed with breast cancer and if it was not for palliative care it would have been worse*…"] **(Participant 14-Female Caregiver)**

One of the caregivers revealed that he had not wasted any financial resources on buying alternative medicine despite the fact that herbalists move around his village marketing their herbal medicine. He further stated that he consults the palliative care team in case there is a challenge with the medicine and they guide appropriately on how best to administer medication to his mother in the right dosage depending on the kind of persistent pain she is experiencing:

> ["…*Palliative care has helped me to save money because in the village we have herbalists selling herbal medicine. In case, I give her the dosage of the liquid morphine as advised by doctor and she still feels the pain I then consult the clinical team and they advise me to double the dose*..."] **(Participant 15-Male Caregiver)**

Hospice also acts as a link between patients and agencies or partners that fund certain forms of cancer treatment. This is an initiative that has been of benefit to patients who cannot afford the much needed cancer treatment:

> [“*... At first life was extremely hard to get chemotherapy due to the cost but I later got support from hospice team and other partners that combined to help my mother so that she can get chemotherapy...*”] **(Participant 15-Male Caregiver)**

According to the next statement by a caregiver, HAU goes an extra mile in ensuring that patients get their medicine regardless of the geographical disparities in location by providing some caregivers with transport to collect medicine for the patients:

> [“*…Every time I come here to collect my mother’s medicine I spend a lot on transport which is a challenge for me and so the Hospice team gives me transport fare sometimes when I come to pick medicine. This is done to ensure that the patient gets access to medicine…*”] **(Participant 15-Male Caregiver)**

The caregiver revealed that she found relief after her mother’s pain was managed to the extent that she can now manage to work without pain hence palliative care also addresses the needs of caregivers as well:

> [“*…Before she started receiving Palliative Care at Hospice, I used to worry so much about her but from the moment she started receiving palliative care I kind of got a relief that her pain can be managed when it manifests. Currently, she can now to go to work in the market where she has a stall without pain…*”] **(Participant 16-Female Caregiver)**

Palliative care to both the patients and caregivers is emphasised as the very important thing as stated by some caregivers. The medicine to relieve pain is usually packaged to last for one week until the next appointment:

> [“*…I have no fears at all now because I know she is in safe hands at Hospice. The most important thing with palliative care is that she gets medicine to manage her pain and that is what matters most to me...*”] **(Participant 16-Female Caregiver)**

4.3.6 Food Support

Hospice Africa Uganda at times provides food support to patients in need only when the food is available. The food supplied to patients includes; grains like rice, maize flour and sugar. Food support enables patients to manage throughout the week until they return to the agency for their next assessment usually every Tuesday although one can come over when there is need during the course of the week. Notably, patients on palliative care find relief to carry on taking their medication if there is food security.

There were views from some participants that expressed total appreciation of palliative care context at Hospice Africa Uganda while other views expressed great need for increased food support. For instance; the food supplied by the agency is part of the support services that patients consider valuable and of benefit to them. This is evidenced in the significant statements suggesting that this support improves the palliative care package provided by HAU because the patients deem it appropriate:

> [“…*Obujjanjabi obuweweza kubulumi bunyambye nyo n’amaka gange okukendeza ku kwelarikirila ekyokulabilako nfuna ekyokulya ng’ekyenkya ne’kyemisana nga nzizewano era ne’motoka ye’kitongole etunona ne’tuzzayo buli lwakubiri. Oluusi tuwebwa emere etuyisa mu’wiki*…”] **Participant 2**

> [“...Palliative care has relieved me and my family of a lot of stress for example I get what to eat especially when I am here I get breakfast, lunch and the agency car picks us from home and returns us after the day care. Sometimes we are given food that takes us through the week...”] **(Participant 2-Female Patient)**

> [“…*Sikyangu okubeera kuddagala ate no’gatako ebula lye’mere kubanga olumu ozukuka nga tewali mere munyumba ate nga olina okumila eddagala lyasirimu ne kookolo. Muganda wange omusomesa ansasulila sente ze’nyumba (rent) buterevu kusimu ya’landlord (mobile money) olumala landilodi nga’mpa lisiti*…”] **Participant 2**

> [“…It is not easy to be on medication and lack what to eat as well because sometimes you wake up and there is no food in the house yet you have to take ARV’s and cancer medicine. My brother helps to pay my rent directly to my landlord on her mobile money account and the landlord brings me the receipt…”] **(Participant 2-Female Patient)**

> [“…*There are times when agency has food like rice, beans, maize floor and other foodstuffs they give us to cook at home. I thank God for this agency and for the health care providers at HAU*…”] **(Participant 10-Female Patient)**

4.4 Patients’ perceptions of cancer palliative care at Hospice Africa Uganda

Perceptions of patients in this aspect can be defined as the way patients perceive or understand cancer palliative care at HAU. Patients’ perceptions can either be positive or negative depending on their understanding of the value of the care they receive at HAU compared to the care received from other cancer treatment centres.

4.4.1 Scope of Palliative Care services

The scope of care services in palliative care also involves care given to both patients and their caregivers including; physical, emotional, medical, financial and spiritual care. With palliative care, the participants acknowledge relief from pain and their families also relieved from the concern of medical expenses because at Hospice Africa Uganda care is free of charge.

One participant stated that she does not have to spend at all even when she is coming for review at the agency because the agency transports her from her home to the agency and return her after the day care:

> [“…*Obujjanjabi obuweweza kubulumi bunyambye mungeli nti baganda bange basanyufu nti sikyabatawanya kubateka kubunkenke okwelarikirila okusasanya sente emulago naye mbaburila bubulizi nti nva mu ddwaliro*…”]. **Participant 2**

> [“…Palliative care has helped me in a way that my family is happy in that I no longer put them on pressure to worry about spending money in Mulago but instead I just tell them that I am from the hospital…”] **(Participant 2-Female Patient)**

Some participants commended the empathy and compassion of the palliative care team at HAU because of the care they receive every time they come at the agency. The professional caregivers according to participant statement are so humane in their caregiving because they make her feel loved and cared for when they go out of their way to be concerned about what choice of food she desires to eat while at the agency for a day care on Tuesday:

> [“*…Ndimumativu era nga ndi musanyufu no’obujjanjabi buno, kubanga bano abantu batufaako nyo era batuyisa nga abana abato. Tulibantu bakulu naye bwetugya wano batufaako bulungi nebatubuuza kyetunalya oba kyetwagala okunwa ekituyamba no’kwagala okulya. Mazima aba hosipisi bantu balamu nyo ate balina ekisa…*”] **Participant 3**

> [“…I am very contented and happy with palliative care because these people care so much for us and treat us like babies. They take good care of us and even ask us what kind of food we wish to eat and give us drinks which helps us even get appetite. Indeed the hospice team is very humane and full of empathy…”] **(Participant 3-Female Patient)**

According to the participant statement below, Hospice was and still is a strong support group because she was already among hospice patients being treated for another condition when she was diagnosed with cancer. This helped her to cope and be strong despite being diagnosed with another terminal illness while she was battling another:

> [“*…Natandika okuwulila obulumi nendowooza nti nseke ze’zinuma. Bampa amakelenda neddagala eddala eliweweza kubulumi nga terikola paka abasawo lwebasalawo neyongeleyo okwekebejjebwa. Oluvanyuma kyazulibwa nti nnina kookolo naye nalimugumu kubanga nalina abantu abanzizamu amanyi ku hosipisi…*”] **Participant 2**

> [“…I started feeling pain and I thought it is the fallopian tubes paining me. They used to give me painkillers to relieve the pain until they suggested that I go for further testing. After the tests were carried out it confirmed the presence of cancer

> but I was somehow strong because I had a strong support group with HAU…”] **(Participant 2-Female Patient)**

The views by one of the patients who participated indicates that the quality of her life has tremendously improved after she started receiving palliative care compared to the past when she was so weak and could not walk on her own. The improved quality of life is clearly manifested in the renewed abilities like walking, ability to work again and dignity that comes with confidence and independence:

> [“…*Okuva lwenatandika okufuna obujjanjabi obuweweza kubulumi, obulamu bwange bwakyukiladdala n’okutuusa kati abaana bange bewunya byensobola okukola. Mutabani wange eyaddamu okundaba oluvanyuma lwakabanga takikiriza nti yenze kubanga embeera yo’bulamu bwange yali nnungi nyo*…”] **Participant 4**

> [“…Since I started receiving palliative care, my life has tremendously improved to the extent that my family marvels at what I’m capable of doing now. My son saw me again after a long time and couldn’t believe it was me because the quality of my life had improved so much…”] **(Participant 4-Female Patient)**

Another participant who was a patient with the agency also acknowledged relief from pain after she uses morphine, but also she mentioned a recent re-occurrence of stomach pains that at times cause her to bleed and make her feel so uncomfortable:

> [“…*Obujjanjabi obuweweza kubulumi bunyambye obutaba nabulumi wadde buno obulumi obwazze jjuuzi mulubuto lwange bundetela no’kukulukuta oluusi bumbuzizaako emirembe naye omusawo nakimugambyeko. Bwenwa eddagala lya hospice ne’mpeke ezimpebwa okusa kukiwundu mpulila obuwewevu*…”] **Participant 5**

> [“…Palliative care has helped me not to have any pain at all but this recent pain that turns in my stomach and causes bleeding sometimes is making me uncomfortable but I told the doctor about it. When I take the medicine given here at Hospice and the tablets given to put on my wound I feel some relief…”] **(Participant 5-Female Patient)**

At Hospice Africa Uganda, there are no penalties for missing an appointment like in Mulago Hospital which is a good aspect because there may be various reasons as to why a patient or their caregiver would miss an appointment for assessment and receipt of medicine:

> [“*…When I came here I was amazed that the professional caregivers at hospice are well trained in caring for patients for example they care so much for us that even if you miss your appointment you are not chased away the next time that you are able to come like it is at Mulago Hospital…*”] **(Participant10 -Female Patient)**

4.4.2 Knowledge of Palliative Care Services

The term Knowledge means information or awareness gained through information or experience. In this case, knowledge in palliative care refers to the level of awareness about the existence of palliative care and its purpose.

Most participants interviewed revealed to have discovered about palliative care through other patients at Mulago Hospital or through friends while others were referred by Doctors. There is need to prepare the caregivers about any eventualities by full disclosure of any information regarding the progress of disease in the life of their loved one.

Professional caregivers do not disclose information to the patients and caregivers regarding the progress of disease. More so, there is no clear explanation as to why they are receiving palliative care at that particular time. Failure to disclose information to caregivers about the goals of palliative care leaves patients in uncertainty:

> [“*…The Doctor said some people might tell me that cancer is incurable yet it can be cured but when I asked him to give me real facts about her type of cancer and whether she will recover from it at this stage, he was not even able to tell me the correct information…*”] **(Participant 13-Male Caregiver)**

> [“*…I wonder if my patients’ cancer will cure* now *that she is receiving palliative care because I was told that it had spread to the lungs and it is in the third stage…*”] **(Participant 14-Female Caregiver)**

The majority of caregivers are never equipped with basic skills in caregiving but learn with experience by either following instructions on administering medication and gaining confidence to inquire from health workers about any health issues that may arise. Caregiving is therefore an experience through which family caregivers learn and acquire positive attributes like empathy or being able to understand the pain of the patient:

> ["…*Caregiving has been a learning opportunity for me regarding human behaviours because in the past I used to think that my wife was trying to cheat me whenever she would request for 20,000 shillings to go for antenatal care. These days I am so different and am confident to consult health professional about anything*…"] **(Participant 15-Male Caregiver)**

> ["…*There are no skills that I was equipped with as a caregiver and so I always read the instructions on the medicine and follow them promptly. As a caregiver, I also make sure the medicine is administered timely and that she gets her meals regularly*…"] **(Participant 16-Female Caregiver)**

4.4.3 Improved quality of life

Improve quality of life in palliative care is the ability of palliative care to restore a patient's strength, abilities to carryout day to day activities and eventually enable them to die in dignity. According to the interviews with the patients, most of them attributed their improved quality of life to the palliative care they receive at HAU.

Caregivers clearly indicate a renewed outlook on life and restored hope with new abilities while receiving palliative care. The quality of life has been significantly improved for the patients with renewed abilities and energy:

> ["…*Obulamu bwanjjawulo nganfuna obujjanjabi obuweweza kubulumi kubanga oba olina esuubi. Mubutuufu obujjanjabi buno bwongedde okulongoosa embeera yobulamu bwange era waliwo enjjawulo nnene nyo mungeli gyendabika*

> *bwogelagelanya nebwe nali ndabika nga sinagya wano ku hosipisi…*”] **Participant 7**

> [“...Life is completely different when receiving treatment because then you have hope. Actually with palliative care, my quality of life greatly improved and there is a great difference in how I look compared to how I was before I came to HAU…”] **(Participant 7- Male Patient)**

> [“*…I really cannot believe how palliative care has improved the quality of my life. Imagine you even entered my house and found me in deep sleep that I couldn't hear you walk in. Indeed it is amazing that I can even sleep or rest whenever I am tired. I'm grateful for the care I get from Hospice…*”] **(Participant 9-Female Patient)**

> [“*...In the short time (two weeks) we have been here, I now realize that the recommendation given to us by the doctor was a great idea. This is because my father's condition has tremendously improved since he started receiving treatment from HAU…*”] **(Participant 12 - Male Caregiver)**

> [“*...When we were referred to Hospice for palliative care, her condition improved. Palliative care has improved the quality of my mother's life because when we first came here I used to carry her but now she can walk on her own and cook her own food. I really take long to even hear her complain of any illness or pains…*”] **(Participant 15-Male Caregiver)**

4.5 Caregivers' perceptions of cancer palliative care at Hospice Africa Uganda

Perceptions refer to the way of seeing things or an understanding of the importance of something. The perceptions caregivers are reflected in the significant statements below and notably the majority of caregivers' perceptions are positive towards palliative care with exception of some who may not have fully understood what the care is all about.

4.5.1 Prolonged Life

Prolonging life in relation to palliative care refers improving the quality of life or ability for palliative care to extend life for a patient with chronic illness to another level thus granting them more abilities and helps them to die in dignity. Basically, the goal of palliative care is to relieve patient's pain and manage symptoms of the disease which in turn improves the quality of life thereby prolonging the lives of the patients that receive palliative care to a certain extent as revealed by the patients and their caregivers in the interviews carried out throughout the study.

There were caregivers who revealed that the lives of their loved ones has been prolonged because before they started receiving palliative care they expected their loved ones to die sooner but once the patients started receiving palliative care there was a drastic improvement in the quality of their lives. The caregivers therefore attribute the prolonged life of their loved ones to palliative care and estimate that with palliative care their loved ones may be able to live another year or two:

> [“*...Palliative care has greatly prolonged my mother’s life and basically improved her quality of life because I always thought her time of death is close and we used to give her two or three days but now I’m confident that she will make it even beyond this year…*”] **(Participant 11-Male Caregiver)**
>
> [“*…Now with palliative care she is now able to sleep at night peacefully so I believe there has been a positive change in her life. I also believe PC has somehow prolonged her life because at some point I thought the time for her death was close but now I can see her able to manage her daily life well which is amazing…*”] **(Participant 15-Male Caregiver)**
>
> [“*…Previously when I used to carry her up I had a fear that she would die any time from then but now she is strong and in better condition compared to other patients who can no longer carry out personal activities. Currently, I no longer worry about how I would manage in case she passes on…*”] **(Participant 15-Male Caregiver)**

4.5.2 Empathy and Compassion in Palliative Care

Compassion in the context of palliative care is to have genuine concern for patients while empathy is putting oneself in another person’s position or have an ability to understand or share the feelings of another. In palliative care, the essence of it all is for professional caregivers to be able understand or share the feelings of patients and informal caregivers. This can be manifested in being sensitive to the experiences of patients and informal caregivers in the process of providing palliative care.

The statement of the caregiver 11 reveals that caregiving is a life transforming experience in that he has been influenced to care not only for his mother but all people with advanced age in his village because he has the capacity. He also vowed to carry on caring for old people even after his mother passes on because according to him the number of people with advanced age is overwhelming even to the government yet most of them lack basic needs in life even when they do not have terminal illnesses like cancer:

> [“... *After consultations it seemed that the best alternative was Hospice Africa Uganda for palliative care and so far I am okay with them they are doing well. Palliative care has had a great impact because they receive us well every time and when you call them, they respond and also do home visits when necessary…*”] **(Participant 11-Male Caregiver)**
>
> [“*...I don’t only look after my mother but also care for many other people as long as they are connected to me and I think after my mother I will set up a standard whereby I will be looking after whoever clocks 90 years in my village. I will welcome them all and I take care of them for free by meeting all their needs* …”] **(Participant 11-Male Caregiver)**
>
> ***(Caregiver is overwhelmed by emotions and breaks down and wipes the tears thereafter the interview continues)***

Caregiving as stated by participant 14 is a selfless experience that requires dedication of the caregiver because she has to frequently be away from work and her colleagues stand in for her so that she can be with her mother in law in the hospital. This does not differ so much to the majority of cancer caregivers who at times have to give up their work to become full time caregivers to their loved ones. Basically, the lives of caregivers are transformed suddenly after their loved ones are diagnosed with cancer and they decide to provide care either on part time or full time basis:

> [“*…I am working in Ggaba and I’m also the main caregiver for Mercy but when I’m not at home there is a young man who stays there to care for her. I am called upon in case of emergencies and that’s when I request time off work but this has put my job at risk and yet I need it…*”] **(Participant 14-Female Caregiver)**

Despite being sick, it is important as highlighted by the caregiver to continue valuing the patients input for example if they have been involved in decision making process of the family they should continue being consulted on some issues so that they do not feel left out of operations of the family. One of the caregiver's revealed how he has kept on consulting his mother simply because he values her experience in life and wisdom. This can be therapeutic to the patient because it helps them feel they are still in control of their senses and running of their family affairs:

> ["*...I personally experience bigger challenges but I have learned to value my mother's wisdom because she is more experienced in life than I am and consult her and let her know that her guidance is still valued in my life…*"] **(Participant 15-Male Caregiver)**

4.5.3 Anxieties of Caregivers

Caregivers experience a lot of psychosocial challenges in the process of caring for their loved ones. There were views by some participants revealing that caregivers worry a lot in addition to living in a state of uneasiness throughout the caregiving process. There was some caregivers'who revealed that palliative care package at HAU also relieves them of the trauma they experience in caring for a loved one in pain. When they access palliative care they are pain free something that relieves both the patient and their caregivers of all worries.

Although the impact of palliative care is instant to the patient in that someone who has been restless and in pain all the time is finally able to live pain free and can sleep comfortably after receiving palliative care, this in turn benefits the caregivers as well in that all anxieties of the caregivers are relieved. With palliative care, caregivers are able to deal with and solve many other psychosocial issues they experience in the caregiving process:

> ["*...There are a number of challenges I experience as a caregiver on a daily basis for example I am so stressed that I feel I cannot take it anymore especially when my dad becomes so tough and agitated. At times, he raises his tone against me and locks himself in his room which makes us worry more that we cannot access him…*"] **(Participant 12 - Male Caregiver)**

With palliative care, caregivers aired out views that during the cargiving experience there were strong bonds or relationships between the patient and the caregiver in that a patients warms up to their caregivers in most cases after they overcome the bitterness of having the disease. This relationship is strengthened when the caregiver relentlessly gives care without ceasing or getting weary but takes the caregiving process as a day to day learning process:

> ["*…I feel good when she is not in pain and every time I see her playing I am filled with great hope. Palliative care has not fully addressed the psychosocial needs of people like me. I am 17 years and I was in school in Karamoja but I decided to quit school to help my young sister to go through her cancer treatment…*"] **(Participant 13- Male Caregiver)**

> ["*...Palliative care has greatly improved the quality of mercy's life by reducing her pain tremendously and relieved me as well of the trauma I always felt every time I heard her groan in pain all night...*"] **(Participant 14 - Female Caregiver)**

> ["*...It is a blessing to care for my mother in law because her last born daughter stays with us but is not fully involved in her care. Mercy is now happy with the care I give her and every time someone asks her anything regarding her treatment she refers them me because I know all the details about her treatment...*"] **(Participant 14 - Female Caregiver)**

4.6 Quality of Care in Pallaitive Care

Quality of care in palliative care is the acceptable standard of care in palliative care which is holistic and includes caring for both patients and their family caregivers. The care provided addresses the patients and caregivers needs according to their given context. Palliative care effectiveness is whereby the care given has a positive impact or results.

In this case, the care given at Hospice Africa Uganda can be used to provide feedback to the agency on the services provided to patients and their families as they give feedback through various mechanisms in place. The following were identified as ways through which quality of care in palliative care can provide feedback to the agency regarding the care given to clients.

4.6.1 Waiting Time for Patients and Caregivers

The waiting time for both patients and caregivers at the agency was found to be quite long even when there seemed to be a few patiens at the reception area. The act of how patients and their caregivers are received at the agency and the reaction of professional caregivers thereafter can either influence positive or negative feedback regarding the service provision. In regards to the patient and professional caregiver ratio at HAU and the time taken to process the liquid morphine for the patients it is reasonable that delays can occur but there is need for the agency to tone down the operational practice of ***"first come first serve"*** as stated by one of the key workers so as to address the urgent needs of patients who either come or are brought in with extreme pain and require urgent medical attention.

Long waiting time at the agency also contributes to negative perceptions of palliative care among patients and caregivers. Patients and caregivers experience the challenge of long waiting time at the reception when they come to collect medicine at Hospice Africa Uganda:

> ["*...Sometimes I sit here for a long time waiting for a doctor to make assessment so that I can get my mother's medication. But somehow, I feel like the team here does not care about the time we spend waiting here. Apart from the long waiting time, they are really excellent in providing care to patients...*"] **(Participant 11-Male Caregiver)**

> ["*...Patient's and caregiver's experience long waiting time which makes patients who come for review feel like they are not cared for. As a caregiver, I come to collect medication for my father but I feel that the waiting time is exhaustive and draining...*"] **(Participant 12- Male Caregiver)**

4.6.2 Client Feedback and Communication

Clients of the agency have opportunity to express their perceptions of the care package received at the agency through participating in research projects by researchers at the agency and visiting researchers. Research is one way the agency can obtain feedback from the beneficiaries of palliative care service regarding the quality of care given and hence enabling monitoring and evaluation of agency performance in providing care to patients and their families.

Observation in Patient waiting room (Reception) on 28th-06-2016

Looking at the patients' faces and tone of voice I realized that their expressions came with a lot of pain for instance in a discussion among patients at the reception one of the oldest patients at HAU said that:

> ["…*The patient waiting time is getting worse by the day. Imagine we have been waiting here for over an hour for review but they haven't called in anybody yet we are few. Hmm if you think it is better now then you don't know how it was in 2003 when the agency had just started. The pioneer palliative care team used to provide comprehensive care. They would even carry us out of the car and back but now hmmm the team they left only have their own programs. I guess they are doing their own things. When you come here these days you have to be extremely patient until they decide to call you in for review…*"] **(Patients discussion in waiting room).**

4.6.3 Patient-Centered Care

Patient-centred care is key to breaking down any barriers to effective feedback mechanisms because once patients and their informal caregivers sense any resentment or distance between them and professional caregivers they will be inhibited to opening up especially in regards to personal of social issues affecting them and the care they receive at HAU:

> ["…*Kyetagisa okusaawo enzijjanjaba eye'sigamye enyo kubalwadde okusobola okugyawo emiziziko gyona egyiziyiza abalwadde nabajjanjabi okwogela kunsonga zonna ezibakwatako era ngaziyinza okulemesa enzijjanjaba eweweza obulumi bwa kookolo okukola obulungi*…"] **Participant 7**
>
> ["...There is a need to establish a care package that is more patient-centred to help break down any barriers that hinder patients and their informal caregiver's from opening up more about social issues that could hinder progress of the palliative care package..."] **(Participant 7- Male Patient)**

The participants expressed views suggesting that if Hospice Africa Uganda, Uganda Cancer Institute and Mulago Hospital coordinate in service provision the unexplained delays and bureaucratic tendencies within some of these agencies will be over with. Coordination between Hospice Africa Uganda and other cancer treatment centres is called upon so as to help patients to access all forms of treatment required without unnecessary delays. Patients believe that Hospice Africa Uganda can influence the health care workers in Mulago to understand the urgency of receiving the treatment they require in time:

> [“*...I recommend Hospice to help take patients to Mulago Hospital for chemotherapy or maybe help speed up treatment because at Mulago Hospital they (patients) are told to buy the medicine and then after spending all day there they are then asked to return another day which is more stressful and wasteful at the same time*…”] **(Participant 14- Female Caregiver)**

4.6.4 Formal and Informal Caregivers

Caregivers refers to those individuals who provide ongoing care and assistance to patients with terminal illnesses. They are classified into; formal or professional caregivers and informal caregivers. Formal caregivers include; Doctors, Palliative Care Nurses and social workers while informal caregivers include; family members and friends. Therefore, there is need for a strong working relationship between professional caregivers and patients so as to foster a care package that is appropriate and full of empathy:

> [“…*Ndowooza obujjanjabi obuweweza kubulumi bwa kookolo buyiinza okulongoosebwamu okusobola okulowooza kubyetaago bya balwaddde singa kisoboka kyandibadde kilungi. Nandi wabudde abajjanjabi okuteekawo enkolagana eyamanyi na’balwadde okwongela okufaayo mu nzijjanjaba yabwe*…”**] Participant 7**

> [“...I think palliative care package can also be modified or improved to address all needs of the patients. If palliative care is modified it would be a great idea. Actually,

> professional caregivers ought to establish strong relations or bonds with the patients to instil more empathy in their care giving package…”] **(Participant 7- Male Patient)**

Caregivers are called upon to intensively monitor the care they provide to the patient and not compromise in any way regardless of any the location of the patient. Monitoring and evaluation gives feedback to both formal and informal caregivers on the care provided to patients and the feedback whether positive or negative helps to improve the caregiving experience:

> [“…*There is a great need to give serious monitoring to the patient because the moment you forget the routines like administering medication then the standard care is likely to be compromised. It important to ensure that you are monitoring whether the patient is in the village or in town*...”] **(Participant 11- Male Patient)**

Although Patients are living with cancer, there is great need to maintain their human dignity throughout the whole experience of care giving. Human dignity is manifested in the mode of care given by both professional and family caregiver:

> [“...*Mercy is on good terms with God, her children and grandchildren. I ensure that her dignity is maintained despite her illness by ensuring that her home is kept clean. She can now watch television and listen to radio in her room. There is also a young man at home who takes care of her while I’m away*...”] **(Participant 14- Female Caregiver)**

4.7 Roles in Health Care

The roles in health care are defined as obligations or responsibilities of all stakeholders in provision of care to patients and their family members. It was found out that both the government and the individuals have a role to play in provision of health care. While these roles differ in magnitude, they are clearly vital in meeting the needs of patients who are experiencing pain with terminal illnesses like cancer.

4.7.1 Roles of Government

The Government is obliged to address the rise in non-communicable diseases like cancer by investing more in creating awareness among Ugandans with a major goal of educating the people on how to prevent cancer and measures to take so as to address the problem of cancer. There is need for government to integrate palliative care in the education curriculum and equip all hospitals and health centres with personnel and equipment to facilitate cancer screening by all Ugandans without any hindrances. This can only be achieved if the government prioritises cancer prevention and treatment in Uganda:

> [“*…The government should put emphasis on prevention and treatment of cancer. This saddened me when I found out because after the doctor checked my mother he told me she has a terminal illness and that she will not die soon*...”] **(Participant 15- Male Caregiver)**

4.7.2 Roles of Individuals

Caregivers strongly believe it is their obligation to care for their family members who are diagnosed with terminal illnesses. Given the strong support system in the African culture whereby every one supports each other in time of need; it is reasonable that patients are supported by their family members or community in which they live so as to go through the ordeal as a community. This strong support system helps the patient going through the pain to understand that they are not alone through the trying moments of their lives:

> [“*...It is obvious that every time someone gets sick it is the responsibility of the family members to care for them but there are diseases that overwhelm us as caregivers and that is why we need for support from government…”*] **(Participant 15- Male Caregiver)**

> [“*…I am requesting that they consider providing some facilitation for patients like me who are overwhelmed with social needs. Most of us struggle to even get what to eat yet we are on strong medication and we have been incapacitated by our health*

> *conditions and cannot easily get involved in gainful employment…*”] **(Participant 6-Male Patient)**

4.8 Lessons Learned

The lessons learnt were quite many and some emerged from the participants as well. For example, I was able to understand the value of routine body screenings (body checkups) and self-examination to identify any growths on the body so as to enhance early case detection and management.

The government of Uganda was urged to put more emphasis on the treatment of cancer by increasing funding for the Ministry of Health. It was also emphasized that priority needs to be focused more on the prevention of cancer than treatment because the burden of treating the disease is overwhelming to the government and the majority of Ugandans. One participant urged government to equip all regional hospitals and health Centre’s with equipment to screen cancer and necessary medicine:

> [“…*There is no much reason why everyone should travel to Mulago Hospital in Kampala because the government can equip all regional hospitals with facilities and equipment to screen and treat cancer so that all women and young girls have access to routine screenings...*”] **(Participant 15- Male Caregiver)**

4.9 Summary of Key findings

This study vital information in relation to the perspectives of patients and family caregivers on cancer palliative care at Hospice Africa Uganda. The key issues which emerged according to the objectives of the study were:

Objective 1:

The views of caregivers are quite divergent from the patients experiencing the pain which implies that there is no clear understanding of the nature of support to the patients and caregivers. Nevertheless, it was recognized that Hospice Africa Uganda gives medical, financial and food support to patients. However, financial support differs between rural and urban centers of the agency, it was inadequate and access to financial support was found to be inequitable between cancer and HIV/AIDS patients.

Objective 2:

The study found out that palliative care has improved the quality of life of patients while the caregivers’ anxieties were significantly reduced when their patients started receiving palliative care. Caregivers also strongly believe that the lives of their loved ones have been prolonged due to palliative care. However, some participants aired out views that professional caregivers withhold information regarding progress of disease and purpose of care given to both the patients and their caregivers.

Objective 3:

Given the fact that client feedback and communication is a vital measure of determining the quality of care provided to the patients and their caregivers. The study found out that mechanism of feedback at Hospice Africa Uganda had gaps and because of such gaps it means that patients were either suffering silently because there was no clear client feedback and communication mechanism. The roles in health care among individuals towards their loved ones were found to be clearly known although many caregivers were overwhelmed by the care burden and required urgent support from government whose roles in health care need to be emphasized so as to efficiently manage the burden of cancer treatment.

CHAPTER FIVE

DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.0 Introduction

This chapter provides a discussion of the findings of this research and the emergent themes from the findings of the study are discussed through the conceptual lens of available research and literature. The chapter concludes with a presentation of an overall emergent concepts in the context of the explicated themes.

5.1 Discussion of Results

The following is a discussion of the emergent themes in the context of existing literature that relates to patients and informal caregivers on cancer palliative care at Hospice Africa Uganda. The four emergent themes were: Nature of support at Hospice Arica Uganda, Patients' perceptions of cancer palliative care, Caregivers' perceptions of cancer palliative care and the Effectiveness of feedback mechanism at HAU.

5.2 Nature of Support at Hospice Africa Uganda

About the nature of support given by Hospice Africa Uganda, one of the key findings was that the financial support which was as per the view points above later on stopped due to the decline in donor funding and for this reason the inadequacies, disparities or inequities in access to care can be justified given the fact that the agency majorly depends on donor support to operate.

Different views were aired by the participants in the research about the nature of support at HAU and the key category was of those who said the nature of support was that of the medical support, food support and financial support. However, some participants stated that financial support differs between urban and rural settings. Inequitable access and inadequate palliative care services is a major challenge in sub-Saharan Africa given the rising social needs of patients and caregivers while seeking for cancer therapies. By the time most patients get diagnosed with cancer, they can no longer sustain themselves and need extra support so that they can easily access the much needed medical care. This is particularly so in case of severe symptoms or co-morbidities such as HIV/AIDS and cancer.

Looking at the nature of support, many of the participants argued that medical support and financial support were the main kinds of support required by the participants and this is in agreement with HAU (2006), which noted that patients may experience recurrent infections and painful conditions when they come to Hospice but once these are managed and treated, the patient no longer complain of symptoms and may not require palliative care until the next episode of pain or symptom but may require other supportive care such as spiritual care, social support, and counseling. The need for palliative care, especially pain and symptom control increases as the disease progresses (HAU, 2006).

The difference in financial support between patients in rural and urban areas may be due to the arrangement of financial facilitation to patients at HAU which differs from that followed by rural branches of the agency. It is believed that social and medical needs of patients in rural areas are higher than those of patients in urban settings.Vilalta *et al*, (2014) is divergent in his arguement that in palliative care the emphasis is majorly on how palliative care is provided in all its components plus other aspects so as to ensure that the care package maintains the dignity of the patients and their families. Clearly, inequities in access to care do not maintain dignity in the care package of Palliative care for patients and informal caregivers. This is in line with *Siebel et al*, (2014), who argued that physicians need to develop a reflective attitude and a patient approach which truly enables the terminally ill to participate in shared decision making.

With reduction of donor support, the agency downsized its operations by ensuring that only the main needs (medical) of patients are met except in extreme cases. This concurs with Rosenberg *et al*, (2013), who noted that cancer care ought to include the provision of appropriate integrated services to optimize psychosocial outcomes. In addition, Hudson & Payne, (2011), argued that public health approaches should also focus on addressing the lack of support for caregivers in impoverished regions and for minority caregiver groups.

Furthermore, inequitable access to palliative care for some patients manifested in views emphasised by the participants. Existing inequities in financial support between HIV/AIDS and Cancer patients reveal that sub Saharan states have a long journey to the elimination of such barriers to palliative care let alone ensuring accessibility for all in pain as a basic human right given the rising need for the palliative care specialty. However, the general lack adequate palliative care services in Uganda is a major challenge given the steady rise in cancer cases globally. This is divergent to Harding&Higginson, (2005), who argued that palliative care in African countries is designed to fit within the cultural, spiritual and social contexts within Africa. Harding&Higginson, (2005), further noted that palliative care needs in Africa include home and respite care, pain and symptom control, financial, emotional and spiritual support, and also food, shelter, legal help, and school fees. Therefore, if any of these aspects of care is adopted it ought to be fairly distributed according to the needs of all patients regardless of any other factors.

More so, it was discovered that the financial support provided to patients at HAU was inadequate given the multiple social needs they face on day to day basis. This is divergent with Hudson and Payne, (2011) who argued that there should be substantial and sustained commitments to improve services and resources for family caregivers, by governments, health authorities, and research councils in order for palliative care to deliver upon its core function of adequately supporting the patient along with the family. Radbruch *et al*, (2013), was of the view that palliative care can effectively relieve pain or suffering and can be provided at relative low cost and access to palliative care has to be considered as a human right. In cases of particularly severe suffering, failure to provide palliative care may constitute cruel, inhuman, or degrading treatment.

In terms of the nature of support therefore, medical support was over riding all other kinds of support as indicated by the majority of participants interviewed. However, this is quite different to what is emphasised by Hudson &Payne, (2011), who argues that the kinds of support in palliative care should be inclusive of both the patient and family caregiver hence the health services are mandated to support the family alongside the person diagnosed with a life-threatening illness. Unless there are substantial and sustained commitments to improve services and resources for family caregivers, by governments, health authorities, and research councils, palliative care will fail to deliver upon its core function of adequately supporting the patient along with the family.

When you look at medicine, even Harding &Higginson, (2005), emphasised that meaningful palliative care in Africa includes; home and respite care, pain and symptom control (medical), financial, emotional and spiritual support, and also food, shelter, legal help, and school fees. This mode of support may obviously differ from country to country depending on the context of that particular nation. According to (WHO, 2002), Holistic care treats the patient as a whole person, not just as a medical case. This approach focuses not only on physical care, but also psychological (emotional), social and spiritual care. This psychological and emotional support and care should be available for the caregivers as well as the patient. Family members, community volunteers, professional care and support workers (health workers, counselors, social workers), work together before, during and after periods of care giving.

Given the emphases by above scholars, it seems clear that this integrated or holistic support is vital when offering palliative care to patients and their family caregivers according to their given context. Therefore, medical support as revealed is most required by patients but this kind of support is not a stand-alone type of support however effective it may be. In order to achieve the ultimate goal of palliative care of ensuring pain relief for all and symptom control, palliative care ought to be completely inclusive of both the patients and family caregivers so as to minimise the other factors that hinder effectiveness of the care received by the clients to fit into the context of Uganda. Although the setting or context of care may differ, one aspect remains constant that palliative care is necessary now in Uganda and other developing countries more than ever before given the incidence of cancer and the estimated number of cancer cases in the near future not forgetting the changing trends of non- communicable diseases globally.

5.3 Perceptions of Patients on Cancer Palliative Care

In regards to the perceptions of patients, the major perceptions of patients that stood out were; scope of care services, knowledge of care and improved quality of life. The key views aired out by patients interviewed revealed their contentment of the care services in the palliative care package and equally attributed their improved quality of life to palliative care at Hospice Africa Uganda. This is in agreement with Taylor *et al*, (2014), who argued that the perceptions of patients ought to be acknowledged and clearly understood in case reviews or multidisciplinary meetings by specialists in treatment discussion of the prognosis and treatment of patients due to the insight these views provide on the patient’s feelings and effect of the care received. Considering the views of pateints is vital in providing feedback to the agency regarding the scope of care in palliative care service directly from the beneficiaries of the care.

About the knowledge of palliative care, the views of participants were equally balanced in that two of the participants who were notably caregivers expressed concern over the fact that the information regarding the progress of care for their loved ones is not fully disclosed by health care workers while the other two caregivers revealed that caregiving to them has been a continuous learning process. This however was divergent to Gonsalves *et al*, (2011), who argued that consults may potentially decrease the extent of aggressive cancer care near the end of life. This implies that patients who are informed about palliative care and consult in time may benefit from the available care service hence the need for formal caregivers to disclose the prognosis (progress of disease) as part of end of life care for both patients and their informal caregivers.

Withholding information from patients and their caregivers may have dire consequences and hence Back *et al*, (2014), argued that early palliative care provides better quality of life, increased prognostic awareness and even improved survival for patients with advanced cancer thereby contributing to prolonged life. This concurred with Temel (2010), also emphasized that timely introduction of palliative care may serve to mitigate unnecessary and burdensome personal and societal costs.

Some patients aired out their appreciation and contentment of care services at HAU and the how palliative care has improved quality of life of patients above all. However, much as that was the case there were views expressed by other participants that professional caregivers withhold information regarding patients care to both patients and caregivers; an act that is divergent to the arguments of the scholars above that consults may potentially decrease the extent of aggressive cancer care near the end of life. It is therefore vital to ensure timely access to cancer palliative care and increase consults and discussions between patients and formal caregivers intended to equip patients with information about progress of care and the way forward so that they are equipped with the necessary knowledge which will further improve the quality of their lives and help them plan appropriately.

5.4 Perceptions of Caregivers on Cancer Palliative Care

About the perceptions of caregivers, the major perception which was somehow relatedly over riding others was prolonged life of their loved ones and anxieties of caregivers. The reasons given as being helpful were directly linked to the psychological relief that caregivers feel after their patients start accessing palliative care at HAU and the resulting extended life of the patients with renewed abilities are valid because of the nature of repeated statements as perceived by caregivers who participated in the study.

From the psychological point of view, the mental health of the caregivers is important if they are to remain empathic and effective in the giving care and support to the patients in palliative care (HAU, 2006). This concurs with Rosenberg *et al*, (2013), who argued that cancer care includes the provision of appropriate integrated services to optimize psychosocial outcomes of both patients and their family caregivers. This care for the whole patient must include care for parents and family members in particular, in the setting of pediatric cancer. Caregivers' anxieties are reduced and to eliminated a certain extent when patients start receiving palliative care. This is due to the fact that patients' pain and symptoms are managed which contributes to living a pain free life thereby reducing all fears and worries of their caregivers.

Ciemens (2014), concurred with Rosenberg *et al*, (2013) that understanding patient and family perspectives of a positive palliative care experience is essential in providing high-quality Palliative care. O'Connor *et al*, (2014) on the other hand argued that patient and family perception in patients with advanced disease and that end-of-life discussions do not take place in a timely manner, if at all, for many patients. Such implies that palliative care should be promoted and ways of including both patient and family caregivers should be found since it is already given that it is good and effective.

Ciemins *et al*, (2014) argues that perspectives of informal caregivers and professional caregivers on other diseases differ from those of formal or informal caregivers in such a way that health care professionals' (HCPs) perspectives on end-of life-care have been well-documented but less focus has been placed on patients' and families' perceptions and experiences. Focus on patients' perspectives has often been limited to specific disease states, for example, cancer, with emphasis on the illness itself, rather than the care received.

Looking at the perceptions of caregivers and those of the patients there is a clear indication that both patients and caregivers are not briefed in detail, if at all about the palliative care package they are going to receive when they come to the agency for the first time and this was expressed in the views about patients and caregivers expectations of what should be included in the care package.

Conclusively therefore, it was found that the views of caregivers are quite divergent from those of patients experiencing the pain which implies that there is no clear understanding of the nature of support and its importance to the patients and caregivers yet the two should appreciate the kinds of support and understand why they are receiving it from HAU.

5.5 Roles in Health Care

In regards to the roles in health care provision, the views that were outstanding among several participants were that diseases like cancer are on the rise in Uganda. Caregivers and government are never prepared for the burden of treating cancer and although many family caregivers are trying their roles of caregiving there is urgent need for increased government support for cancer patients and their family caregivers to relieve them of the burden of disease. Hudson and Payne (2011) who argued that, there should be substantial and sustained commitments to improve services and resources for family caregivers, by governments, health authorities, and research councils in order for palliative care to deliver upon its core function of adequately supporting the patient along with the family. Vilalta *et al*, (2014), noted that there is more need for care services among terminally ill patients so to maintain their personal dignity as human beings despite the weak health status they are experiencing. Ferrel *et al*, (2014), critically observed that governments are unlikely to have additional revenue to spend on cancer in the near future but the good news is that palliative care can help address these issues by providing the type of care that patients and families want at an affordable cost. Knowledge of palliative care service therefore helps both patients and caregivers to seek access to the much needed help in time and avoid alternative therapies that may not be required at that particular stage of the disease thereby saving resources.

5.6 Quality of Care in Palliative Care

In terms of quality of care in palliative care at HAU, the following viewpoints were aired out by the participants; client feedback and communication, waiting time of patients and caregivers, patient-centered care and feedback through formal and informal caregivers. Some participants strongly emphasized that they endure long waiting time at the reception and despite their dissatisfaction nothing significant has been done about it.

The participants mostly caregivers who highlighted the issue of long waiting time mentioned that they wait for over an hour even when they are less than three patients and family caregivers. In such cases, the procedure governing receipt of care of **“first come first serve”** as mentioned by one of the key workers ought to be reviewed by ensuring that patient to doctor ratio is adequate enough to meet the needs of patients with extreme pain in time and hasten the production of liquid morphine with quality in mind and thereafter implement the rules and regulations followed to access medicine at HAU. Additionally, the key worker explained and attributed delays in being reviewed and access to medication to the doctor to patient ratio at the agency currently.

More so, it was further clarified that preparation of liquid morphine can take a bit of time while the patient or caregiver is being assessed by the doctor.

Client feedback and communication was identified as a mechanism of feedback to the agency regarding the service provided. For instance, through research there are areas of strength and weakness that can be identified from participants' views plus suggestions for further research and recommendations identified by different researchers within the agency and visiting researchers. The Institute of Hospice and Palliative Care in Africa (IHPCA) as well may apply such findings to strengthen the education and skills in the palliative care specialty. Some measures in place currently wouldn't be possible if it hadn't been for previous research informing the agency operations.

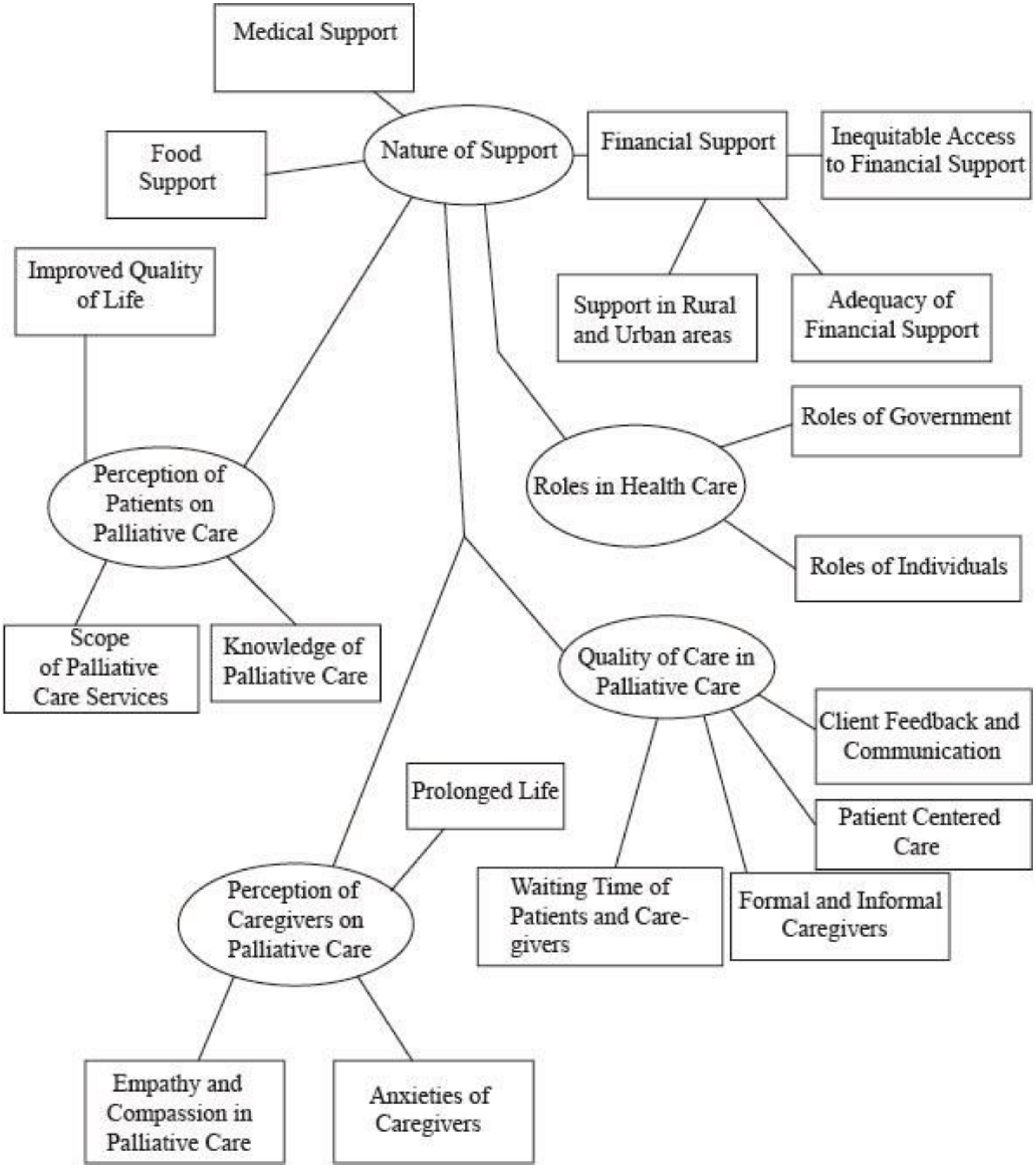
Ferrell *et al*, (2014), argued that on-going research or information seeking by caregivers regarding cancer is vital in order to be equipped with the latest knowledge and skills which in turn will benefit both family and professional caregivers and the patients receiving the care. Agar *et al*, (2013), concurs with the findings in the argument that research in palliative care amplifies several aspects of informed consent, given the nature of the populations and the studies that can inform better quality of care. Formal and informal (family) caregivers are a source of feedback to the agency regarding the care package given and received respectively. This in line with Michael *et al*, (2013), who argued that during times of sickness of any condition it is the role of family caregivers to provide support to patients through careful initiation of discussion in regards to advanced care planning incase patients refuse therefore caregivers can be conduits through which hospitals can assist patients to approach care and sensitively help in initiation of care with patients.

According Voice in Health Policy (2004), informal caregivers providing hospice palliative care at home are undertaking a wider range of tasks like psychological, social and spiritual care;

personal care; medical care like administration of medications and injections; advocacy and care-coordination in an environment where they have less support from professional caregivers. Care-coordination among caregivers in palliative care provides them vast experience that can effectively give feedback to professional caregivers about the care package. This is in agreement with Taylor *et al*, (2014), who emphasized that perceptions of patients ought to be acknowledged and clearly understood in case reviews or multidisciplinary meetings by specialists in treatment discussion of the prognosis and treatment of patients due to the insight these views provide on the patient's feelings and effect of the care received. From the above discussion, it is becoming evident that the mechanisms of feedback at HAU had gaps and because of such gaps it means that the patients were either suffering silently because there was no clear client feedback and communication mechanisms or they were somehow half hazard.

In conclusion, client feedback and communication is important in promotion and improving the quality of care in palliative care. It is therefore right to say that the findings may be a form of direct feedback from the patients and caregivers to the professional caregivers, administrators of Hospice Africa Uganda and all other stakeholders. This may in turn may contribute towards the improvement of the quality of palliative care, and may also justify the great need palliative care in Uganda. Strengthening the relationship between formal and informal caregivers as well is highly projected to improve the quality of care in palliative care at Hospice Africa Uganda because Informal caregivers provide professional caregivers with information about the progress of the disease and the impact of palliative care given to patients and informal caregivers.

Figure 2: Thematic Map integrating findings from different Themes with Nature of Support. (Source: Field Findings)



5.6 Conclusion

The findings of the study revealed that holistic support is vital when you are offering palliative care to patients. Looking at the perceptions of caregivers and those of the patients. It was found that the views of caregivers are quite divergent from those of patients experiencing the pain which implies that there is no clear understanding of the nature of support to the patients and caregivers. Nevertheless, it was recognized that Hospice Africa Uganda gives medical, financial and food support to patients and some caregivers. However, the financial support at HAU differed from that given by branches of HAU in rural areas like Hoima. Access to financial support was found to be inequitable among cancer and HIV/AIDS patients and this facilitation was inadequate given the social needs experienced by patients. The participants emphasized that equitable financial and food support will add to the relief of patients.

One would say therefore that by listening to the views of patients and caregivers about the kind of support it would help the agency to be relieved of giving what may not be fully required by the patients or what is inadequate because being palliative the patients would be able to have a say simply because a good support should have originated from the views of patients. Given the views of the patients therefore, one would conclude that by spreading the support; the organization would have better made a more holistic support by emphasizing this to the satisfaction of the patients in line with their views.

5.7 Recommendations

It is recommended that the organization needs to offer the kind of support which the patients are emphasizing. The following recommendations are therefore given regarding how best to address the gaps in place.

- I recommend that Hospice Africa Uganda administration streamlines the operations to include some patients and caregivers so as to get their views for purposes of management of the nature of support efficiently.

- I recommend that Hospice Africa Uganda administration carry out routine evaluations on the kinds of support given to patients so as to get a mediated sense of service to the patients and ensure equity in provision of support. There may also be dynamic staff interactions with client, to enable detailed discussions on the care package.

- Integration of patients and caregivers in palliative care at all levels in order to understand their views would be of advantage to Hospice Africa Uganda in enabling effective feedback mechanisms. Meetings between administration, patients and family caregivers at regular intervals may contribute to understanding one another through that interface thereby acting as a mechanism of feedback.

- I recommend that Hospice Africa Uganda narrow the doctor to patient ratio in order to reduce the challenges faced by the clients like long waiting time at the reception. This will greatly contribute to giving appropriate assessment of all patients and caregivers.

5.8 Suggestions for Further Research

- Research in the nature of support in palliative care especially equity in access to care and adequacy of care of is highly suggested.
- Further studies into the knowledge of palliative care in the population are suggested in order to bridge the lack of awareness in the general public.
- More studies are recommended into patient and informal caregiver’s integration in palliative care at all levels to enable effective feedback mechanisms in palliative care at Hospice Africa Uganda.

5.9 Limitations of the study

Limitations refer to restrictions in the study over which the researcher has no control. (Rudestam and Newton, 2007 pg105). The fact that the study was carried out among people with a chronic illnesses in advanced stages, care was taken to respect human dignity and secure informed consent from all the participants and also work closely within their given timeframe although this may have affected the set work plan for the study and thereby caused delays in submission of the final report.

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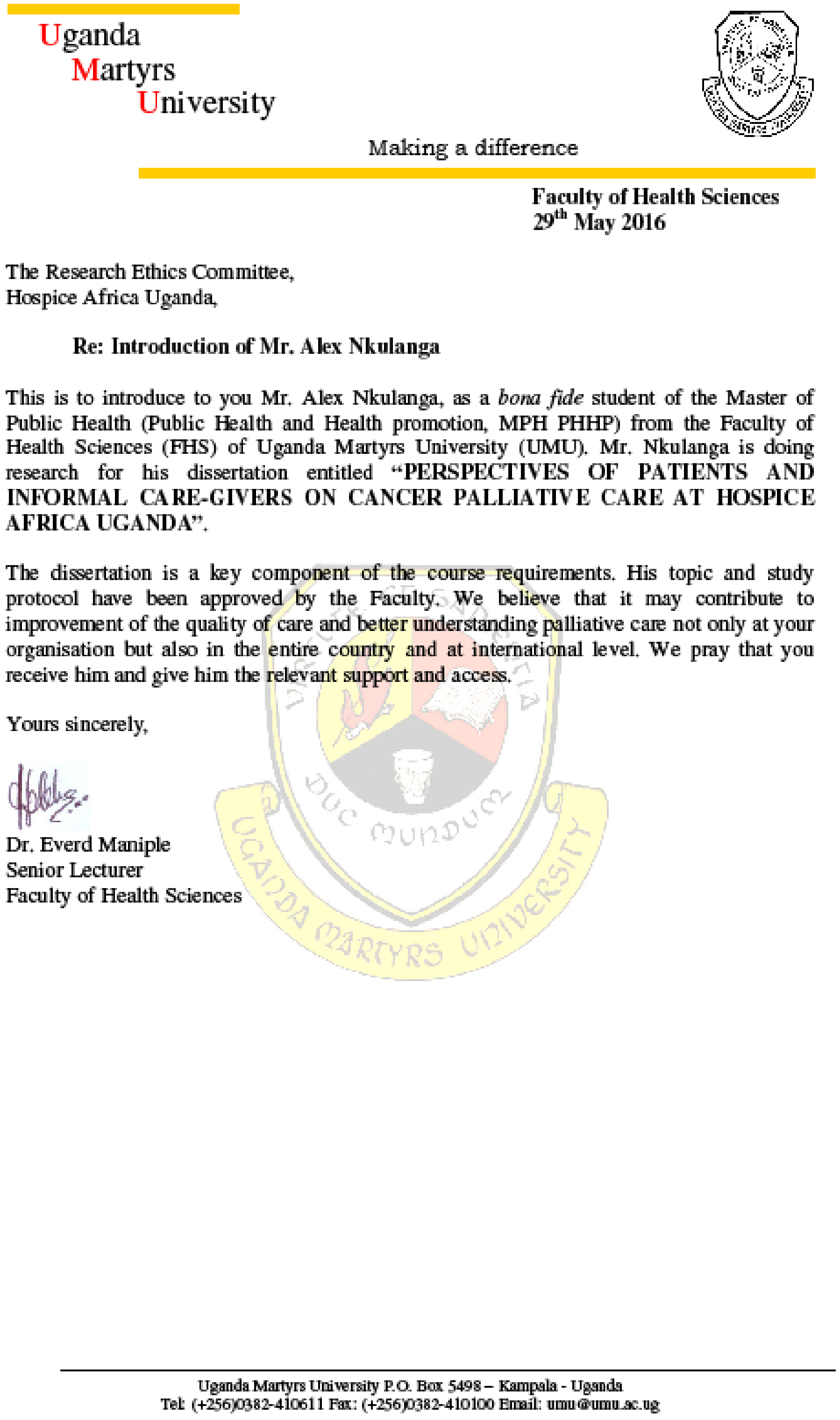
APPENDIX: I



Uganda
Martyrs
University

Making a difference

Faculty of Health Sciences
29th May 2016

The Research Ethics Committee,
Hospice Africa Uganda,

Re: Introduction of Mr. Alex Nkulanga

This is to introduce to you Mr. Alex Nkulanga, as a *bona fide* student of the Master of Public Health (Public Health and Health promotion, MPH PHHP) from the Faculty of Health Sciences (FHS) of Uganda Martyrs University (UMU). Mr. Nkulanga is doing research for his dissertation entitled **"PERSPECTIVES OF PATIENTS AND INFORMAL CARE-GIVERS ON CANCER PALLIATIVE CARE AT HOSPICE AFRICA UGANDA"**.

The dissertation is a key component of the course requirements. His topic and study protocol have been approved by the Faculty. We believe that it may contribute to improvement of the quality of care and better understanding palliative care not only at your organisation but also in the entire country and at international level. We pray that you receive him and give him the relevant support and access.

Yours sincerely,

Dr. Everd Maniple
Senior Lecturer
Faculty of Health Sciences

Uganda Martyrs University P.O. Box 5498 – Kampala - Uganda
Tel: (+256)0382-410611 Fax: (+256)0382-410100 Email: umu@umu.ac.ug

APPENDIX II: HAUREC LETTER OF APPROVAL

Institute of Hospice and Palliative Care in Africa (IHPCA)

Hospice Kampala(HKLA): Kampala
Plot 130 Makindye Road- Makindye
Mobile Hospice Mbarara(MHM): Mbarara
Plot 2A/4A/6A Kabazaire Rd
Little Hospice Hoima(LHH): Hoima
Plot 2A Kijungu Hill

P.O.Box 7757 Kampala, Uganda
Tel: + 256-414-266867
+ 256-414-266187
+ 256-701-968098
+ 256-392-766857

E-mail: education@hospiceafrica.or.ug
ar@hospiceafrica.or.ug
Website: www.hospiceafrica.or.ug

HAU IHPCA

13th June2016

Category of review undertaken

☐ **Initial review**

Mr Nkulanga Alex,
Uganda Martyrs University – Nkozi
Faculty of Health Sciences

Dear Nkulanga,

RE: APPROVAL OF PROTOCOL HAUREC-024/16:"PERSPECTIVES OF PATIENTS AND INFORMAL CARE GIVERS ON CANCER PALLIATIVE CARE AT HOSPICE AFRICA UGANDA"

Greetings from Hospice Africa Uganda Research and Ethics Committee (HAUREC). I am pleased to inform you that HAUREC has approved the study protocol referenced above. The approval of the research project is for the period of 13th June 2016 to 13th June 2017. Beyond the stipulated period, you will be required to request for extension through chairman of HAUREC. Application for extension should be submitted 2 months before expiry date of approval.

The approval covers the protocol and the following documents;

- Consent form
- Interview guide (s)

Any serious problem related to the execution of research should be promptly reported to HAUREC. Changes to the research protocol should not be implemented without approval from HAUREC, except when necessary to remove apparent immediate hazards to the research participants. It is a requirement by the institution that you submit a final report after completion of the study.

Note; you are advised to seek administrative clearance from your study site(s).

Wishing you well as we promote research while protecting human participants.

Yours sincerely,

……………………………
Prof Wilson Acuda
Chairman HAUREC

Hospice Africa Uganda
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VALID UNTIL
13 JUN 2017
RESEARCH & ETHICS COMMITTEE
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Palliative Care reaching all in need in Africa

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OUR MISSION
To be a center of excellence providing and facilitating affordable, suitable and accessible Palliative Care in Uganda and other African Countries.

APPENDIX I1: PARTICIPANT INFORMATION SHEET

INTRODUCTION

My name is NKULANGA ALEX and I am a post graduate student at Uganda Martyrs University. I am undertaking a study on "Perspectives of patients and informal care-givers on cancer palliative care at Hospice Africa Uganda", which I have determined that you are eligible for because you are a client who receives palliative care services from HAU. If you are interested in participating, I will go ahead explain a few things about the study and what your role as a participant will be. You will be asked to sign this consent form or provide your thumbprint in presence of a witness to indicate your consent and you will be given a copy to keep for records purposes.

May I continue? ____________

The study is organized by the faculty of Health Sciences of Uganda Martyrs University Nkozi. All research in Uganda has to be approved before it begins by a committee which looks carefully at the planned work. The committee must agree that the research is important and relevant to Uganda and follows nationally and internationally agreed-to research guidelines. This includes ensuring that all participants' safety and rights are respected. This study has been approved by the Hospice Africa Uganda Ethics and Research Committee (HAUREC)

If you choose to participate in this study, you will contribute to knowledge about the quality and effectiveness of palliative care services towards the all clients. The knowledge gained from this study has the potential to help guide future programs and policies and guide advocacy activities for inclusion of palliative care in health sciences curriculum and to help Hospice Africa Uganda improve palliative care services for clients. The study could lead to better, more effective care for you and other patients.

Your participation in this study is completely voluntary. If you decide you do not want to continue to participate in the study at any time and for any reason, this will not affect your care at HAU. No information that identifies you or other participants will be shared outside of the study unless permission to do so is granted by you.

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The findings from this study may be published in a medical journal. The study participants will not be identified by name in any publications unless permission is granted. After the study is completed, a report of the findings will be provided to Uganda Martyrs University and to Hospice Africa Uganda.

You are free to ask any questions about this study. If you have any further questions about this study, you may contact the researcher **Nkulanga Alex** on **+256782834988** or **+256752834988** and on either of these emails: aleklanga3@gmail.com or ankulanga@yahoo.com.

You can also contact my supervisor **Dr. Everd Maniple B** on the address below:

+256772592506

maniple77@gmail.com

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APPENDIX III: CONSENT FORM

A copy of this consent form will be given to you and your signature or thumbprint below means that you have understood the study and you have had the opportunity to ask questions about your participation. If you wish to continue to participate in this study, you should sign or place your thumbprint below.

Name of Participant

____

Signature or Fingerprint * of Participant ______________ Date/Time ______________

Name of Researcher Administering Consent ______________ Position/Title ______________

____

Signature of Researcher Administering Consent ______________ Date/Time ______________

*If the participant is unable to read and/or write, an impartial witness should be present during the informed consent discussion. After the written informed consent form is read and explained to the participant, and after they have orally consented to their participation in the study, and have either signed the consent form or provided their fingerprint, the witness should sign and personally date the consent form. By signing the consent form, the witness attests that the information in the consent form and any other written information was accurately explained to, and apparently understood by, the participant, and that informed consent was freely given by the participant.

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APPENDIX IV: EKIWANDDIKO KYOKUMANYA KU MUSOMO

Amanya gange nze NKULANGA ALEX era ndi muyizi owa diguri eyokubiri ku Uganda Martyrs University Nkozi. Nkola omusomo ku bilowoozo bya balwadde nabajjanjabi ku bujjanjabi obuweweza ku bulwadde bwa kookolo era nga ndabye nti gwe nga afuna obujjanjabi buno okuva mu' Hospice Africa Uganda osaanidde okugwetabaamu. Bwoba nga wandi yagadde okwetaba mumusomo guno, ngenda kukunyonyola ebikwata ku musomo guno nebwogenda okugwetaba mu. Ojjakusabibwa okusa omukono gwo ku kiwandiiko eky'okukaanya oba okutekako ekyenkumu okulaga nti okiliza. Era onawebwa ekiwandiiko kino okukitereka bwoba ng'okyetaaze.

Ngende Mumaso? __________________

Omusomo guno gutekatekedwa esomero lye byoblamu mu Uganda Martyrs University Nkozi. Okunonyereza kwona mu Uganda kutekwa okukasibwa akakiiko ake'kaanya omusomo ogutegekedwa. Akakiiko katekwa okukiriza nti omusomo gwamugaso era nga gwetagisa mu Uganda ate nga gugobelela emitendela gye'nsi namawanga age'bweru. Bino nga osaako okukakasa nti obulamu ne'dembbe lya abo abetabamu lisibwamu ekitibwa. Omusomo guno gukakasidwa akakiiko ke byempisa nokunoyereza ku Hopice Africa Uganda. (HAUREC)

Bwosalawo okwetaba mu musommo guno, onaba oyambye mu kwongela ku kumanya kubukugu nomutiindo ogwo'bujjanjabi obuweweza kubulwadde bwa kookolo (PC) eri abalwadde bona. Okumanya oku naava mu musomo guno kulina obusobozi obulungamya entekateka eze mirembe egyijja namateeka nga kwogasse nebikolwa ebyo kulwanirila obujjanjabi buno okugatibwa kumisomo egyebyobulamu mu Uganda ate era nokuyambako Hospice Africa Uganda okwongeramu kubujjanjabi obuweweza obulumi mu balwadde bakookolo. Omusomo guno gusobola okwongela kubulingi bwobujjanjabi, ne ngeri gyo jjanjabwamu nga omulwadde oba abalwadde abalala.

Okwetabaa'kwo mumusomo guno kuna ssinz'ila kukusalawo kwo. Bwosalawo obuteyongela mu maso na musomo guno kubudde bwona nolwensonga yonna, kino tekijja kukosa bujjanjabi byofuna ku Hospice Africa Uganda. Tewali mawulire gonna agakwogelako nga eyetabye oba abetabye mumusomo guno aganafulumizibwa ebwelu womusomo okujjako nga olukusa

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luweledwa gwe. Ebinazuulwa mu kunonyereza bisobola okutekebwa mu katabo ke byobulamu kumutimbagano gwa yintaneti. Amanya g'abanetaba mumusomo guno tegajja kubikulilwa mubiwandiiko byona okujjako nga olukusa luweredwa eyetabyemu eri oyo anonyereza. Omusomo bwe gunagwa alipoota kubivudde mukunonyereza enawebwa Uganda Martyrs University ne kitongole kya Hospice Africa Uganda.

Oliwa ddembe okubuza ekibuzo kyona ku musomo guno nga oyita mu simu zino: **+256782834988** oba **+256752834988**

Nekumutimbagano gwa yintaneti ku: **aleklanga3@gmail.com** oba **ankulanga@yahoo.com.**

Bwoba nga olina kyobuuza ekisingawo ku musomo guno osobola okutukirila omukebezi wo'musomo guno omukulu ayitibwa **Dr. Everd Maniple B**. ku simu eno: **+256772592506**

oba kumutimbagano gwa'yintaneti ku; **maniple77@gmail.com**

APPENDIX V: EKIWANDIKO KYO'KUKAANYA KU MUSOMO

Kopi yekiwandiko kino egya kuwebwa. Omukono gwo oba ekyenkumu kyo wansi bitegeza nti otegedde omusomo guno ate nga ofunye omukisa okubuza ebibuuzo ebikwata kukwetabamu. Bwoba nga oyagadde okwongela okwetaba mu musomo guno, osobola okuteeka omukono gwo oba ose'ekyenkumukyo wano.

____

Amanya g'eyetabyemu ____________________

____

Omukono gw'etabyebyemu ________________ Enakuz'omwezi / Esawa ________________

Amanya g'omunonyereza ____________________ Ekifo/Kitibwa ________________

____

Omukono gwo'munonyereza ______________ Enakuz'omwezi / Esawa ________________

*Omuntu yena eyetaba mumusomo guno waba nga tasobola kusoma oba okuwandika,wanabawo omujjulizi atayina ludda mukunyonyola ekiwandiiko kyokukaanya. Oluvanyuma lwo kusoma nokunyonyola ekiwandiko kyokukaanya eri abanetaba mumusomo nga nabo bakiriza mukigambo okusa omukono oba ekyenkumu ku kiwandiiko, Omujjulizi anasa omukono gwe kukiwandiiko kulwa oyo gwakikiridde ne naku zomwezi lwakikoze. Okusa omukono kukiwandiiko, Omujjulizi akakasa nti byona ebili mukiwandiiko binyonyodwa bulungi nga ate abitegedde era nga akiliza muddembe okwetabamu.

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APPENDIX VI: INTERVIEW GUIDE FOR PATIENTS

A. Demographic information

I. How old are you? __________

II. Did you grow up in an urban or rural environment? ____________________

III. What is your ethnicity/race? ______________________________________

IV. Are you a resident of Kampala? If so, which division?

B. Personal experiences questions

1) How did you learn of the illness?
2) How long have you received palliative care?
3) When did you first see and feel the signs of illness in your body? How did you feel about the illness?
4) How did you know about the existence of palliative care?
5) What is your experiences while receiving palliative care? (Good, bad, at home, in health care facility etc.)
6) How has palliative care impacted the way society views you?
7) How has Palliative care contributed the care received as a patient?
8) What other mode of care do you receive apart from palliative care? Why?
9) Are you satisfied with the help from HAU? If not, what are the causes your experience?
10) Have you got any recommendations on how palliative care can be improved to satisfy the diverse needs of patients? Can you elaborate more on these suggestions?

C. INTERVIEW GUIDE FOR INFORMAL CAREGIVERS (Attendants)

1) Tell me about your experience as an informal caregiver to a loved one and the factors that encouraged your decision to become a caregiver?

2) How has palliative care influenced you as an informal caregiver?

3) Apart from helping to meet the needs of the patients, what other needs are met by palliative care?

4) What basic skills have you been equipped with by professional caregivers in providing palliative care?

5) Have there been moments when you feel palliative care has improved the quality of your life?

6) What are some of the day to day challenges that you experience as an informal caregiver to a loved one with advanced cancer? What can you recommend to professional caregivers regarding the care package?

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APPENDIX VI: EBIBUUZO EBILUNGAMYA OKUNONYEREZA KU'NDOWOOZA ZA'BALWADDE NABAJJANJABI KU'BUJJANJABI OBU'WEWEZA KUBULUMI OBULETEBWA OBULWADDE BWA KOOKOLO.

A. Ebikukwatako

1) Olina emyaka emeka? __________

2) Wakulira mumbera zo'mukibuga oba mukyalo? ____________________

3) Oliwa gwanga ki? ______________________________________

4) Oli mutuuze wa' Kampala? Oba ye, mu'kitundu ki?

B. Byoyisemu ng'omuntu

1) Wamanya oya kubulwadde bwa kookolo?

2) Omaze banga ki nga ofuna obujjanjbi obuweweza kubulwadde bwa kookolo (PC)?

3) Wamanya otya ku'bujjanjabi obuweweza kubulwadde bwa kookolo (PC)?

4) Watandika ddi okulaba n'okuwulira obubonero bwo'bulwadde mububiri gwo?

5) Yogera kubilowoozo ne'mbera zewayitamu mukisera ekyo?

6) Obulamu obusanze otya nga ofuna obujjanjabi bwoku'weweza obulumi (PC) bwo'bugerageranya kubwe'wali nga tonafuna buno obujjanjabi?

7) Obujjanjabi obuweweza kubulumi(PC) bukyusiza butya engeri abantu gyebakulaba mu?

8) Nga ogyeko obujjanjabi obuweweza kubulumi bwa kookolo,waliwo obujjanjabi obulala bwofuna? Era lwaki?

9) Olimumativu n'obuyambi bwo'funa okuva mu' HAU? Oba nedda, Kiki elileta endowooza yo? Waliwo obujjanjabi obulala bwona bwofuna nga ogyeko obuweweza kubulumi? Nsonga ki?

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10 Olina kyewandi yagadde okuwabula ku ngeli obujjanjabi buno bwebuyinza okulongosebwaamu? Tunyonyole ku’kutesa kwo?

C. EBIBUUZO ERI ABA’JJANJABI.

1) Mbulira ku’byoyisemu ng’omujjanjabi eri’omulwadde n’embera eza’kuwa amanyi okusalawo okubeera omujjanjabi?
2) Obujjanjabi obuweweza kubulumi bwa kookolo (PC) bukuyambye butya ku’bujjanjabi bwowa omulwadde?
3) Ng’ogyeeko okuyamba omulwadde okufuna ebyetaago bye, obujjanjabi buno bukuyambye okufuna ebyetaago byo ng’omuntu?
4) Bukugu ki bwewa webwa abakugu munzijjanjaba eno okuwa obujjanjabi obuweweza obulumi mubulwadde bwa kookolo?
5) Wabaddewo ebiseera byo’lowooza nti obujjanjabi buno bu’wangazza oba bwongedde ku mbera yo bulamu bwo mulwadde? Osobola okunyonyola kubisera ebyo nebirowoozo byewayitamu?
6) Buzibu ki bwoyitamu gwe nga omujjanjabi womulwadde wa kookolo? Oyinza kuwabula otya abajjanjabi abakugu kunzijjanjaba eno?

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Tel: + 256-414-266867
+ 256-414-268187
+ 256-312-261488
+ 256-392-766867

E-mail: info@hospiceafrica.or.ug
Website: www.hospiceafrica.or.ug

HAU IHPCA

15th June 2016

Mr. Nkulanga Alex

Dear Alex,

RE: LETTER OF ACCEPTANCE FOR RESEARCH UNDERTAKING

Hospice Africa Uganda (HAU) (registration number: 1182) is a non – governmental organization, whose role is to promote palliative care that includes pain and symptom control for patients living with cancer and HIV/AIDS. HAU strives to uphold excellent clinical standards and provides quality education and advocacy activities to promote palliative care availability to all throughout Uganda.

Following your application for research undertaking with Hospice Africa Uganda, I am delighted to inform you that you have been considered to undertake your research within the Institute of Hospice and Palliative Care (IHPCA) at our Kampala site for a period of five weeks starting 20th June 2016, ending on 31st July 2016 (2 days each week in the month of June 2016 and four weeks in July 2016).

You are required to make a contribution of twenty thousand shillings (20,000/=) per week payable preferably in full amount at the start of your research or in two installments before the end of the research period.

Please do not hesitate to contact the undersigned, should you have any questions or require further information.

Yours Sincerely,

Milly N. Nsubuga
Chief Operations Director

Hospice Africa Uganda
15 JUN 2016
HAU IHPCA
Plot 130, Mobutu Road - Makindye
P. O. Box 7757, Kampala
Uganda

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Patron: The Nnabagereka of Buganda Kingdom
Her Royal Highness Sylvia Nagginda

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To provide and facilitating affordable, suitable and accessible palliative care in Uganda and other African countries

APPENDIX IX: WORKPLAN

Activity		Time Frame						
		May	June	July	August	September	October	November
Completion of report			■	■				
Pretesting of tools					■			
Data collection					■			
Analysis of Results					■			
Handing of first draft					■			
Defending Dissertation						■		
Submission of Final Copy							■	

APPENDIX X: BUDGET

Item	Cost (UGX)	Cost ($)	Total Cost
HAUREC Fees (1st Review)	3480	50	174000 Shs.
Administrative fees			40,000 Shs.
Printing 1000pp			200,000 Shs.
Photocopying 1000pp			50,000 Shs.
Paper			50,000 Shs.
Transport			250,000 Shs.
Final printing and Binding Hard bound (4) copies	30,000 Shs		120,000 Shs.
Other materials			250000 Shs.
Miscellaneous			500,000 Shs.
Grand Total			**1,634,000 Shs**

APPENDIX XI: AERIAL MAP OF HAU (Geographical Scope)

SOURCE: (Google Maps)