Exploring the Experiences of Family Caregivers of Persons Living with Advanced Cancer in Ghana

by

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Abstract

Background: Every year, over 20 thousand new cancer cases are diagnosed in Ghana, the majority of which are at an advanced stage. Health services for persons living with advanced cancer are limited in Ghana and thus family members are usually the sole responsible caregivers.

Purpose: The purpose of this study was to explore the experiences of family caregivers of persons living with advanced cancer receiving palliative care in Ghana.

Research Design: A qualitative research methodology suitable to investigate health related phenomena, specifically Thorne's interpretive description, was utilized. Study participants were recruited from the Palliative Care Outpatients Unit at a teaching hospital in Ghana. Following ethics and site approvals, 16 English or Twi speaking family caregivers living in the Greater Accra region, and seven palliative care providers participated in this study. Family caregiver participants took part in 50-75 minute audio recorded telephone interviews. Palliative care providers participated in two online focus groups. Interviews and focus groups were audio recorded and transcribed verbatim. Interviews in Twi were translated into English for the analysis. Focus groups were conducted in English. Data were initially sorted and coded; codes were then synthesized into categories that led to the development of themes.

Findings: The majority of family caregivers were spouses and daughters between 18 and 72 years of age. The majority of palliative care providers had full-time positions, and had worked in palliative care for more than 2 years. An overarching theme of the experience of family caregivers was identified as *'Darkness and Light'* with sub-themes of a) care that never ends, b) distressing and satisfying health care experiences, c) the pain we endure, d) spirituality, and e) valued relationships. There were two context-related themes, namely *Socio-cultural influences,* and *Context of underlying disparities.* The contextual themes portray the influence of family caregivers' Ghanaian cultural views and beliefs in their experiences of caregiving, and the impact of serious socioeconomic disparities which often resulted in late access to cancer care, difficulties affording health care costs and the care of their relative. The overarching theme, darkness and light, reveals the serious struggles of family caregivers through their experiences of caring, as well as moments of relief when they found needed health care, and family and social supports. In addition to their own familial and work responsibilities, family caregivers engaged in never ending caregiving tasks with limited support, and performed multiple responsibilities such as addressing basic care needs, managing health care appointments, and monitoring and managing symptom control. Participants reported both distressing and satisfying experiences with health care, and described exceptionally positive experiences with the palliative care team. Participants referred to their own spirituality and their relationship with their ill relative as sources of strength.

Conclusion: The experiences of family caregivers of people with advanced cancer reveal the multiple challenges they face, and the need for responsive and comprehensive health care services. Findings suggest a need for palliative care services in the community. Findings strongly show the need for policies to improve access to early cancer diagnoses, universal insurance to cover the cost of cancer treatment, and an urgency to improve early access to palliative care nationwide.

Keywords: Palliative care, family caregivers, experiences, advanced cancer, caregiving, Ghana, cancer care, sub-Saharan Africa

Preface

This thesis is an original work by Bisi Adewale. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board [REB 1] (Pro00096564, April 14, 2020) and the Ethics Board at Korle-Bu Teaching Hospital (KBTH-STC/IRB/00071/2020, July 16, 2020) for project name: “Exploring the Experiences of Family Caregivers of Persons Living with Advanced Cancer in Ghana”.

Dedication

I would like to dedicate my dissertation to all family caregivers who participated in my study. Without them this dissertation and my overall understanding of their experiences would have been incomplete. I believe that letting the family caregivers share their experiences supported them and gave them an opportunity to express their feelings with me. It also gave me an insight that caregiving "*is not how much you do, but how much love you put in the doing*"- Mother Theresa. Being a nurse and a researcher, I can reinforce such humanistic values to generate the true meaning of caregiving and nursing.

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I would also like to extend my sincere thanks to my examiner, Dr. Shelley Raffin-Bouchal for her insightful contribution to my dissertation. My sincere thanks to Dr. Brenda Cameron and Dr. Pauline Paul for being on my dissertation examining committee, and their insightful comments on my dissertation.

I would also like to acknowledge my family, especially my husband and children. Without their continuous support, encouragement and understanding, this research would not have been a reality. I came to Canada as an international student alone in 2016 to start my Ph.D. My last boy was only 5 years when I left home, this was difficult for me. They sacrificed a lot without my presence all these years, and I had to go home during every break to perform my responsibilities. I would also like to acknowledge my mother who had to stand in for me despite her age to take care of my family back home in my absence. Despite all these experiences, conducting my Ph.D. research felt like a fulfillment to me, leading to my personal and professional growth. I see myself a stronger and better individual.

My friends were major sources of support throughout my entire PhD journey. They kept me motivated, inspired, and goal driven. They guided me well in all the steps of this wonderful journey.

My special thanks to all the family caregivers for their time and effort in sharing their valuable experiences with me and for their contributions towards generating a deeper knowledge about caregiving. I would also like to thank the health care professionals at the palliative care unit for their ongoing support and assistance in my research.

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Chapter One: Background

Palliative care is an approach that improves the quality of life and wellbeing of persons with advanced illness and their families (World Health Organization [WHO], 2020). The need to increase access to palliative care will continue to rise with the escalating burden of non-communicable diseases (NCDs) and aging populations around the world (WHO, 2020). Cancer is the second leading cause of death worldwide with an estimated number of 10 million deaths annually (WHO, 2022), nearly 70% of which occur in low- and middle-income countries (LMICs) (WHO, 2022). The overwhelming number of annual cancer cases reported world wide has led to a global call on the need for interventions to improve the quality of life of persons living with advanced cancer. Globally, poverty and inequity in health systems have deprived many of access to quality health care, particularly at the end of life (Knaul et al., 2018).

Advanced cancer refers to cases that are deemed incurable and cannot be controlled with treatment (National Cancer Institute [NCI], n.d.; Canadian Cancer Society [CCS], n.d., para 1). The focus of care at this stage is towards physical, emotional, and psychosocial support, and control of symptoms (CCS, n.d.), rather than cure. Persons living with advanced cancer and unable to access palliative care services may experience unnecessary suffering and pain, swinging daily from hope to despair. This reduces their quality of life and results in psychological and social difficulties for families dealing with the care of their relatives suffering from advanced illnesses (Murray et al., 2003; Ntizimira et al., 2014).

Annually around 40 million people need palliative care worldwide, with 78% of them located in LMICs (WHO, 2020). Access to palliative care is an urgent need for all persons with chronic illnesses in every country. The WHO has declared the provision of palliative care as a significant step to improving the quality of life of persons living with cancer (WHO, 2017). For palliative care to be accessible to all, the WHO must call all countries to ensure universal access to health care (Knaul et al., 2018).

Universal health coverage ensures that every person can access sufficient preventive, curative, rehabilitative, and palliative care services without being exposed to financial hardship (WHO, 2019a). This aligns with sustainable development goal 3 (United Nations, nd), which aims at ensuring “healthy lives and promoting well-being for all at all ages” by the year 2030. The WHO further states that ensuring universal health coverage at all levels of care is a critical step to achieve the sustainable development goals by the year 2030 (WHO, 2019b).

Globally, there is an increase in the need to care for persons diagnosed with advanced chronic illnesses at home, which makes the role of family caregivers very prominent. As well, there is evidence of the significant role family caregivers play in the care provided to persons living with advanced cancer. Funk and Stajduhar (2009) mentioned that “family caregivers represent a group that might be vulnerable to stress and burden” (p.859). The effects of caregiving on the individual family caregiver’s health is seen in various spheres from physical to social, economic, and psychological (Onyeneho & Ilesanmi, 2021).

In sub-Saharan Africa, communities and families of persons living with advanced cancer shoulder a disproportional burden of care because of limited resources in the health care systems (Atobrah & Adomako Ampofo, 2016). It is the responsibility of family caregivers in the region to provide physical as well as emotional support to persons living with advanced cancer, to give them hope through the course of their disease trajectory (Atobrah & Adomako Ampofo, 2016). Family caregivers play a central role in the care of their relatives living with advanced chronic illnesses in the region. In taking up their roles, family caregivers often have limited knowledge and skills for performing tasks and responsibilities associated with caring for persons living with advanced cancer (Muliira et al., 2019). The enormous responsibility taken up by these individuals warrants the need for an exploration of their experiences.

This knowledge can inform the development of programs to support them in performing their roles. My doctoral study purposed to explore the experiences of family caregivers of persons living with advanced cancer in Ghana. This study generated an in-depth understanding of the daily experiences of family caregivers, their challenges and needs, and available supports.

The remainder of this chapter presents a discussion of the palliative care approach as well as the challenges faced in the implementation of palliative care globally, and in the sub-Saharan African region. The Ghana health care system and the state of palliative care implementation in Ghana will also be discussed. These discussions inform the problem statement, the research purpose, and the significance of the study. Definition of the terms used in the research are also described.

The Ghanaian Context

Ghana is located in sub-Saharan Africa, and in 1957 was the first country in the sub-Saharan region to gain independence, following three hundred years of colonization and crude slavery trade, and exploitation first by the Portuguese and then extensively by the British. The sub-Saharan African countries comprise all countries in the African continent located partially or fully in the southern part of the Sahara. Ghana is located in West Africa and was known pre-independence as the Gold Coast. Ghana shares its borders with the Ivory Coast on the west, Togo on the east, Burkina Faso to the north, and the Gulf of Guinea and the Atlantic Ocean to the south. Politically, Ghana has been sectioned into 16 regions subdivided into 216 districts. The sixteen regions are named Ahafo, Ashanti, Bono, Bono East, Central, Eastern, Greater Accra, Oti, Northern, North East, Savannah, Upper East, Upper West, Volta, Western, and the Western North regions.

English is considered the country's official language for both government transactions and education. There is rich linguistic diversity in Ghana with about 250 spoken languages in the country due to the diversity of Ghanaian tribes (Embassy of the Republic of Ghana, 2017). Currently, Ghana spans a land area of 238,533 km^2 with a population of 32,395,450 million, representing 0.41% of the world's population, with an annual population growth of 2.15% (World Population Review, 2022). There are three main faith traditions practiced in the country--Christianity, Islamic and the traditional religion--though the country is predominantly Christianity. Despite the government of Ghana's continuous effort in collaboration with organizations such as the United Nations, social and cultural prejudice on education still exist, with girls usually facing major disadvantages. Especially in the Northern sector, where poverty and the Islamic faith are more prevalent, it is common to see female children deprived of formal education by their families (United Nations Girl Child Initiative, n d).

Ghana is classified as a lower middle-income country (LMIC) gifted with natural resources such as gold, cocoa, diamonds, bauxite, manganese, and oil. In spite of being enriched with these natural resources, the Ghanaian economy still faces challenges such as provision of infrastructure, water and sanitation, energy, road networks and transportation, as well as budgetary deficits and a high inflation rate. It is projected that in 2030 Ghana will be the first sub-Saharan African country to become technologically advanced (Food and Agriculture Organization, 2015), yet there still exist severe inequities and regional differences with regards to allocation of resources, and infrastructure development. Economically, the poverty gap between rural and urban areas continues to widen, especially in the northern belt of the country where the poverty rate remains tremendously high (CIDA, 2009).

The Ghanaian unemployment rate in 2020 was 4.5%, with a minimum living wage of 900 GHC per month, equivalent to approximately $156 USD (Trading Economics, 2022). The current human development index for the country is 0.611 with a gross national income of USD 5,269 (United Nation Development Program, 2020). The average life expectancy for the general population in 2018 was 63.4 years (64.4 years for females and 62.5 years for males) (World Health Ranking, 2018). Currently, the ten leading causes of death in the country include malaria, lower respiratory infections, neonatal disorders, ischemic heart disease, stroke, HIV/AID, tuberculosis, diarrheal diseases, road injuries, and diabetes (Center for Disease Control and Prevention, 2019). Although the Ghana Health Service lacks a national cancer registry, GLOBACAN (2020) identifies 24,009 new cancer cases reported in Ghana annually.

The Palliative Care Approach

The World Health Organization (Sepúlveda et al., 2002) defines palliative care as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through impeccable assessment and treatment of pain and other symptoms" (p. 94). Palliative care offers patients and their families hope to live throughout the disease trajectory and ideally to attain optimal comfort (Bunt & Plessis, 2015; Partridge et al., 2014). Palliative care is provided by a multidisciplinary team to persons suffering from life-limiting illnesses with the aim of improving their quality of life by promoting psychosocial, spiritual, and physical wellbeing (Mok & Chui, 2004; NCI, 2010; National Institute of Aging, 2017). Palliative care through a team approach provides comprehensive care and support to persons living with advanced cancer, and their family caregivers (Sujatha & Jayagowri, 2017;

WHO, 2020; Wu & Volker, 2011). This also includes providing bereavement support to the family caregiver, and significant others after the death of their loved ones (WHO, 2020). WHO (2016), as part of its 2013-2020 global action plan for non-communicable diseases, states that palliative care upholds the dignity and improves the quality of life of persons with chronic illnesses by providing assistance in the adjustment to progressive diseases.

Delivery of palliative care can be done both in an institution and in the community. Delivery models vary among and within countries depending on the context and availability of resources (Wiencek & Coyne, 2014). The WHO strongly suggests that all countries should develop palliative care programs based on resource availability, and recommends home-based care for the delivery of palliative care in countries with scarce resources (WHO, 2017). Home-based care is relatively inexpensive, and more accessible to persons living with advanced cancer and other chronic illnesses and their families in Africa (Hannon et al., 2016). In this regard, the WHO (2016) has developed a guide for the implementation of palliative care in a variety of settings such as hospitals, hospices and the community.

Global Perspective on Palliative Care delivery

In 2015, the WHO stated, “Palliative care is an urgent humanitarian need for people with cancer” (para 2), particularly in LMICs where a high proportion of patients present with late stage diagnoses (Rivera-Franco & Leon-Rodriguez, 2018; Vacccarella et al., 2019). They have also stated that early access to palliative care reduces excessive hospitalizations (WHO, 2020). The anticipated growth in cancer morbidity and mortality in LMICs highlights the need to increase access to palliative care (Hannon et al., 2016). Internationally, only 14% of persons in need of palliative currently receive it (WHO, 2020). These numbers show that the majority of persons throughout the world are deprived of access to palliative care.

Access to palliative care services differs widely even within and among high-income countries, and often starts far too late in the illness trajectory thereby limiting its beneficial effects (Hannon et al., 2016). The Lancet commission declared that access to palliative care and pain medication is a human right which has unfortunately been neglected by many health care systems (Knaul et al., 2018). Although palliative care has been widely considered a human right, it is rarely available in resource-limited settings (Ntizimira et al., 2014). Worldwide, there are challenges in the implementation of palliative care as most ministries of health globally are burdened by the lack of resources and political will to serve patients in moderate to severe pain (Ntizimira et al., 2014).

The provision of palliative care is still a new concept to health care systems in sub-Saharan Africa (Downing, Powell & Powell, 2010), however, the African Palliative Care Association (APCA, 2017) addresses the issue of the continued need for palliative care access at the end of life in most African countries. Out of 53 African countries only Kenya, South Africa, Tanzania, and Uganda are reported to have integrated palliative care into healthcare delivery strategies (Ntizimira et al., 2014). Disparities in access to quality palliative care among persons living with advanced cancer are associated with variations in the availability of health care resources in a geographical area (Sussman et al., 2011). At the same time, developing countries face many challenges in the implementation of palliative care, including conflicts regarding what a good death means (McIlfatrick et al., 2013), lack of funding, cultural beliefs on end of life, lack of public awareness of palliative care, and restrictive policies on access to opioids and other medications (APCA, 2017; Ntizimira et al., 2014; Ojimadu & Okwuonu, 2015; Syed et al., 2017).

In sub-Saharan Africa, female family members are usually the primary care providers for persons living with advanced cancer (Atobrah & Adomako Ampofo, 2016). Due cultural and social beliefs women have traditionally been assigned the responsibility to care for their husbands and children. As well as facing challenges of caring for persons living with cancer, family caregivers are expected to carry on with their personal life demands such as employment and familial responsibilities (Muliira et al., 2019) resulting in financial burden, and detrimental effects to their jobs and social roles (Nemati et al., 2017). These challenges also negatively affect their ill relatives.

The Ghana Health Care System and Palliative Care Delivery in Ghana

The Ghana Health Service is challenged with issues of inequity and inequality in the distribution of access to health care delivery services that privilege those in urban centres with greater access to health care at all levels, from preventive care to specialist care. Despite the introduction of the National Health Insurance Scheme (NHIS) in 2004, with its aim to promote access to all regardless of economic status (Gobah & Zhang, 2011), many Ghanaians are still unable to afford the annual health insurance premium which is close to CAD $13 and CAD $3 for adults and children (12 years and below) respectively. This can be particularly burdensome for those who require palliative care for advanced cancer.

Ghana faces a major challenge in the implementation of palliative care for persons living with advanced cancer (Edwin et al., 2016). Currently, out of the 16 regions in the country, palliative care services run in only two government funded hospitals in two urban regions. In the absence of hospices in the country, hospital beds are frequently occupied by persons living with advanced cancer with family members taking on the majority of caregiving duties (Ghanney et al., 2015). As well, nationwide restricted access to opioids, scarce resources, and limited health care professional education and public awareness of palliative care are serious challenges to the implementation of palliative care in Ghana (Edwin et al., 2016; Opoku et al., 2012). Those palliative care programs that do exist are found to be lacking in the specialized knowledge and skills required for optimal palliation. For example, persons with advanced cancer and their families have reported negative end of life experiences at the Kole-bu Teaching Hospital, where there is access to a variety of treatment interventions (Edwin et al., 2016). In the absence of support services from the Ghana health care system, Ghanaians diagnosed with cancer are forced to develop their own personal support systems (Binka et al., 2018). It is not uncommon to see family caregivers become the only source of support for persons living with advanced cancer (Binka et al., 2018).

The scarcity of palliative services is exacerbated by the high cost of care that further decreases accessibility for much of the population. Financial inaccessibility of palliative care support services in Ghana leads to suffering and painful death of many persons affected by advanced cancer. (Edwin et al., 2016). Though the Ghanaian National Health Insurance Scheme offers limited medication coverage, persons with cancer are expected to personally finance the majority of the cost related to diagnosis and treatment (Opoku et al., 2012). The high cost of services poses a barrier to access to cancer care which results in persons living with advanced cancer abandoning medical treatment and seeking complementary and alternative medicines (Opoku et al., 2012).

The situation of family caregivers of persons living with advanced cancer in Ghana is unfortunate, despite global calls for universal health coverage. We anticipated that after the declaration made by the African Ministers of Health to “strengthening palliative care as a component of comprehensive care throughout the life course in Africa” during the 2nd African

Ministers of Health session in Kampala (Worldwide Hospice Palliative Care Alliance [WHCPA], 2016; Hospice and Palliative Care, 2016), family caregivers of persons living with advanced cancer in Ghana would have been recognized for their roles and received needed support. This declaration, made in line with the statement of the World Health Assembly (WHA) resolution on palliative care 'WHA 67.19' (WHA, 2014), has not yet improved the situations of family caregivers of persons living with advanced cancer in Ghana.

Caregiving in the African Context

Unique cultural values and beliefs of the people of Africa contribute to their knowledge development in life. Gyekye (2013) argued that "development must be perceived in terms of adequate responses to the entire existential condition in which a human being function" (p. 29). African countries each have their own rich culture learned by every member of a distinct society, as they interact with each other either formally or informally. Culture plays an eminent role in the lives of every individual (Anngela-Cole & Busch, 2011).

Culture is demonstrated when a group of individuals situated in a particular geographical location have shared philosophies, rules, and a way of life with the aim to achieve specific goals (Gyekye, 2013). The affiliation of a person to a particular culture influences one's actions, thoughts, and decision making throughout their life. The individual is brought up to apply the core values or philosophies learned about their culture into every aspect of their lives (Gyekye, 2013).

The uniqueness of an individual culture is exhibited in their way of life, ideology, and values, as well as their moral conduct, which is shared collectively amongst the members of the group (Gyekye, 2013). The ideology of individuality amongst the people is not encouraged in African society. Rather each person is expected to be their brother's or sister's keeper. The communality amongst the people primarily incorporates the idea of caring for other persons belonging to the same kinship, clan or community (Gyekye, 1996). In Africa, the family system dictates the cultural expectations and responsibilities of every member of the family at each stage of their lives (Anngela-Cole & Busch, 2011; Gyekye, 1996). These responsibilities become an obligation expected to be performed by the individual. Issues pertaining to who cares for whom at every point in time, who makes specific decisions, and specific cultural values and practices are defined in every family structure (Gyekye, 1996; Gyekye, 2013). Culturally, the impact of dictatorship on the responsibilities of each family member is continuously passed on from generation to generation (Anngela-Cole & Busch, 2011). However, in an era where families live far apart from each other and most people have busy schedules, this is a challenge. The family decides as a group to assign one person to take up the caregiving role while others provide support when they can.

In African society, the roles of male and female are distinctly defined. These gender roles are culture specific and are passed on from older adults to the youth. Culturally, females are assigned and nurtured by the African community to be care providers in the family (Dilworth-Anderson & Gibson, 2002). Females learn to bathe the younger ones, feed them, and perform all other house chores. While males are seen as the man of the house and not expected to perform house chores, they are expected to protect the family and provide for their financial needs (Gyekye, 1996). Knowledge acquired regarding caregiving roles gradually develops into behaviors and perceptions that are adopted and exhibited by family caregivers at the end of a relative’s life. In Africa, there are do’s and don’ts to which everyone belonging to a particular culture must conform. This idea may reflect the predominant view and may not apply to groups that are traditionally underrepresented in Ghana.

Even as family members take up caregiving roles for persons living with advanced chronic illnesses, they may not be allowed to perform certain personal tasks, such as bathing, for their parents, or use certain languages or words. Doing the contrary is regarded as taboo and is accompanied by social sanction. Additionally, as stated above, decision making in the African context is assigned to particular people in the family. This norm extends to the end of life of an ill family member, where family caregivers often have minimum or no say in the decisions made. The family caregiver is usually expected to take the necessary instructions from the family head, who is the final decision maker.

In the literature review, in chapter two of this dissertation, studies have shown how culture influences the roles family caregivers play in the African context (Atobrah & Adomako Ampofo, 2016; Githaiga, 2016; Githiaga & Swartz, 2017; Murray et al., 2003; Kangethe, 2009; Muliira et al., 2019; Oyegbile & Brysiewicz, 2016). The culture of the individual is a part of them and cannot be separated from their actions even when they are outside their own communities. Culture is unique to a particular group of people, is dynamic, and can be learned (Gyekye, 2013). Significantly, one needs to note the position of an individual’s cultural values and beliefs when interacting with them. Particularly health care teams in Africa need to ensure they understand the values and beliefs of each individual when working with them to provide support.

How I Became a Passionate Palliative Care Advocate

After completing a master’s degree, I continued working for the Nursing and Midwifery Training College Korle-Bu, Ghana as an educator. As a nurse educator, I was actively engaged in palliative care education in Ghana. I was assigned to teach an introductory palliative care course at the Nursing and Midwifery Training College when it was initially introduced into the nursing curriculum in 2007. In preparation, I attended palliative care and oncology workshops locally. I also read widely from palliative care and oncology textbooks to best equip myself to deliver quality lectures.

As palliative care was novel to nursing education in Ghana, my position as lecturer lead to opportunities to be appointed as a part time lecturer in a few universities in Ghana, including the Central University College, and the St. Karol School of Nursing, both private universities in the country. I am a member of the Palliative Care Faculty of the Ghana College of Nurses and Midwives, and was invited in 2017 to facilitate a workshop on end of life care organised by the Nurses and Midwives Council of Ghana.

Through my involvement in palliative care in Ghana I have had the opportunity to participate in various dialogues on palliative and oncology care in the country which have assisted me to identify the existing gaps in delivery of care for persons living with advanced cancer where resources are scarce. As a palliative care nurse educator, I witnessed the devastating impacts on persons living with advanced cancer and their family caregivers as a result of the limited attention given to their needs for physical, psychosocial, and spiritual support. Through these experiences, I realized it was important to address the problem, from the perspective of those directly involved in the care, that is, family caregivers themselves. In my PhD program, I decided to explore the experiences of family caregivers of persons living with advanced cancer to gain an in-depth understanding of what they go through while caring for their family members.

Problem Statement

In view of the tragedy that many persons living with advanced cancer and their family members experience today in Ghana, access to palliative care is a pressing necessity. In Ghana, given the impact that caring for persons living with advanced cancer has on family caregivers, understanding their personal experiences as a whole is paramount. Though a few studies in the reviewed literature explored the experiences of family caregivers in sub-Saharan Africa, no studies were found to explore the experiences of family caregivers of persons living with advanced cancer in general in Ghana at the time of the review in 2019.

Since then, I found two Ghanaian studies published in 2020 (Kusi et al., 2020) and 2021 (Salifu et al., 2021). These studies focused on an aspect of the experiences of family caregivers of persons diagnosed with cancer of the breast and prostate, and were more descriptive and less interpretative. With just two studies, there is still very little literature on the experiences of family caregivers in Ghana. Thus, this doctoral study makes a significant contribution to the literature.

My doctoral study investigated broadly the daily experiences of family caregivers of persons living with advanced cancer in Ghana, their challenges, the current existing and needed supports, and the role their cultural values play in their caregiving experiences. The in-depth understanding gained from the experiences of the family caregiver is critical to improving palliative care delivery in Ghana.

Purpose of the Study

The primary aim of this study was to explore the experiences of family caregivers of persons living with advanced cancer receiving palliative care in Ghana. I sought to develop an in-depth understanding of their experiences, their needs, challenges, and support services available to them when caring for someone with advanced cancer receiving palliative care. In addition, I also explored how the cultural context shaped their experiences of caregiving in

Ghana, given that studies in Africa show that cultural values play a role in how family caregivers provide care.

Definition of Terms

Family Caregiver

A family caregiver in this study is a family member or a friend who has been identified to provide continuous support to the person receiving palliative care for no fee or payment (Duggleby et al., 2016). The family caregiver is identified by the person living with advanced cancer to be responsible for providing physical or financial support. Also, whenever the term family caregiver is employed in this text, it refers to caregivers of a person living with advanced cancer who is receiving palliative care in Ghana, except for the literature review chapter.

Advanced Cancer

Advanced cancer is cancer which has no cure and cannot be controlled with treatment (National Cancer Institute [NCI], n.d.; Canadian Cancer Society [CCS], n.d., para 1). Advanced cancer is sometimes referred to as “secondary, metastatic, terminal or end-stage cancer” (CCS, n.d., para 2). In advanced cancer there is a spread of the cancer from where it started to nearby tissues, lymph nodes, or other parts of the body (NCI, n.d.). The focus of care at this stage of the cancer is usually towards physical, emotional, and psychosocial support (CCS, n.d.), and symptom management instead of cure.

Palliative Care.

According to WHO, 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 impeccable assessment and treatment of pain and other symptoms” (Sepúlveda et al., 2002).

Culture

Culture can be defined as "a real entity that exerts its effects on individual's belief and behavior internally, although it is learned externally through interaction with others" (Dilworth-Anderson & Gibson, 2002, p. S56). Culture is a way of life of a group of people sharing common beliefs, values, and norms. Culture is unique to a particular group of people, it is dynamic, and can be learned (Gyekye, 2013).

Significance of the Study

Considering the 2021 global annual statistics for cancer deaths highlighted earlier, understanding the experiences of the family caregivers of persons living with advanced cancer is crucial in health research. The significant role family caregivers play by shouldering the caregiving responsibilities of persons living with advanced cancer in Ghana (Binka et al., 2018) warrants the need to study their experiences. Findings generated from this study provide needed knowledge to inform the decisions and practices of policy makers, palliative care providers, and other relevant stakeholders on the experiences of family caregivers of persons living with advanced cancer in Ghana. Understanding these experiences provided me with a picture of the reality of problems associated with caring for someone with advanced cancer.

The new knowledge acquired from this study could guide the development of context specific palliative care services or programs that include increasing supports for family caregivers. Programs developed to support family caregivers could positively impact those suffering from advanced illnesses. Also, the findings of this study could be valuable to other countries in the sub-Saharan region and beyond, especially low- and middle-income earning countries, where family caregivers play an eminent role in the lives of persons living with advanced cancer and other chronic illnesses.

Research Questions

How can we better understand the caregiving experiences of family caregivers of persons living with advanced cancer receiving palliative care in Ghana?

The question above is in line with the interpretive description research approach I explain later in this dissertation. In order to study this research question, I developed the following sub-questions that I pursued in this doctoral research study:

1. What are the experiences of family caregivers caring for someone with advanced cancer?
2. What would help family caregivers when caring for someone with advanced cancer?
3. In what ways does the cultural context shape the caregiving experiences of family caregivers of persons with advanced cancer in Ghana?

Organisation of this Dissertation

This doctoral dissertation was conducted to understand what family caregivers of persons living with advanced cancer experience as they provide care for their ill relatives. It is organised into six chapters. In chapter one, I provide a background to the phenomenon being studied, and a brief description of the Ghanaian context. In chapter two, the existing literature on the experiences of family caregivers in sub-Saharan Africa is reviewed and discussed. The step-by-step process for conducting the research using an Interpretive Description approach is described in chapter three. Chapter four describes the findings of the research after interviews were conducted with family caregivers, and focus group discussions were done with health care professionals. An overarching theme, darkness and light, was used to describe the experiences of family caregivers who participated in this doctoral study. The findings of the study are discussed and interpreted in chapter five, and similarities and uniqueness of these findings are compared with those of other studies. In the final chapter the implications of study findings to practice, policy, education and research are highlighted.

Chapter Two: Review of the Literature

This chapter focuses on the current literature on the experiences of family caregivers of persons living with advanced cancer and other chronic illnesses in sub-Saharan African countries accessed through an integrative review conducted in 2019. An integrative review allows one to visualize relevant issues in providing care, and their impact on treatment, hence making it appropriate for issues related to evidence based practice (de Souza et al., 2010). This type of review allowed the researcher to explore and critically analyze existing studies on the topic, identify gaps in the literature, and promote further research to add to previous knowledge on the topic. After the review was completed in 2019, more recent literature was found and is incorporated into the discussion chapter of this dissertation.

Below, I present review findings regarding the experiences of family caregivers of persons diagnosed with cancer, HIV/AIDS, and chronic organ failure in sub-Saharan Africa. This is followed by a discussion of these findings and their significance, gaps identified in the review, and review limitations.

To conduct an integrative review of peer-reviewed literature from the sub-Saharan African region, the SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) tool (Cooke et al., 2012) was used to search for existing literature on the topic. With the help of a librarian, the following databases were included in the search: CINAHL, MEDLINE, EBSCO Discovery Service, and Google Scholar. Table one below shows the inclusion and exclusion criteria used for the search for peer reviewed literature from the Sub-Saharan African region. There was no time limit for this search because existing literature showed a limited number of published articles in sub-Saharan Africa on the experiences of family caregivers of persons living with advanced chronic illnesses.

Table 1

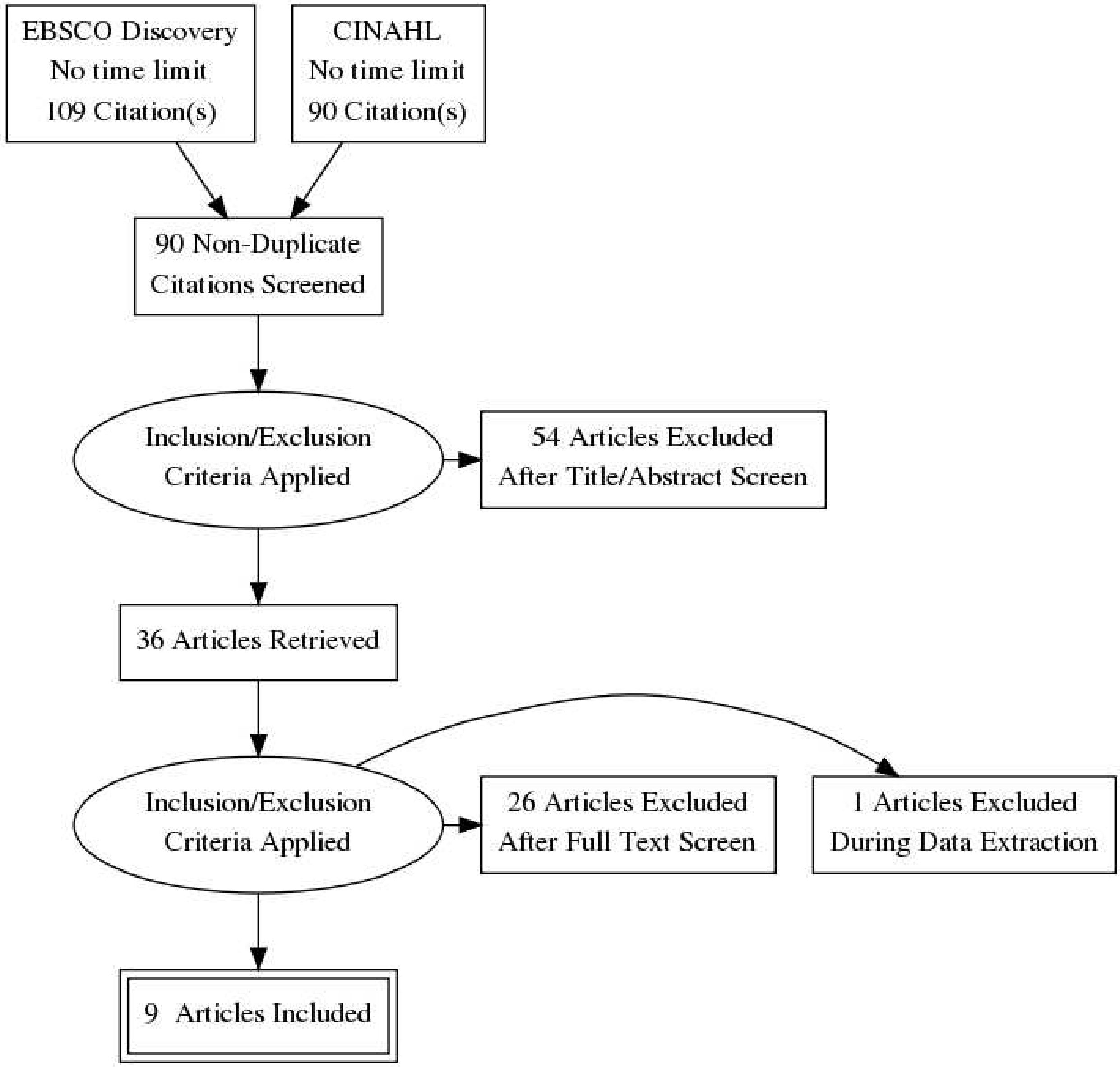
Literature Review Inclusion and Exclusion Criteria

Criteria	**Inclusion**	**Exclusion**
Type of publication	Peer reviewed research studies	Dissertations and reports
Types of research studies	Qualitative, Quantitative and Mixed methods research designs	Discussion papers, literature reviews
Study population	Family caregivers of persons with advanced illnesses patients.	Health care providers, persons with advanced illnesses (not involving family caregivers)
Study focus	The experiences of the family caregivers of persons living with advanced illnesses such as cancer, HIV/AIDS, and major organ failures in Sub-Saharan Africa	The experiences of family caregivers of persons who are not living with advanced illnesses
Publication Language	English	All Non-English Publications were excluded
Settings	Sub-Saharan African Countries (community, inpatient, outpatient)	Countries other than a Sub-Saharan African country

Data extracted was managed with Refworks for screening and identification of duplicates. A PRISMA flow diagram was also used to help track the number of articles that were included or excluded in the literature review (Figure one). The initial search from the CINAHL MEDLINE, EBSCO Discovery Service generated 197 articles. After the removal of duplicates, 90 articles were retrieved. Of the 90 articles, 36 were chosen for full text reading, following screening of titles and abstract. Finally, nine articles were selected and included in this review, after the inclusion and exclusion criteria were applied.

Figure 1

PRISMA Flow Diagram



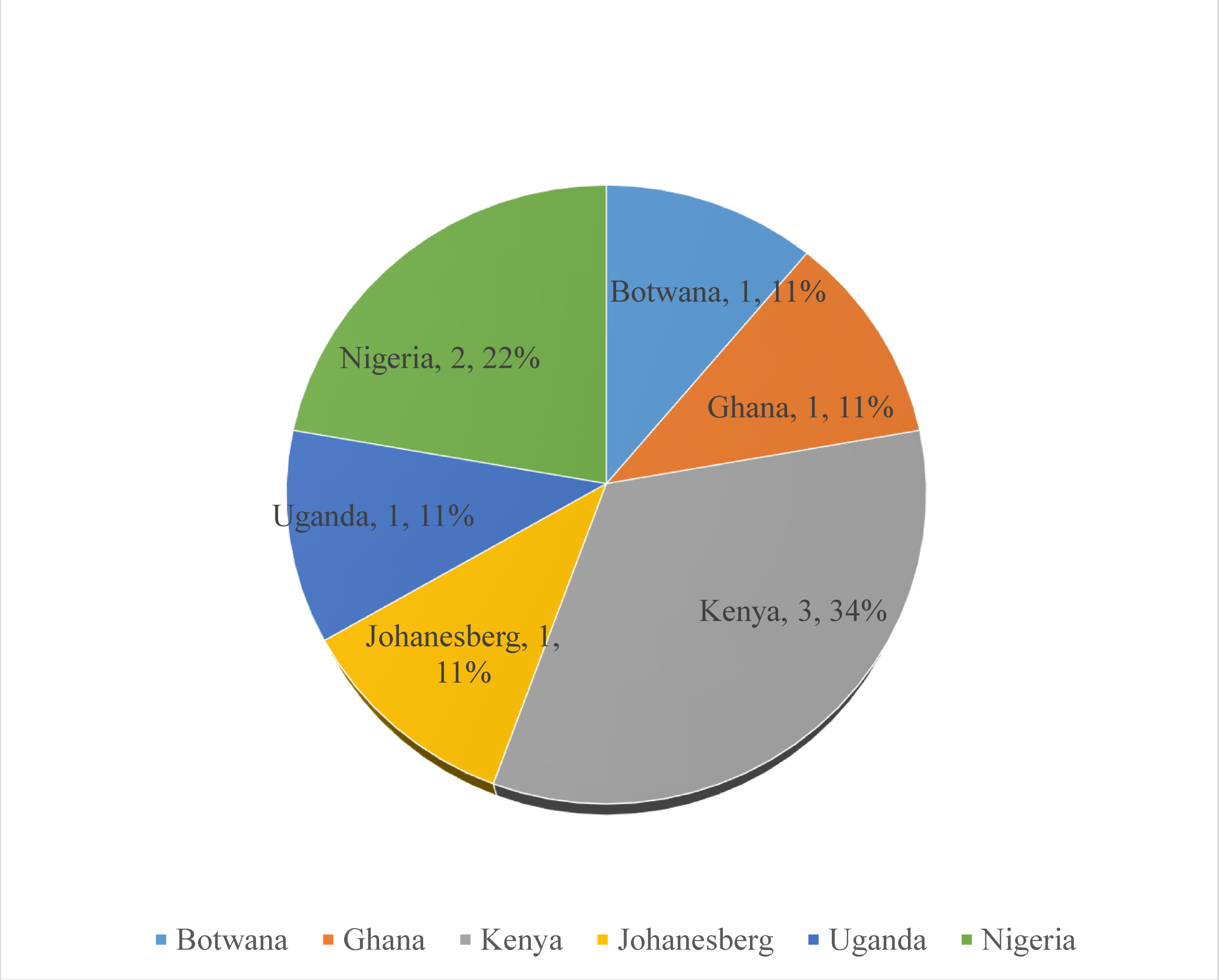
Sub-Saharan Perspective on the Experiences of Family Caregivers

In this section, I present review findings on the experiences of family caregivers of persons living with advanced cancer and other chronic illnesses in sub-Saharan Africa. As mentioned in chapter one, sub-Saharan African countries refers to all countries in the continent located partially or fully at the southern part of the Sahara.

Out of the nine articles selected and included in this review, five used qualitative designs, three were quantitative (one cross-sectional and two retrospective studies) and one employed a mixed-methods design. Specific research designs used included one ethnographic study, two retrospective quantitative studies, one qualitative descriptive study, one cross-sectional study, and the remaining four were not specific. Four of the studies conducted interviews, two conducted both interviews and focus group discussions, one was a chart/record review, one used a semi-structured questionnaire, and one used interviews and chart review. In total, the studies enrolled 508 caregivers as research participants. Eight studies reported the gender of the family caregivers with the majority being females (78.5%) (Githaiga 2016; Githiaga & Swartz, 2017; Murray et al., 2003; Kangethe, 2009; Muliira et al., 2019; Oyegbile& Brysiewicz, 2016). Three of the studies (Murray et al., 2003; Omoyeni et al., 2014; O'Neil et al., 2018) did not report the ages of the family caregivers. Among those that reported age, caregivers ranged from 18 to 75 years. One study reported that family caregivers who were 60 years or older had limited physical ability to provide care (Kangethe, 2009). Figure two below represents countries where studies included in this review were conducted.

Figure 2

Sub-Saharan African Countries Included in the Review



From this literature review, five major themes were identified related to the experiences of family caregivers. These were: (1) caregiving tasks, burden and challenges of family caregivers; (2) access to health care and other system supports; (3) cultural influences on caregiving; (4) meaning of illness, death and dying, and advance care planning; and (5) rewarding experiences and coping strategies of family caregivers.

Caregiving Tasks, Burden and Challenges of Family Caregivers

The burden that family caregivers experienced affected a variety of dimensions (Muliira et al., 2019) including social, physical and emotional wellbeing (Kangethe, 2009; Muliira et al., 2019). One study found that family caregivers who had to care for their ill relative on their own tended to cry a lot, lose weight, and worry about their significant ones (Murray et al., 2003). In addition to providing care to their ill relative, family caregivers had to respond to their own social and work responsibilities. This intensified their caregiving burden experience. Kangethe (2009), in studying family caregivers of persons with HIV/AIDS, asserted that in some situations caregivers who did not earn any salary were burdened with having to provide for the nutritional needs of themselves, as well as that of the person they were caring for. The burden of caregiving restricted family caregivers from going about their regular daily activities leading some to postpone their personal life activities (Oyegbile & Brysiewicz, 2016).

The multiple tasks required of family caregivers in providing care for their ill relatives presented significant challenges that increased perceived burden of care. A few studies showed that family caregivers were expected to perform tasks and take up roles which required high-level skills (Muliira et al., 2019). For example, family caregivers assumed responsibility for management of end-of-life symptoms, both physical and psychological (O'Neil et al., 2018). They were also expected to manage their relative's pain, urine and feces incontinence, insomnia, and weakness in the extremities (O'Neil et al., 2018), administer medications, transport patients for medical appointments, feed and prepare patient meals (Muliira et al., 2019), and assist them with their emotional symptoms (Muliira et al., 2019; O'Neil et al., 2018). One study found that even when persons living with advanced cancer were admitted to the hospital, family caregivers were expected to perform tasks such as lifting, feeding, supporting ambulatory patients, and changing patient's positions (Muliira et al., 2019).

Family caregivers were challenged with feelings of general strain, isolation and disappointment from performing unfamiliar and highly skilled or professional tasks (Muliira et al., 2019). Though family caregivers bore all the burden of providing care, they were sometimes left in the dark with minimum or no information regarding the patients' condition, treatment and prognosis, which made them feel like "fools being tossed around" (Oyegbile & Brysiewicz, 2016, p. 2628).

Another burden experienced by family caregivers was the reality of having to provide care alone with no support from relatives, government, or community members (Kangethe, 2009). This often resulted in additional stress. Though in some cases family caregivers enjoyed what they were doing, they were often psychologically distressed with the patient's condition. A study of persons with end-stage renal disease found that family caregivers perceived their caregiving role as "never ending" because of their expectations of a cure that never occurred (Oyegbile & Brysiewicz, 2016, p.2628). Managing end of life symptoms of persons living with advanced chronic illnesses at home was another burden for family caregivers (O'Neil et al., 2018).

When the person living with advanced cancer was admitted to hospital, family care givers were burdened with running errands in and around the hospital, as well as to and from the hospital and the house, with those doing this for longer durations feeling more fatigued (Muliira et al., 2019). One study also found that, with hospitalization, family caregivers' inability to stay by the patient's bedside was another source of emotional stress (O'Neil et al., 2018). Unfortunately, in most sub-Saharan African countries, health care facilities are not structured to have family caregivers by the bedsides of their significant ones on admission. Most of the wards are open wards with limited privacy provided for individual families. Thus, the wish of most family caregivers to be present by their significant one when death occurs can be challenging.

Access to Health Care and Other System Supports

Some of the articles included in this review reported the family caregivers' experiences with accessing palliative care, and other health care services. Caring for an ill relative requires physical, psychosocial, spiritual, and financial support. In Ibadan, Nigeria, family caregivers received physical, psychological, and financial support through a much appreciated public service home-based palliative care program (Omoyeni et al., 2014). The same study found that persons with HIV/AIDS who required palliative care received services such as pain and symptom control, psychological counselling, physiotherapy services, and a comfort package (food and toiletries) as a form of home-based support from a public program (Omoyeni et al., 2014). This represented a relief for family caregivers.

This same study (Omoyeni et al., 2014) found that family caregivers received training on wound dressing, safe patient handling, drug administration, and providing care, as well as follow-up phone calls and bereavement support. This was well appreciated by family caregivers. Their burden was further alleviated by financial support to assist with hospital treatment and care costs.

In contrast, a study in Botswana by Kangethe (2009), reported how family caregivers enrolled in a community home based program showed displeasure with the limitation in visits, counseling, and supervision received from the healthcare team. In this study family caregivers reported delays in receiving assessment response from social workers to enable to them to receive a food basket, and expressed the need to be motivated, and provided with psychological support (Kangethe, 2009). These studies (Kangethe, 2009; Omoyeni et al., 2014) show that the quality of palliative care services differs contextually since the family caregivers' experiences varied.

Issues related to living conditions and lack of access to health resources affected the experiences of family caregivers. Only one study (Murray et al., 2003) described significant housing issues. This study, conducted in rural Kenya, found that severe crowding and poor sanitary conditions obstructed the provision of care (Murray et al., 2003). Family caregivers' homes had limited space, and lacked running tap water and indoor toilets. In addition, lack of available resources such as gloves and sterile dressing materials made it difficult for caregivers to cope with care provided at home (Murray et al., 2003). Inability to access medications to manage patients' symptoms was another challenge for caregivers (Murray et al., 2003). On the other hand, a study by O'Neil et al. (2018) reported family caregivers were challenged with the inability to relieve patient's pain even when they were able to access medications.

Kangethe (2009) found that family caregivers of persons living with HIV/AIDS expressed the need for community and family support such as help with the care of their relative, transportation assistance, and support from other family members. Similarly, in a study conducted in rural Kenya, family caregivers expressed the need for physical, emotional, social and spiritual support from their relatives as well as the health care system (Murray et al., 2003). In a Ugandan study, family caregivers of hospitalized persons living with advanced cancer requested health care system support to assist them with care during the admission period, to reduce the strain they experienced (Muliira et al., 2019).

In most sub-Saharan African countries, access to specialist health care is challenging, especially for persons living in rural settings. Persons from rural areas living with advanced cancer were usually referred to hospitals in the city to access specialist services. This resulted in their need to find accommodation in the homes of family members who lived closer to health care facilities (Githaiga, 2016). Family caregivers in this study reported that this situation made them feel like a burden to others.

Cultural Influences on Family Caregiving

In sub-Saharan Africa, culture has a great influence on individual actions. The reviewed articles showed the impact of culture on family caregivers' experiences as reflected in the roles family caregivers played (Atobrah & Adomako Ampofo, 2016; Githaiga, 2016; Oyegbile & Brysiewicz, 2016). Family caregivers viewed their actions as a "role reversal in parental caregiving", thus the care parents with advanced cancer received was regarded as an obligation by their children because this was a cultural expectation (Githaiga, 2016, p.1595). Similarly, providing care for an ill family member was culturally regarded as the full responsibility of family members (Oyegbile & Brysiewicz, 2016). In Kenya, culture demands that women who are married provided the care needed by the husbands' family (in-laws) especially the parents (Githaiga, 2016). A study in Ghana by Atobrah and Adomako Ampofo (2016), reported that spouses of women diagnosed with cancer were responsible culturally to provide all the needed financial support. Notwithstanding, they sometimes received financial support from other family and community members.

Culture also posed certain restrictions on the caregivers' activities. For example, family caregivers were unable to provide baths for their ill family (parents) because culturally it was prohibited to see the nakedness of a parent or seniors in the family (Githaiga, 2016; Murray et al., 2003; Oyegbile & Brysiewicz, 2016). In a Kenyan study, a married woman reported it was a taboo to care for their ill family members, other than their spouse and children, in their matrimonial homes even if they were the only option available (Githaiga, 2016). Another study in rural Kenya reported how family caregivers were challenged because of cultural restrictions to discuss issues of approaching death. This was difficult especially when close relatives (children) demanded information (Murray et al., 2003). Cultural traditions and norms often made it challenging for caregivers to meet the needs of their ill relatives (Murray et al., 2003).

Although seeing the nakedness of parents was regarded as “striping the dignity of their parents”, few family caregivers had to go against this cultural norm to provide the care needed (Githaiga, 2016, p. 1596); however, in doing so, they feared the consequences of a taboo (Oyegbile & Brysiewicz, 2016). In a Ghanaian study, husbands could not support their ill wives by cooking in the kitchen, doing the laundry, and performing other chores because of the cultural belief that the man must not perform certain tasks in the home (Atobrah & Adomako Ampofo, 2016). Also, the study by Githaiga (2016), found married women who went against cultural norms by accommodating their family members without the full support of their husbands, ended up creating pressure in their marital homes.

Meanings of Illness, Death and Dying, and their Influence on Advance Care Planning

In sub-Saharan Africa, having a conversation regarding impending death or a patient’s poor prognosis is difficult even for health care professionals. This was reflected in some of the studies that were included in this literature review. A study in Kenya reported how family caregivers expressed fear when an initial diagnosis of an incurable disease (cancer or HIV/AIDS) was mentioned, resulting in a lack of acceptance of this incurable condition. This led them to explore other alternatives such as herbal clinics and traditional healers for a cure, but later they came to the realization that this was giving them false hope (Murray, et al., 2003). Further, in this study, family caregivers kept the news about patients' prognoses from the patients for a long period of time until they were deteriorating. Although such an act seems unfair, family caregivers had a positive reason of protecting patients from the trauma (Murray et al., 2003).

The reviewed literature showed that speaking about death was prohibited in some cultures, making it difficult to hold discussions on advance directives among the healthcare team, patient, and family members (Githaiga & Swartz, 2017). In some circumstances, there was a dilemma between patients wanting to prepare family by initiating death talks or writing wills, and the family not wanting to hear anything about death, or vice versa (Githaiga & Swartz, 2017). In situations where advance directives were needed to facilitate the care of persons living with chronic illnesses, culture demanded that family caregivers involve other significant family members in making the final decision when necessary (Githaiga & Swartz, 2017). Although this could be demeaning, especially when the family caregiver was a spouse, the cultural norm had to be followed.

Rewarding Experiences and Coping Strategies

Although caregiving was a burden to many family caregivers, it also promoted positive feelings between both patients and their caregivers according to one of the articles reviewed. Family caregivers who were not close in relation expressed how providing care had promoted stronger bonds with their ill relative (Oyegbile & Brysiewicz, 2016). Women who were caring for their husbands with end-stage renal disease uttered how playing the role as caregivers had "provided fulfilments in their marriage" and strengthened the love they shared (Oyegbile & Brysiewicz, 2016, p. 2629). Caregivers also expressed how the time spent in providing care for their relatives was well appreciated by the patient who would pray for them (Oyegbile & Brysiewicz, 2016). Additionally, a Nigerian study also found bereaved family caregivers were content with their caregiving roles when their ill relative was alive. This assisted them to experience a healthy bereavement after the death of their significant one (Omoyeni et al., 2014).

How family caregivers coped with the provision of care was explored by only one study, conducted in Ghana. Researchers found that husbands of female cancer patients distanced themselves from their wives when they became palliative. This was a coping strategy they developed because of their powerlessness to “save” their wives from the devastating experience (Atobrah & Adomako Ampofo, 2016, p. 190).

Discussion

This review revealed much about the experiences of family caregivers in Sub-Saharan countries, and identified research gaps in this context. Overall, review findings reveal a concerning lack of accessibility and availability of palliative care services in the countries of review studies. Another salient finding was the multiple challenges faced by family caregivers to care for their ill relatives without prior knowledge of how to do this, and with limited support from health care professionals. This forced them to perform care tasks for which they felt ill prepared. The influence of culture on their overall experiences was also a significant highlight of this review. Cultural values, beliefs, and norms imposed restrictions on their ability to fully care for their relatives and make decisions. Finally, this review also revealed positive aspects of caregiving that made their experiences meaningful and worthwhile in the views of family caregivers. Below, I offer a discussion of these key findings followed by research gaps, study implications, and review limitations.

Accessibility and Availability of Palliative Care Services

Review studies identify several problems related to access to health care services in their study populations. This includes the need to relocate to urban areas, accommodation challenges, lack of access to medications and health resources, and a need for support from health care professionals and others. Review findings reveal limited availability of palliative care services in the countries studied and the need to increase access to these, particularly for those living in rural areas. Family caregivers' perceptions of palliative care services also vary (Kangethe, 2009; Omoyeni et al., 2014).

In sub-Saharan Africa, those from rural or suburban geographical areas face multiple inequities in access to health care due to transportation issues, lack of health care facilities, poor road conditions, and weather conditions, among others. The burden on family caregivers that results from barriers in access to health care is not limited to the sub-Saharan African region. This is similar to the findings in Australian Indigenous family caregivers who were found to be burdened with the cost of transportation to access health care for their relatives (Reilly et al., 2018). In Reilly et al.'s (2018) study, family caregivers had to choose less expensive options such as taking buses with the patient to access health care in the city since they were unable to afford air transport. While in sub-Saharan Africa family caregivers may at times be able to stay with other relatives in the city, family caregivers in the Australian study had to sleep in the hospital's day room (Reilly et al., 2018). In Ghana, family caregivers who cannot access family support for accommodation are often forced to sleep in open spaces within the hospital premises such as department corridors, reception areas, parking lots, or the gardens. Such challenges create severe discomfort for the family caregiver as well as potential health risks.

Review findings also suggest that family caregivers need ongoing support from health care professionals. The support of palliative care professionals to family caregivers has been found to have a positive impact on their lives. This is similar to other countries. For example, in Norway, continuous interaction of the health care team with family caregivers, through palliative care services, made them feel that their work was appreciated (Røen et al., 2018). Findings from this review suggest the need for further research in the context of sub-Saharan countries about the potential impact of the support of palliative care providers on family caregivers' experiences. In addition, review findings suggest the need to understand contextual differences in access to palliative care within and among countries. This knowledge would assist in the development of appropriate interventions needed by family caregivers.

Another salient finding from this review was family caregivers' need for support in their homes to enable them to care for their relatives (Kangethe, 2009; Muliira et al., 2019). In most sub-Saharan African countries, limited resources make home based care the best option for persons living with advanced cancer, and other chronic illnesses. The significant role family caregivers play in the health care of persons living with advanced cancer and other chronic illnesses requires the support of governments, health care systems, and the allied health care team, especially nurses. Studies conducted in other countries found how existing support from the health care team, and other family members helped family caregivers manage the situation with the patient's diagnosis at home (Hendriksen et al., 2019; Sparla et al., 2016). This support received from the health care team, and other family members, helped the family caregiver to cope psychologically (Sparla et al., 2016). In addition, challenges in accessing specialist services and medications in a number of sub-Saharan African countries must also be addressed. Issues related to housing conditions as reported by Murray et al. (2003) such as water, living space, and sanitation, require attention to give family caregivers' the ability to provide optimal care.

The support family caregivers received from other family members during the provision of care was very limited in the literature reviewed. The reviewed studies did not explore the reasons for this lack of extended family support experienced by family caregivers. A potential explanation for this was found in a study in the Netherlands. They found that at times persons living with advanced cancer conveyed a pleasant appearance when they interacted with other family members and friends, in order not to appear to be a burden (van Roij et al., 2019). This positive outlook misled other family members and friends to believe that there was no additional need for support. In turn, this negatively affected the support family caregivers received from others. This necessitates further exploration to understand the main supports received by family caregivers, and conditions that prevent members of the extended family from taking part in the provision of care. Potential reasons such as the ill health, or the financial states of other extended family members could also be further explored to better understand this limitation in support.

Caregiving Challenges and Burden of Family Caregivers

A few studies found that individual family members were appointed to take up the role of family caregiver without any prior training (Muliira et al., 2019; O'Neil et al., 2018). In addition to battling psychologically with accepting their significant ones' current health condition (Mosher et al., 2015), family caregivers from included studies had to physically, psychosocially, spiritually, and sometimes financially support the person living with advanced cancer. Studies included in this review also found that the tasks performed by family caregivers affected their caregiving activities, especially in most cases where they lacked knowledge on what to do (Kangethe, 2009; Muliira et al., 2019; O'Neil et al., 2018). This is challenging for family caregivers performing enormous tasks in the provision of care for the person living with advanced chronic illness in resource-deprived settings.

Caregiving in palliative care is a complex and demanding role routinely played by untrained persons such as the patient's family or friends. The process of transition from a former relationship (spouse, sibling, parent, daughter, son, in-law or friend) with the person living with advanced chronic illnesses to a caregiver can be challenging (Montgomery et al., 2016). Family caregivers take up the responsibility of caregiving out of their own will to care, or because of a societal obligation due to their relationship with the recipient of care (Sherman, McGuire, & Cheon, 2014). The caregivers' role transition can be unexpected and novel, creating hesitation, anxiety, and distress (Sparla et al., 2017). Challenges faced by caregivers may indirectly affect the relative receiving care. There is a need to recognize and address the challenges family caregivers experience to increase family caregivers' satisfaction and strength, consequently converting their caregiving experience into a rewarding, worthwhile and meaningful one.

Studies in other countries have found that family caregivers feel helpless and distressed when they cannot relieve their relatives' pain after trying numerous interventions (Hackett et al., 2016). Family caregivers can become anxious when taking up their roles, which causes symptoms such as muscle tension, gastrointestinal distress, disrupted sleep, and palpitations. A study in the United States found that symptoms such as these affect the quality of their well-being, and in turn could result in serious health problems (Hendriksen et al., 2019). The findings from this review suggest the need for family caregivers to access basic training regarding how to care for someone with advanced illness in their own homes.

Also salient in this reviewed literature was how individual family caregivers performing their roles alone had to combine the caregiving role with other responsibilities at home and at work (Murray et al., 2003; Muliira et al., 2019). Playing such multiple roles was reported by a study in the Netherlands to be very challenging for family caregivers (van Roij et al., 2019). In addition, the burden experienced by family caregivers was described as a humiliating situation even by relatives receiving care (Murray et al., 2003). Support from the multidisciplinary team is required to improve the delivery of palliative care for both the person living with advanced cancer and other chronic illnesses, and their family caregivers.

A gender disparity was found in this review with the majority of caregivers being females. The gender imbalance in the distribution of persons who took on the roles of family caregiver is puzzling. Understanding the reasons for it is beyond the scope of this review. Our findings suggest the need to explore them in future work. Although the African culture is known to raise a female child as though they are to be fully responsible for caregiving roles (Dilworth-Anderson & Gibson, 2002), one cannot assume this cultural norm as the primary reason why there were more female caregivers than males. Although this may be viewed from a perspective of existing gender inequity in the African context, such decisions might also be due to the busy schedule, and financial status of other family members. Kangethe (2009) reported women of low socioeconomic status were mostly expected to play the role of providing care for their relatives. This socioeconomic disparity suggests the need to examine how socioeconomic status may also influence caregiving roles.

Cultural Influences on the Family Caregivers' Experiences

In sub-Saharan Africa the uniqueness of various cultural values plays a significant role in the day-to-day activities of every individual. Studies reviewed show the extent to which an individual's cultural values and beliefs affect their caregiving experiences and attitudes towards death and dying (Atobrah & Adomako Ampofo, 2016; Githaiga & Swartz, 2017). The family caregiver's personal and cultural values are inseparable from their caregiving experiences. Studies from this review also found how prominent it was for most family caregivers to take up their roles as caregivers because it was considered a cultural obligation (Atobrah & Adomako Ampofo, 2016; Oyegbile & Brysiewicz, 2016).

Additionally, this review found how culture at times prevented family caregivers from performing certain caregiving tasks for a relative living with advanced chronic illnesses (Atobrah & Adomako Ampofo, 2016; Githaiga, 2016; Murray et al., 2003; Oyegbile & Brysiewicz, 2016). Modernization and urbanization have prompted, in some cases, the need to readjust cultural norms to provide the needed care for family members, creating fear about the consequences this may cause (Githaiga, 2016; Oyegbile & Brysiewicz, 2016).

Another significant finding was how culture forbade the use of certain expressions at the end of life, discussions pertaining to topics on death and dying, and advance care planning in sub-Saharan Africa (Githaiga & Swartz, 2017). Health care professionals need to keep in mind these cultural restrictions during end-of-life discussions with family caregivers. It was also prominent in a study by Githaiga and Swartz (2017), how spousal caregivers did not have a say in the decision making process. In most African cultures, decision making on sensitive issues is the responsibility of the person who is regarded as the ‘family head’ (Gyekye, 1996). In sub-Saharan Africa, it is a normal practice for the health care team to deal with multiple family caregivers when the person living with advanced chronic illnesses is at the end of life. In Ghana the saying “Abusua do Fun” literally means “family loves corpse.” In the Ghanaian context, this saying refers to the multiple family members who appear when death is approaching or finally occurs. Review findings suggested that health care professionals need to be aware of the cultural norms of the individual and their family, and understand the respective roles family members play.

From my experience as a health care professional, I understand it is difficult to inform family members about the prognosis of a relative at the end of life. As reported in one study included in this review (Githaiga & Swartz, 2017), discussions on advance care planning, and the writing of wills are believed to invoke death, which is culturally perceived to be a ‘calamity’. However, where family caregivers are not allowed to have such conversations with their significant ones, there is usually a feeling of unpreparedness towards death when it occurs. An Australian study by Collins et al., (2017) found that family caregivers requested information on death and dying in plain language to adequately prepare for their relatives’ end of life. Though discussions on advance care planning are important, this review suggests that family caregivers must be allowed to decide if they wish to discuss the topic or not.

My findings suggest the need for the palliative care team to consider the patients’ and their families’ cultural and personal values when engaging them in discussions on advance care planning. In considering the cultural influences on family caregivers in Ghana, it is important to examine family caregiving roles with regards to the decision making process, the financial and economic support, and other factors in the context of the individual situation, and not only with regards to cultural expectations. The burden and challenges that family caregivers face as identified in this review pose the need to revisit these cultural norms to make caregiving less challenging for family caregivers.

Rewarding Experiences and Coping

The reviewed literature reported salient findings of how family caregivers were very glad to be providing care despite the burden they experienced (Oyegbile & Brysiewicz, 2016). A study reported bereaved family caregivers’ contentment in their previous caregiving roles, which contributed to a healthy bereavement (Omoyeni et al., 2014). This is similar to findings from a study in the United States that showed that even though they experienced frustration at times, family caregivers made the best out of whatever time they had left with their significant one. Family caregivers were time conscious of the days and months they had to spend together with their significant ones (Hendriksen et al., 2019). The positive aspects of caregiving and its potential impact on family caregivers' experiences requires further exploration.

Initiating support from the palliative care team in the patient's home can make a difference in alleviating the burden, as indicated in the findings of a study by Omoyeni et al. (2014). Factors such as gender, personal resources, finding meaning, and social resources have been found to be associated with positive outcomes of caregiving in developed countries (Young & Snowden, 2017). However, these factors could also vary contextually. Hence, further research is encouraged for an in-depth understanding of the relationship between these factors and outcomes in caregiving.

Gaps in the Literature

One of the aims of reviewing existing literature on a particular phenomenon in health research is to identify the gaps in the literature and build on previous knowledge by promoting further research. During the review, a number of gaps were identified which will be discussed in this section. The most noticeable finding of the literature review focused on the experiences of family caregivers was the relatively small number of studies that have been undertaken in this area. This is of concern particularly in sub-Saharan Africa where understanding the experiences of family caregivers is critical considering their responsibility in providing the majority of the care for persons living with advanced cancer. The reviewed literature shows that the topic on the experiences of family caregivers has not been well explored. The need for further research is to be encouraged especially in sub-Saharan Africa to help guide the implementation of programs to support family caregivers. Considering the statistics for cancer deaths in low and middle-income countries mentioned above, a gap in studies focusing in this area needs to be addressed. More research on the experiences of family caregivers for this population in the sub-Saharan African region is encouraged.

The majority of included studies focused on family caregivers of persons living with advanced cancer (Atobrah & Adomako Ampofo, 2016; Githaiga, 2016; Githaiga & Swartz, 2017; Muliira et al., 2019; Oyegbile & Brysiewicz, 2016). However, an important aspect of this topic, which was least explored, was how the severity of symptoms presented by the person with chronic illness determined the family caregivers' experience. The need to further understand how the presenting symptoms define the family caregivers' experiences is highly recommended. Also, missing in the peer-reviewed literature was how the family caregivers' relationship with the care recipient influenced their experiences. This is a very significant issue that also needs further exploration.

Furthermore, flaws were identified in the research designs of some of the peer-reviewed articles from both Sub-Saharan African and Western studies used to explore the family caregivers' experiences. Although the majority of the studies reviewed used a qualitative approach, most of the research was highly descriptive. An in-depth interpretation of what was found was not reported, limiting readers understanding on the topic. A few included in this review conducted retrospective studies by interviewing family caregivers after the patient's death (Githaiga & Swartz, 2017). While this approach is usually valid, family caregivers may only recall the issues that stood out in their experiences, and not report some important experiences. Since the perception of the experiences of family caregivers might change overtime, interviewing family caregivers who are actively providing care will reduce such biases. Correspondingly, questionnaires used as a tool to retrieve information from family caregivers, such as in the study by Muliira et al. (2019), limits the ability of participants to offer comprehensive responses to the issues being investigated. Questionnaires, though they may contain both open and closed ended questions, can restrict the respondent with how much information to provide. Further responses given on the questionnaire might need additional clarification which would be a challenge for the researcher when such designs are used, creating a gap indicating incomplete information about the topic being explored. Additionally, one of the sub-Saharan studies utilized a chart review to retrieve study data (Omoyeni et al., 2014). Findings reported solely based on existing records might have biases such as incomplete and unreliable information.

It was unclear about how rigor was ensured in the reviewed studies. For example, some of the peer-reviewed literature included in this paper did not report how rigor was ensured in the research. This is a gap which can limit readers understanding of the authenticity of the data reported in these articles. Ensuring rigor is key in every research for quality, credible, and dependable research findings. It is suggested that authors include a brief description of how rigor was ensured in the study, to clear any doubts about reliability of the findings reported.

Lastly, the search showed only one study from Ghana, which focused on the gender disparities in spousal caregiving. This shows there are no known studies on the holistic experience of family caregivers in Ghana. Research to explore the experiences of family caregivers in their wholeness is needed in the country.

Limitations of the Review

The findings of this integrative review may not be generalizable to settings other than Sub-Saharan African countries. This integrative review also only included studies published in English; therefore, studies pertaining to this topic published in any other languages were excluded. In this case, there may be significant findings on the experiences of family caregiver of persons living with advanced chronic illnesses in sub-Saharan Africa which were not captured. Another limitation for this review was that although the inclusion criteria does not limit the settings to only urban settings, the majority of the studies included in this review were conducted in the urban setting. The exclusion of populations located in rural settings in these studies means review findings might not represent the entire picture of the experiences of family caregivers of persons living with advanced chronic illnesses in sub-Saharan Africa.

In addition, since this was an integrative review a quality assessment was not conducted on the studies included. The credibility of the studies included in this review cannot be guaranteed. There were also limitations with the research designs used, indicating there may be biases in the findings presented, as well as a lack of clarity concerning their reliability. More so, the review portrays mostly the experiences of female family caregivers and may not represent the experiences of male family caregivers. In addition, the integrative review was restricted to the experiences of only family caregivers of persons in need of palliative care, so the results of this review cannot be generalised for other family caregivers. Finally, the results presented in this integrative review is a representation of study findings of only 9 studies.

Implications of the Review

Reviewing articles on specific topics is a way to identify existing knowledge gaps on the topic. Findings of literature reviewed in health care provide knowledge on the areas that need further research to improve delivery of care. Identified gaps in the review show the need for further research, which will produce an in-depth understanding and interpretation of the experiences of family caregivers of persons living with advanced cancer. Studies that explore the daily activities of the roles performed by family caregivers, their caregiving needs, and existing caregiving support for family caregivers are needed.

In addition, this integrative review showed the support needs of family caregivers of persons living with advanced chronic illnesses in sub-Saharan African countries. We recommend that health care professionals and other agencies provide physical and psychosocial support to family caregivers of persons living with advanced chronic illnesses in sub-Saharan African countries.

Chapter Three: Methods

Family caregiving experiences are contextually driven and involve multiple meanings that shape the activities of family caregivers in palliative care. The aim of this study was to explore the experiences of family caregivers of persons living with advanced cancer in Ghana. To achieve this aim, the study required a methodology that could provide an in depth understanding of family caregivers' experiences in the context of limited resources. Using a qualitative methodology was appropriate for the exploration of this topic.

Interpretive Description (ID) is an appropriate qualitative design as it allows an intense understanding of the complexities associated with this topic aimed at improving the quality of life of person's involved. In this chapter, I discuss Thorne's (2016) ID approach, its underlying assumptions, and how it guided the entire research process from formulation of research questions through to analysis and findings. This chapter also highlights how data was collected, managed and analyzed, as well as ethical considerations that were undertaken during the study.

Interpretive Description Design: An Approach to Inquiry

ID is a qualitative research design developed by Sally Thorne, Sheryl Reimer Kirkham, and Jane MacDonald-Emes in 1997 which is now gaining popularity in nursing research. The ideology of an ID design is aimed at going beyond just describing findings or evidence to an in-depth understanding of the phenomena. It also has a nursing practice orientation with a focus on building on existing knowledge (Thorne, 2016), and offering practical resolutions relevant to clinical problems (Puplampu et al., 2014; Smith et al., 2011). ID also allows qualitative researchers to develop their study with the epistemological underpinning of the specific discipline for which it is being applied (Thorne, 2016). The ID approach aims to generate new insights, building upon previous knowledge and shaping new inquiries applicable to practice (Thorne, 2016).

ID originates in the traditional qualitative research designs (Thorne, 2016). It is not restricted to structural stages but allows researchers to borrow from existing design techniques with a more significant and applicable disciplinary logic (Thorne, 2016). The ID design aims to address questions from practice which cannot be readily answered using traditional methodologies (Hunt, 2009; Thorne, 2016), and assists researchers to understand and address complicated nursing and healthcare concepts, develop a contextual understanding of these concepts, and develop empirical knowledge for practice. When an ID design is used, new knowledge is developed from the inherent, subjective, and experiential aspects of the experience of the individual (Thorne, 2016) which helps improve the quality of health care delivery.

The use of the ID approach in this study was a first step towards developing new knowledge of the experiences of family caregivers of persons living with advanced cancer in Ghana. The experiential and contextual based knowledge generated from this study promotes an in-depth understanding of the family caregiver experience, and may also serve as a guide for future decisions made in the palliative care setting in Ghana.

Basic Philosophical, Epistemological and Ontological Tenets of Interpretive Description

ID has a philosophical ideology associated with naturalistic inquiry as suggested by Lincoln and Guba (1985). The naturalistic ideology fundamental to ID suggests the nature of human experience is constructed and contextual allowing the presence of shared realities (Thorne et al., 1997).

Thorne et al. (2004) suggest that the philosophical principles of naturalistic inquiry in ID influence the epistemological and ontological underpinnings of the approach. There is a continuous commitment and interaction of both researcher and participant in a natural setting of the study, who together generate a shared understanding and knowledge on the phenomenon. For example, in this study, the researcher interacted with the caregivers through telephone interviews, where a contextual and experiential knowledge on the experiences of caregiving for persons living with advanced cancer was generated and shared. In addition, there is the existence of multiple realities that are complex, constructed, contextual, and ultimately subjective, and can be studied only holistically (Thorne et al., 2004). The complexities associated with the experiences of the family caregivers found in this study are representative of the realities pertaining to this cohort in the Ghanaian context. With ID, the complexities of care described by family caregivers of persons living with advanced cancer were best understood through a continuous interaction between the researcher and the family caregivers. In addition, the data generated from this inquiry were considered in relation to existing literature and theory relevant to caregiving, and this helped in clarifying emerging contextual issues on the phenomenon in the data analysis stage, and in the discussion of the findings.

Epistemologically, an ID confirms that the existence of reality is not an objective entity, but rather must be understood through an individual's subjective experience, usually socially constructed (Thorne, 2008). ID is directly associated with the foundation of the nursing profession, which involves multiple realities leading to multiple ways of knowing (Thorne, 2016). ID does not believe in generating a common truth claim about a phenomenon being studied, but acknowledges that findings of the study are related to a particular context and can evolve in other situations (Thorne, 2016).

In this study, the participant's subjective experience represents the contextual situation, which can enlighten the Ghanaian health care system on how to make practical decisions regarding the implementation of palliative care. Also, the findings in this study may assist nurse researchers to understand the complexities associated with the daily practice settings, and guide the development of sensible and applicable interventions in real practice settings (Thorne, 2016). Studying the experiences of family caregivers of persons living with advanced cancer aids the understanding of complexities associated with the caregiving experience. The findings may also guide palliative care nurses in the practice setting to be well-informed on appropriate interventions needed to support the family caregivers they interact with daily.

Ontologically, an ID, due to its constructivist epistemological underpinning of continuous learning of the human experience, is grounded in interpretivism. Interpretivism is the existence of multiple shared and constructed realities (Guba & Lincoln, 2000). The subjectivism and relativist nature of an ID, allows for findings to be analyzed contextually (Hunt, 2009). According to the claims of ID, researchers must aim at understanding (interpreting) purposes, meanings, and intentions (interpretations) individuals ascribe to their interactions with others in a particular context rather than just describing the actuality of the human consciousness (Thorne 2008). Thus, by using an ID in this study, the researcher understood the reasons (purpose and intentions) behind actions taken by family caregivers of persons living with advanced cancer in Ghana.

Thorne (2016) suggests that in studying a complex clinical phenomenon it might be necessary to seek “multiple angles of vision” (p.86) to better understand a complex clinical problem. ID emboldens the use of multiple data collection tools such as participatory observation, interviews, and focus groups which assist researchers to develop a better understanding of the phenomenon under study (Thorne, 2016). Interviewing the family caregivers in Ghana allowed the researcher to understand and appreciate the reality of their experiences of caregiving. The researcher also incorporated focus group discussions with palliative care providers as a secondary source of data, to understand their perspectives regarding family caregivers' experiences. The members of the palliative care team were identified as a good source of secondary data because of their interaction with the family caregivers.

ID clearly identifies the role of the researchers in determining the nature and outcome of the study (Thorne, 2016). The approach recognizes researchers' experiential knowledge about the phenomena under study, allowing for an intersection of a subjective knowledge which is possessed by both the researcher and the participant. As mentioned in chapter one, this study is a result of a research question arising from my own experience as a palliative care nurse.

ID also allows the flexibility for researchers to study topics relevant to clinical practice based on the nature of the research question and the subject being studied. Considering the roles family caregivers play in the specific context, studying the experiences of family caregivers of persons living with advanced cancer in Ghana is a very relevant topic which needs to be understood.

Although studying the experiences of family caregivers can be done with other qualitative designs, the ID design allows for flexibility to explore the participants' experience, without following any prescheduled instructions, and to construct data which will in the long run be relevant to patient care outcomes and clinical practice (Thorne, 2016). The study aimed to explore and understand the experiences of family caregivers, which are influenced by a cultural and socio-political environment (Githaiga et al., 2017; Kangethe, 2009). The family caregiver's cultural values, to some extent, had an influence on the roles they performed. In this study, the culture of a family caregiver is defined as the way of life of a group of people who associate themselves to a particular clan in the Ghanaian society. For instance, in Ghana, the cultural prohibition of children to see the nakedness of their parents can pose a challenge in caregiving. Similarly, the societal and political institutions, including the health care system, dictate to a degree the expected roles performed by the family caregivers. Limitations of resources in the health care system (Edwin et al., 2016), and the political drive towards what are regarded as priorities for use of those resources influence the roles the family caregiver plays in Ghana. The Ghanaian health care system has been structured in a way that family caregivers of persons living with advanced cancer take on the majority of the responsibilities for care, including paying for the majority of services received, running errands for the patients, as well as providing spiritual, social, and psychological support. By using ID, I was able to create an in-depth contextual understanding of the experiences of family caregivers of persons living with advanced cancer that is meaningful to the health care system in Ghana where resources are scarce.

Research Protocol

Following ethics approvals in both Canada with protocol number Pro00096564, and Ghana with protocol number KBTH-STC/IRB/00071/2020, research activities began. Below I outline the research protocol that was carried out in this study.

Setting

The study was conducted in the city of Accra, located in the southern part of Ghana. This includes the Greater Accra, the Central, Western, and Eastern regions, and part of the Volta and the Ashanti regions of Ghana. The study participants were recruited from the Palliative Care Outpatients Unit at the Korle-Bu Polyclinic, which is part of the Korle-Bu Teaching Hospital, located in the Greater Accra region. This hospital has three centres of excellence (National Cardiothoracic, Plastic and Reconstructive Surgery and Radiotherapy), and also offers a broad range of specialist services including cancer treatments. The hospital is also a referral point for neighboring countries.

The Palliative Care Outpatients Unit receives the majority (90 %) of its referrals from the teaching hospital (A. Boateng, personal communication, December 13, 2018). The outpatient unit is a referral place for palliative care patients from across the country. Data from the Palliative Care Outpatient's Unit showed that 98% of the population they serve are persons living with advanced cancer, with non-malignant late-stage conditions representing the remaining 2% (A. Boateng, personal communication, December 13, 2018). This unit provided only outpatient services at the facility, and supported the patients and family caregivers at home via phone when needed.

Data collection activities occurred at a date and time within the data collection period that was convenient for the participants. Due to the COVID-19 pandemic, data collection was done via telephone with participants (family caregivers), and online via zoom with health care providers. Health care professionals at the palliative care unit were very supportive during the data collection process.

Participants

This study involved family caregivers of persons living with advanced cancer as primary participants, and members of the palliative care team were key informants to inform the data obtained from the family caregiver participants.

A family caregiver is a family member or friend who has been identified to provide continuous support for no fee or payment to the person living with advanced cancer (Duggleby et al., 2016). Family caregivers in this study were those identified by the palliative care nurse or doctor in the Palliative Care Outpatients Unit as current caregivers of persons living with advanced cancer, and were 18 years and older. There were no restrictions on the family caregiver's gender, or relationship with the recipient of care. Family caregivers gave voluntary consent to participate in the study.

All family caregivers in this study lived in the southern part of Ghana and could communicate in English or Twi. Family caregivers who spoke languages other than the ones mentioned in the inclusion criteria were not recruited. The Ghanaian dialect, Twi, was chosen as a second language for interviewing participants because it is commonly spoken across the country, and because of the researcher's fluency. Some family caregivers could not communicate in the English language hence were interviewed in Twi. Since there was only one local language added to the English language, translation challenges were minimized.

Health care professionals who are members of the palliative care team at the Korle-Bu polyclinic were invited to be part of the study. Inclusion criteria were: (a) health professional as defined below, (b) 18 years of age and older, (c) fluent in English, (d) working at the palliative outpatient unit. These included the palliative care consultant, palliative clinical psychologist, palliative care nurses, pharmacist, spiritual leader, or any other health care provider affiliated with this team. Health care professional participants were all licensed to practice in Ghana.

Sampling

In this study, participants were initially recruited through purposive sampling, and then later through theoretical sampling during the data collection process, as this "plays a prominent role in interpretive description" (Thorne, 2016, p. 100). Using purposive sampling, people within a particular setting are recruited to a study based on their experience with the phenomenon under study (Jones et al., 2013). A purposive sampling method was used to select potential family caregiver participants based on their experiences as well as their insightful knowledge with the phenomenon being studied (Thorne, 2016). Based on the review of the literature, the researcher in this study selected family caregivers with different ages, gender, and relationship with the recipient of care. Members of the palliative care team participated in this study because of their experiential knowledge of the family caregiving experience.

Theoretical sampling was utilized in this study when the researcher identified emerging themes during the initial data analysis phase, such as gender, and experiences with the palliative care outpatient unit. Theoretical sampling is the idea of recruiting specific participants, which allow the researcher to achieve a more in-depth understanding of emerging themes and the phenomenon being studied (Thorne, 2016). In theoretical sampling, the specific participants to be recruited are not known until data collection begins. However, it is advisable to make provision for its application prior to the start of the study (Thorne, 2016).

In this study, the patterns of emerging themes at the initial stages of data collection led the researcher to decide on the groups that were to be sampled for further in-depth understanding. The decision was made after consultations with my supervisors via online zoom meetings during the data collection process. Although theoretical sampling played an important role in ID in this study, the aim was to expose other knowledge relevant to applied practice but not necessarily to develop a new theory (Thorne, 2016).

At the initial stage, I anticipated recruiting between 10-15 family caregivers and 4-6 members of the palliative care team based on previous studies (Atobrah & Adomako Ampofo, 2016; Githaiga & Swartz, 2017; Hendriksen et al., 2019; Oyegbile & Brysiewicz, 2016; Reilly et al., 2018). During the data collection process, I ended up recruiting 16 family caregivers with some being multiple family caregivers for the same care recipient, and 7 health care professionals. This variation in anticipated numbers and actual numbers of participants was based on evolving findings, quality of the data received, and the usefulness of the data given by participants (Morse & Field, 1995). As advised by Thorne (2016), a researcher must not use the principle of data saturation as a means to determine sample size, but rather must acknowledge that "… there will always be more to study" (p.108). In this study the sample size was guided by an iterative consideration of the knowledge needed on the experience of family caregivers of persons living with advanced cancer, the approach used to gather this knowledge, and the ethical conduct used for this study (Thorne, 2016). Thorne (2016) suggests that a small sample size can be employed, in a qualitative research study that explores a common clinical phenomenon to gain an in-depth understanding of a subjective experiential nature under study. During the data collection process, there were commonalities amongst the experiences of family caregivers of persons living with advanced cancer in Ghana; hence, this sample size helped the researcher attain an in-depth understanding of the phenomenon.

Recruitment

Family caregivers of persons living with advanced cancer enrolled in the palliative care program at the Korle-Bu Polyclinic in Ghana were recruited for this study. However, due to the Covid-19 restrictions upon arrival in Ghana, I had to put my research temporarily on hold. After making pandemic related amendments to the initial study proposal, such as doing telephone interviews and Zoom online focus group discussion instead of in person interactions, I received ethics approval from the University of Alberta Ethical Review Board and the Ethics Board at Korle-Bu Teaching Hospital. A letter of approval and an introductory letter from the two ethics boards were sent to the palliative care unit through the head of the Korle-Bu Polyclinic. I had already contacted the unit head via telephone upon my arrival in Ghana. A brief presentation of the study was done online via zoom to the palliative care team before the main recruitment activities began.

Family Caregivers Accrual Process

With the assistance of a palliative care nurse, potential study participants who met the inclusion criteria were approached. The nurse was given a short script (please see Appendix A) to describe the study to family caregivers. The researcher allowed the nurse to ask questions after reading the scripts, and all clarifications were done. Family caregivers who were interested in the study were asked to provide verbal consent in English or Twi for the release of their name and telephone number to the researcher. This consent was done verbally via phone because of the COVID-19 pandemic. The nurse then contacted the researcher by telephone and provided the contact information of potential participants. Family caregivers were contacted by the researcher via telephone to set a date and time to explain the study, obtain verbal informed consent to participate in the study, and conduct the initial interview. In addition, family caregivers were asked if there were other relatives in the home performing part of the caregiving role who may also wish to take part in the study. Multiple family caregivers caring for three care recipients were recruited in this study. The interview was then scheduled at this point.

It is important to note that there was one participant who withdrew from this study. During the process of scheduling the interview with this participant, the care recipient died, and the family caregiver was too emotionally unstable to be engaged in a conversation.

Participants gave verbal voluntary consent to take part in the study via telephone. This was recorded directly on the mobile phone device that was designated purposely for data collection in this study. As well as being recorded on the telephone, the interviews were recorded on a digital audio recorder as a backup.

Accrual Process for Health Care Providers

The researcher did a study presentation to the health care team via Zoom, an online video conferencing tool (app). A google document of the study consent form (Appendix E) was emailed to members of the team. Interested participants individually accepted and submitted the google form to the researcher. This indicated their consent to participate in this study voluntarily prior to their involvement in research activities.

Data Collection

This study used six data collection strategies (Appendix B, C, F and G): (a) demographic form; (b) in-depth interviews with family caregivers; (c) focus group discussion with health care providers; (d) reflective journaling; (e) field notes; and (f) memos. Data collection began immediately after the researcher gained ethical clearance in Canada and Ghana.

Demographic Form.

A demographic Form (Appendix B) was used to collect the demographic information about the family caregiver participants, such as participant age, gender, relationship to the care recipient, diagnosis of care recipient, marital status, level of education, employment, and income, as well as care recipient age, gender, and medical diagnosis. This information was collected via telephone, and helped the researcher describe the participant's general characteristics.

A demographic google form (Appendix C) was also completed online by health care professionals in the focus groups. This was used to collect information on their professional designation, level of education, length of time practiced, position at the clinic and their interactions with family caregivers.

Interviews

The researcher interacted with participants (family caregivers) through individual telephone interviews to obtain a rich description of their experience. Interviews were conducted because the researcher was interested in a phenomenon which cannot be studied by observation. As posited by Stake (1995), the interview can lead a researcher to identifying multiple realities, but the researcher needs to have guiding questions planned in advance to answer the research questions. Qualitative health researchers believe that learning from individuals with first-hand information about the phenomenon, specifically those who understand the experience being studied, is very important in health care delivery (Thorne, 2016).

The interviews were conducted in English or Twi, with participants choosing the language with which they were most comfortable. Six of the participants were interviewed in Twi, and the remaining nine were interviewed in English. Interviews were conducted via telephone at an appropriate date and time where participants felt relaxed and comfortable for the data collection process.

To enhance the credibility of the study, the researcher conducted two interviews with some participants in order to have an in-depth understanding, and variation in the conceptualization of the phenomenon being studied (Merriam, 2009). The purpose of the second interview was to clarify what participants said in the first interview, and also to gather additional in-depth data. In this study, three of the 16 family caregiver participants were engaged in two in-depth telephone interviews. One refused a second interview because of limited availability to participate; a second lost her relative after the first interview and was not sufficiently emotionally stable to be engaged in a second interview. The remaining eleven were recruited for theoretical sampling and were engaged in one interview each. A total number of 17 interviews were conducted, including both first interviews, and follow-up interviews.

Semi-structured interviews is one of three main types of research interviews described to be appropriate for qualitative research; the other two types are structured, and unstructured interviews (Merriam & Tisdell, 2016). Semi-structured interviews usually have a predetermined format providing flexibility in questions, allowing them to be altered by the researcher when the research is ongoing. Merriam (2009) mentions that semi-structured interviews use a set of guiding questions concerning the topic to be explored. I used semi-structured interviews for my study because I was able to add new questions to my interview guide as I interviewed my participants.

In this study, a semi-structured interview guide made up of open-ended questions was developed based on the research questions (Appendix F), and interviews lasted for 40-70 minutes. Questions related to the topic being explored were listed in the interview guide but, during the interview, the researcher also asked other questions to further develop understanding of the phenomenon. Semi-structured interviews were done because, from her own experiences, the researcher had an idea of the information needed, and the questions required to yield that information. Questions were focused on the experiences of participants relating to descriptions of their caregiving experiences, what would help them when performing their roles, and how their cultural values shape their caregiving experiences. Also, participants recruited for theoretical sampling were asked additional questions that focused on their experiences with the palliative care unit, culture in caregiving, and the effect of caregiving on their health.

Conducting telephone interviews as compared to face-to-face interviews had both benefits and limitations, Telephone interviews made it easier to schedule interviews with participants because participants had greater opportunity to choose a convenient and appropriate day and time. Telephone interviews also allowed participants to have more privacy in their own homes or chosen space to participate in the study. Another benefit of using telephone interviews was that they allowed participants to express themselves freely during our conversation since there was no eye contact with researcher. However, using telephone interviews limited me from seeing non-verbal cues that could have added to my findings. As well, communication network connectivity issues prevalent in Ghana resulted in a few occasions when our telephone conversations were interrupted.

Focus Groups

Two focus groups were conducted with members of the palliative care team online via Zoom video conference, with the aim of engaging them in a discussion of their perspectives on the experiences of family caregivers of persons living with advanced cancer who are served by their unit. According to Thorne (2016), the focus group is employed when the researcher aims to reveal a shared perspective about a phenomenon from the identified group. This researcher aimed at knowing the perspectives of the palliative care team because of their collective interaction with family caregivers. Focus groups give the researcher the chance to bring experts (in this case the palliative care team) with experiential knowledge about a phenomenon together to relate with each other, and individually contribute towards the issues being discussed (Thorne, 2016). In this study, a focus group was done to allow the members of the palliative care team to have an interactive discussion on the phenomenon. A focus group is very effective when it is coordinated properly with fewer individuals (6-8 people), as a discussion with a larger number in a focus group might be difficult to control (Thorne, 2016).

In this study, I had two focus group discussions with the palliative care team made up of 7 professionals in each group, which was an appropriate data collection tool. As a guide, I had a list of questions (Appendix G) related to the phenomenon being studied that served as focus for the discussion. Guiding questions to direct the focus group were related to: (i) what the family caregiver's caregiving experience is, (ii) what would help family caregivers when performing their roles, and (iii) how the cultural values of family caregivers shape their caregiving role.

Two focus group discussions were conducted via Zoom that lasted between 100-120 minutes and were recorded directly on my personal laptop. The second focus group discussion was done to have further in-depth understanding of what the health care professional participants had said during the first focus group, and what family caregiver participants had said during their interviews. As recommended by Thorne (2016), in this study, I requested the voluntary assistance of a student palliative nurse specialist from the Ghana College of Nurses and Midwives to take notes of points that were raised, indicating who said what in the notes. The student palliative care nurse specialist signed a consent form to take up the task voluntarily and to ensure confidentiality of the discussion.

Prior to having the focus group discussions, I circulated an email to all focus group participants with three prospective dates and times for the Zoom online discussion. Participants returned to me via email the date and time that was convenient for them. Based on the feedback I received, a Zoom meeting was scheduled for the focus group discussions to be held. An invitation with a secured Zoom meeting link, ID and password was sent to all health care professional participants. All communication in the focus groups was in English, which is the language of communication between health care professionals in the institution.

For confidentiality, I ensured all Zoom discussions were recorded during the discussion and saved directly on my personal laptop rather than the cloud. Also, I indicated a confidentiality rule at the beginning of each focus group discussion. The information retrieved from the discussions was kept confidential by the researcher, and was used purposely only for the study.

Reflective Diary

Additionally, I kept a reflective diary to capture reflections on elements of the research process including a personal interpretation or impression of emerging findings as well as thoughts about participants' experiences (Kitchenham, 2010). While the reflexive notes were not analyzed the same way as the interviews, they assisted me to conceptualize the data, and situate the interpretation of participant experiences as a reflection of my personal influence (Thorne, 2016). For example, during analysis of the data related to participants' experiences within the hospital environment, I used the reflexive notes to interpret the experiences as reported by the participants, ensuring my personal experiences as a registered nurse did not influence the data.

Field Notes.

During the telephone interview process, I made notes on the reactions of family caregivers such as anxiety, moaning, anger, fear, or sobbing. The information recorded in the field notes were add-ons for analysis of what the family caregivers had said during the interviews. Additionally, field notes were taken during the focus group discussions. This served as a backup for the voice recording during the discussion. These were used as reference documents for the researcher during data analysis, where some statements were not captured clearly on the voice recorder.

Memos.

During the process of data collection, coding, and analysis, I wrote down my ideas, thoughts, and questions about emerging concepts in memos (Woo, 2019). Memos were used to save the information I found during data collection and analysis which needed a second thought. This served a different purpose to the reflective diary. Writing in memos allowed me to preserve information that may not be initially useful but later be regarded as important, or as needing further queries (Lempert, 2007). In addition, memos helped me to map research activities, extract meanings from the data, and maintain momentum (Birks et al., 2008). In this research, I created a word document of all written memos. I used some of the information saved in the memos I created during my data analysis to report what was found in the data collected. For example, during the process of sorting the data I brought from the field, there were some statements made by participants that I was not initially sure needed to be included in my findings. However, after further thoughts, I found this data relevant to include in my findings.

Data Collection Procedure.

Following informed consent, a demographic form was completed. The first interviews were conducted with each participant, and field notes were taken. The interviews were recorded directly on the mobile phone device used, as well as on a digital recorder during each interview. Participants were contacted via telephone later to schedule a second interview when needed.

Language Considerations

As mentioned above, some interviews were conducted in the local language (Twi). Though the researcher (Bisi Adewale) is fluent in both English and Twi, this caused a language barrier for the supervisors involved in this study (Santos et al., 2015). In qualitative research conducted in languages outside of the fluency of the research team, a translator is needed to translate the documents or interviews into the recommended text (Squires, 2009). Also, publications and presentations related to this study will be in the English language. This required the need to translate 4 interviews that were conducted in Twi into English. Translation of all interviews conducted in Twi was done first by the professional translator, and secondly by the researcher. This was to ensure a uniformity in translation done by both the researcher and the professional translator, therefore limiting errors in data collected. This was done before documents were transcribed into English for analysis.

Data Management and Analysis

Analysis started immediately following the initial interview and continued concurrently. Responses from the data helped me to modify subsequent interviews as the data collection progressed.

Data Management

Data management involved tracking, organizing, and sorting out information the researcher brought from the field (Thorne, 2016). It is suggested that the information which is brought from the field must be a material (e.g., memos, audio-recordings etc.) that the researcher can easily access during the data collection and analytic process (Thorne, 2016). Data management can be done either manually or by using a computer software (Morse & Field, 1995). There are no fixed rules on the approach the researcher must take for a particular research design. Although initially I decided to use NVivo© as a software for data collection, this later changed during the analysis of the data collected. After further deliberations with my supervisors, a manual data analysis was done instead because I felt more comfortable with that.

Thorne (2016) mentions that “field notes and transcription of audio tapes tend to be the mainstay of interpretive description” (p.150). Hence, initially, all audio-recorded data were transcribed in English verbatim by a professional transcriber after every interview session. All interviews conducted in Twi were also transcribed and translated into English verbatim by the professional transcriber and translator. Electronic copies of every transcription were allocated an identification number, and saved on a password protected shared drive in the research directory of one of my supervisors for security. Also saving transcripts on password protected shared drive with pseudonyms helped to ensure confidentiality, as well as easy retrieval of individual interviews. All information retrieved from data collection will be kept for at least 5 years as per the University of Alberta's policy before being destroyed if necessary. Field notes were also securely stored in a password protected shared drive similar to that of the transcribed interviews.

Data Analysis

The essence of data analysis was for the researcher to make sense out of the data collected. The ID design uses a data analysis process which involves inductive reasoning, continual engagement to ascertain relationships and associations within the phenomena, as well as extending conceptualizing, testing, and challenging preliminary interpretations towards the understanding of a phenomenon under study (Thorne, 2008). During the data analysis process, I engaged constantly with my participants, and tried to understand the phenomena being studied. In analyzing participant field notes taken during the interviews, I engaged in "self-checking skills" (Thorne, p. 110, 2016) in order to tease out what was happening to me personally from what I was seeing in the data collected. To generate an in-depth knowledge and understanding of the findings in the study, I generated a description of the study through inherent reflections and searched for underlying reasons of the shared experiences (Thorne et al., 2004).

Interviews and focus group discussion conducted were transcribed verbatim from the device used for the recordings during the discussion. All audio recordings done in the Twi language were translated and transcribed verbatim into the English language before analysis was done, as discussed above. Field notes taken during the interviews were transcribed and extended into a narrative form immediately after each telephone interview. I consulted my supervisors after the first two telephone interviews for discussion on the need to revise the interview guide, to ensure rich quality data. After these initial meetings, we agreed to recruit a few more participants. Hence three more interviews were done using the interview guide. I met with my supervisors on a regular basis throughout the data analysis period.

During the initial analysis, the need for theoretical sampling was discussed with my supervisors to explore in-depth emerging themes and clarify preliminary interpretations. Participants recruited using theoretical sampling were interviewed with a modified interview guide. In addition, questions focusing on their experiences with the palliative care unit, culture in caregiving, and the effect of caregiving on their health were asked. This helped to enrich the data on these topics related to the experiences of family caregivers in Ghana. Memos written during the process were analyzed for better explanation and understanding of the complexity of the phenomenon being studied. Memos also played an important role in maintaining rigor and an audit trail (Morse & Field, 1995).

Individual interviews were analyzed with field notes first, and a narrative was written for each family caregiver participant. Then the health care professional focus group discussions were analyzed. Data from the health care professionals were then added to inform the findings from family caregiver participants in the findings stage. The researcher used the process of finding a pattern among the pieces of data, and interpreted the data based on both the research question, and disciplinary standpoint. An inductive approach was used during the data analysis, which generated startling responses from participants. In this study, analysis was done using the approach proposed by Thorne (2016), which entails sorting and organizing, making sense out of the patterns, and transforming pattern into findings.

At the sorting and organizing phase, I coded all transcripts individually following an open coding process using raw data. The second phase was making sense of pattern phase, in which I classified the identified codes into areas of commonality or patterns that allowed for the consideration of relationships amongst the generated patterns, as well as related it to the larger research question. This process was guided by techniques of constant comparative analysis in which every piece of data was compared to understand similarities and differences amongst data collected. The third and final stage of the analytical process was transforming patterns into findings. At this stage I thought through credible themes and considered what these themes meant individually and collectively. I also looked out for how these themes added on to knowledge that was unlikely before the study (Thorne, 2016). Initially, data collected from each participant's interview were analyzed accordingly, and I looked out for commonalities and differences in the data. Similarly, responses received from members of the palliative care team during the focus group discussion were collectively analyzed, and I looked at evolving themes during this process. Subsequently, I merged the findings from the interviews and the focus group discussion, and while doing this I looked at how the words of all the participants told the experiences of the family caregivers.

Through extensive writing and rewriting, I examined the themes in relation to the original research questions and the overarching aim of the study. This was a critical phase of the data analysis and interpretation stage to make sense of the findings and place them within the larger context in a meaningful way (Thorne, 2016). During data analysis, evolving themes in the current study were compared to existing global literature for similarities and differences. This helped me to know if I needed to conduct additional interviews. Analysis of the data generated into a description of the experiences of family caregivers of persons living with advanced cancer and interpreted within the context of the Ghanaian healthcare system.

Rigor and Reflexivity

I ensured rigor and reflexivity throughout the data collection process and generated rich data that explained the complexity of the experiences of family caregivers of persons living with advanced cancer in Ghana. I engaged in a back-and-forth movement between data collection and analysis to ensure consistencies in the data collected. This helped me limit the mistakes that could occur during the research process. During the research process, I made my stance clear as a nurse researcher. I also had continuous discussions, at least twice a month, with my supervisors on the knowledge that was generated.

To ensure credibility of the knowledge attained during this research, I had continuous engagement with the participants, to have an in-depth understanding and variation on the phenomenon. I made critical choices on the decisions made on the interpretations, methodology, and insight into the research. Finally, I did critical self-reflection throughout the research process using a reflexive diary. I kept notes in a reflexive diary of my personal experiences as a nurse who had interacted with the family caregivers of persons living with advanced cancer to maintain reflexivity. I also tried to understand the participants' viewpoints, and asked questions to clarify my previous personal understanding and misunderstanding of the phenomenon.

Ethical Considerations

Ethical approval was submitted to the Research Ethics Board (REB 1) of the University of Alberta and the ethical review boards of the Korle-Bu teaching hospital in Ghana for ethical approval. Letters of introduction and letters of approval from the above-mentioned ethical boards were sent to the heads of the Korle-Bu Policlinic, and Palliative Care Outpatients Unit at the Korle-Bu polyclinic where I selected the participants for this doctoral study, to seek institutional approval before data collection began. In this research, I obtained informed consents from participants, ensured anonymity and confidentiality, safeguarded the discussions during focus groups, and applied the ethics of information dissemination.

Informed Consent.

In attaining informed consent, I made participants aware of the implications of participating in the research and allowed them to make a decision whether to participate or not. The details of what the study entailed were carefully explained to acquire informed consent individually from participants before the study begun. The informed consent letter entailed an introduction to the research process, participant selection, description of the risk and benefits of participating, assurance of confidentiality and anonymity, data collection procedures (direct voice recording done on the mobile phone device during interviews and online via zoom during focus group discussion), and options to withdraw from the study anytime during the research process (Byrne, 2001). For family caregivers, the letter was read to the participants over the telephone for verbal consents to be obtained. For health care professionals a google form was generated and sent to the participants via email. Interested participants had to hit a submit button, which indicated the participant had voluntarily consented to be part in the study.

I reminded participants during every interaction about their freedom to withdraw from the study at any point in time. They were also informed that withdrawal from the study would not affect their care from the palliative care unit. The content of the informed consent form was translated verbally by the researcher into the Twi language to participants who could not speak English.

I provided emotional support to some participants when they felt emotional while sharing their experiences. To support participants emotionally, I showed empathy by providing words of encouragement. Although none of the participants were referred to the clinical psychologist, they were informed of the availability of one if needed.

Anonymity and Confidentiality

To ensure safeguarding the information of participants, a letter of agreement to maintain confidentiality of the participants was signed by the palliative care nurse who assisted me with recruitment, as well as the student who assisted with focus groups. Family caregivers were identified by numbers according to how they were interviewed. For example, the first family caregiver that was interviewed was identified as Family Caregiver Participant (FCG)1. Health care professionals were also identified by number. For example, the first health care professional is identified as Health Care Professional (HCP)1. All names and identifying information were removed from the transcripts. I secured all audio recordings during interviews and focus group discussion, field notes, transcriptions, and analyzed data on a password protected shared drive to ensure confidentiality of participant's information. While reporting my findings I protected the identity of HCPs who participated in the study and avoided being judgemental. In addition, I also avoided mentioning the positions of HCPs when reporting the findings. Additionally, since 7 of the palliative care team members were involved in a focus group discussion, to ensure everything discussed remained in the online meeting room, I stated the confidentiality rules and regulations at the beginning of the discussion. I made all health care professionals present in the focus group pledge to keep everything discussed in the room to themselves to maintain confidentiality.

Summary

The qualitative design chosen for this study is the ID approach usually used to explore complex phenomenon related to human experiences, with the aim of informing evidence-based clinical practice. In this approach, the intention is to go beyond just describing the complex phenomenon but also to give an in-depth understanding into the phenomenon by relating similarities and differences in themes, to produce an interpretation meant to improve clinical practice contextually (Thorne, 2016). The knowledge generated in this research process using the ID approach contributes to an in-depth conceptual and contextual understanding of the complex phenomenon of experiences of family caregivers of persons living with advanced cancer and other chronic illnesses in sub-Saharan Africa, specifically Ghana. The interpretations of the findings from this study will serve as a basis to improve upon the palliative care implementation program for palliative patients and their family caregivers in Ghana.

Chapter Four: Study Findings

In the following chapter, I present the findings of my study. Engaging family caregivers in a discussion about their experiences was challenging and emotional but also an exciting experience for me. As family caregivers shared their stories, I understood how all aspects of their lives were entrenched as they performed caregiving tasks. Family caregiver's individual stories gave a unique representation of their caregiving experiences which was evident through their passionate, anxious, fatigued, and hopeful voices. Health care professionals (HCP) who participated in the focus group discussions shared their perceptions with passion, desperation, and advocacy for the family caregivers.

The characteristics of the study participants will be presented followed by the major themes of the caregiving experience: a. understanding prevailing socio-cultural influences, b. a context of underlying disparities, and c. darkness and light.

Demographic Characteristics of Study Participants

Participants included in this study were family caregivers of individuals living with advanced cancer, and health care professionals who interacted with them. Family caregivers were the primary source of data collection, while health care professionals supported by adding to what family caregivers said about their experiences. The demographic data of the family caregivers and the health care professionals are provided below under separate sub-headings.

Demographic Characteristics of Family Caregivers

A total number of 16 family caregivers participated in this study. The demographic variables of the family caregivers are shown in Table 1 below.

Table 2

Demographic Characteristic of Family Caregiver Participants

Characteristics of Family Caregivers		Number (N=16)	Percentage (%)
Age of Family Caregiver Mean: 45.38 Range: 18-72 years Standard Deviation (SD): 15.82	18-25 years	3	19%
	26-35 years	2	13%
	36-45 years	3	19%
	46-59 years	5	31%
	60-75 years	3	19%
Gender	Male	6	38%
	Female	10	63 %
Marital Status	Married	10	63%
	Single	4	25%
	Divorced	2	13%
Educational Level	Primary & Junior High	3	19%
	Secondary	9	56%
	Tertiary	4	25%
Relationship with Care Recipient	Spouse	5	31%
	Daughter	6	38%
	Son	2	13%
	Sister	2	13%
	Niece	1	6%
Length of Caregiving	<1 year	3	19%
	1-2 years	6	38%
	2-3 years	4	25%
	>3 years	3	19%
Occupation	Self-Employed	6	38%
	Administrative Job	3	19%
	Retailer	1	6%
	Student/Internship	2	13%
	Pastor	1	6%
	Retired	3	19%
Monthly Earnings	No monthly earnings	6	38%
	< 50 CAD	2	13%
	50 – 200 CAD	4	25%
	200 – 500 CAD	4	25%

The age of family caregivers ranged from 18-72 years, with a mean age of 45.38, and standard deviation of 15.82. The majority (63%; 10/16) of the caregivers were females. Ten were married, and the remaining were single (4) or divorced (2). Six had no specific monthly earnings, and the remaining 10 earned between $40-$500 Canadian dollars (CAD) a month. Six of the family caregivers were care recipients' daughters, five were spousal caregivers, two were sons, two were sisters, and one was a niece to the care recipient.

Demographic Characteristics of Healthcare Professionals

Seven health care professionals were engaged in two focus group discussions. They were all working at the palliative care unit, at the Korle-Bu Teaching Hospital. The demographic data of the health care professionals are shown in table 2 below.

Table 3

Demographic Characteristic of Health Care Professional Participants

Characteristics of Health Care Professionals		**Number (N=7)**	**Percentage (%)**
Highest level of Education	Postgraduate	4	57%
	Undergraduate	1	14%
	Diploma	2	29%
Number of Practicing Years	1-2 years	1	14%
	2-4 years	1	14%
	Above 4 years	5	71%
Professional position held at the Palliative Care Unit	Lead Physician	1	14%
	Palliative Care Nurse Specialist	3	43%
	Registered General Nurse	2	29%
	Clinical Psychology	1	14%
Duration Practicing at the Palliative Care Unit.	<1 year	1	14%
	1-2 years	2	29%
	Above 2 years	4	57%
Position	Full Time	6	86%
	Part Time	1	14%

Health care professionals included in the focus group discussion were a family physician, five nurses (3 palliative care nurse specialists, and 2 registered general nurses), and one clinical psychologist. Four (4/7; 57%) of the health care professionals had been working at the palliative care unit for more than 3 years, two (2/7; 29%) had been working with the unit for less than 2 years, and one (1/7; 14%) had been working with the unit for less than a year. The majority (86%; 6/7) of the health care professionals were full-time employed at the unit.

Understanding Prevailing Socio-cultural Influences

The socio-cultural influences on the caregiving experience were described by study participants. The term 'socio' refers to the social aspects of participants' lives which described how their interaction with others influenced their caregiving experience. Participants also described how their cultural values and beliefs influenced their experiences. The socio-cultural influences on the caregiving experience were described in two themes: a. Africanity and the influence of culture on caregiving, and b. gender inequality and socio-cultural expectations of illness.

Africanity and the Influence of Culture on Caregiving

Africanity is defined as "the values indigenous to a group which identifies with African ways of being and thinking" (Landman & Yates, 2017, p. 2). In Africa, every individual belongs to a family or community with shared cultural values and norms that influence their way of life. Thus, being an African or having an African origin implies the person is affiliated with a specific culture either paternally or maternally. In this study, caregiver participants said they attributed their caregiving experiences to being Ghanaians or Africans. A female caregiver participant said: "as Ghanaians or Africans we need to also help each other no matter whether they are related to you or not" (Family Caregiver Participant [FCP] 3). Similarly, a male caregiver participant who was an immigrant to Ghana said that caring for the sick and helping someone in need was part of his culture. He said he was surprised anytime when he witnessed people suffering or in pain at the hospital, and there was no one to help them. A 25-year-old female caregiver participant said the culture influenced her interactions with her relative. She said:

> For me, the only thing I think is, is the fact that because she is older than you and I have to respect elderly people. So even if there is something that I have to stern on her and force her to do it, you can't because if you do it you are a disrespectful child. … As we all know in our settings too the elder person is always right. (FCP2)

In contrast, two family caregivers said that they did not believe that culture influenced their caregiving experience. They said they were providing care because they saw it as a responsibility because of their religious beliefs rather than a cultural expectation. These two caregiver participants said they did not pay attention to what others said.

> I accept the challenge. So, me the culture believes, I don't see it as others see it, I don't care about what family will say, what friends will say or the environment, but I base it on religious background that it is my challenge or my responsibility. (FCP12)

A male spousal family caregiver expressed resentment about his in-law's failure to meet his cultural expectations for caregiving, as he felt they did not share the caregiving tasks. This was because they had different cultural values and beliefs. This unmet cultural expectation from the care recipient's extended family emotionally disturbed the family caregiver.

> Another thing is that it is as if her family has deserted her which is worrying. My mother's sister, she is 92 years, she heard it she said she was coming to Accra to come and stay and I said no … the way and manner we will try to assist, I'm not seeing that from the family. (FCP8)

He further explained that he rejected his auntie's offer of help because of her age, as he didn't want to burden her. Also, he felt from a cultural perspective it was more appropriate for the care recipient's family to come and support with the provision of physical care, which they had refused.

In some cases, I found the cultural beliefs of family caregivers seemed to influence their understanding of their ill relative’s diagnosis. Although the majority of family caregivers perceived their relatives advanced cancer diagnosis as a medical condition, some family caregivers attributed their family member’s condition to attacks from supernatural forces. Two caregiver participants mentioned that they believed their family members were being attacked by an enemy who wanted to kill them. In this context, family caregivers believed in the need to help their relative go through the disease trajectory to recover. Although there were clear signs of no cure for their relatives, a male spousal caregiver still believed in winning the battle after fighting the enemy.

> It was hidden, so I believe that what is going on is an attack. It is an attack yeah, it is a real attack. Yeah, I believe it is spiritual. Than to think negative, you understand, even though if it is someone who is doing it, I have to know that God can heal, God can deliver, do you understand. Even though if it is witches or something I believe that. (FCP7)

In another situation, three family caregiver participants who were caring for their 98 years old mother, perceived that their mother’s advanced diagnosis was part of aging. As stated by one of them:

> We know she is grown up and there is so many complications, there is nothing we can do, is the old age and old age comes with so many complications so [mmm] we are not thinking of any bad thing. (FCP9)

Their mindset was that their mother’s diagnosis was part of the aging process rather than the advanced disease trajectory.

Health care professionals who participated in the focus group discussion said that the Ghanaian culture prohibited discussion of death, although this was not reported by caregiver participants. One participant said: “It looks like culturally people have difficulties in talking about death and since we have tagged it as end of life” (HCP2). In other words, what HCP2 meant was that the discussion on the topic around death is frowned upon culturally. This she said made it difficult for health care professionals to communicate effectively on the care recipient’s prognosis. This was another example of the influence of culture on the caregiving experience.

Gender Inequality and Socio-cultural Expectations

The position of caregiver was seen as a female responsibility by some family caregivers, reflecting predominant cultural beliefs in the Ghanaian and, more broadly, African context. This perception created unequal opportunities for female caregivers. For example, some female participants perceived that males were incapable of carrying out caregiving, thus performing the tasks all by themselves. Two female family caregivers stated that their place in the family as female children to the care recipients made them responsible to provide care. They both perceived caregiving to be their responsibility as females. One of them said:

> No, actually, I am her only daughter…Oh a certain circumstance I think a woman taking care of everybody. When you see the men how they are made you know, you may get a man who will do a similar thing like a woman. It won’t be like a woman doing it with the passion. It is not a cultural thing is the way we were made. (FCP15)

This female family caregiver believed that it was her responsibility to take up the provision of physical care since she was the care recipient's only female child. In that case, she asked her siblings to support her financially, since they were all males. She perceived the physical aspect of the provision of care as the responsibility of the female, and that she alone could provide quality care.

A male family caregiver participant said the caregiving tasks he performed were culturally the responsibility of women. He said: “This care that am giving, if you bring it to the cultural perspective, it is supposed to be handled by a female” (FCP5). HCPs mentioned that the majority of family caregivers they interacted with were females. They believed it was because of cultural values in the Ghanaian society.

HCPs during our discussion also raised how males and females might react differently to their experiences as caregivers. During our discussion on gender, an HCP said: “The male tends to have different experiences and it may look like they have the milder experiences, mild caregiver stress than their female counterpart” (HCP5). Speaking further on this point HCPs highlighted that in the Ghanaian community, a male was expected to be strong emotionally, and complaining could mean you were not man enough. This aligned with one HCP’s perspective that sometimes males hid the way they felt and suffered, which could be detrimental to their health.

> The male caregivers and the female caregivers end up having different stresses or may be different perceptions of what are to provide. … Sometimes they hide it very well, they will say oh, I’m fine, I’m fine but they are not fine, they are suffering so being able to evaluate caregiver burden or stress in some way is, is very important. (HCP1)

Predominant Ghanaian culture’s dictated social norms contributed to the experience of family caregivers irrespective of their situations. A family member was obliged to take care of their sick relative, making it difficult for the family caregiver to ignore their responsibility. When they did not care for their relative, they sometimes experienced societal accusations. As one HCP noted, “They are afraid to admit their true feelings to someone because it will be frown upon by society, so which makes it difficult for them to unburden themselves”. (HCP3)

In the given context, some family caregivers saw the caregiving responsibility as an obligation they could not ignore. Personally, they felt obliged to take care of their relatives because no one else would. A female family caregiver said that she had to take up the caregiving responsibility of her brother since their parents were dead, and she was the eldest. She also added that she needed to do her best to make sure her brother gets better. She said: “You will even feel guilty if someone gets to know your brother is sick and you couldn’t go and care for him”(FCP16).

During our focus group discussion HCPs shared additional insights that served to expand our understanding of the influences of culture on caregiving in Ghana. They mentioned that family caregivers masked their feelings because they wanted to please others in their community. Family caregivers were conscious about what they do so that people would not blame them when something went wrong, or see them to be ignoring their responsibilities.

> When they know that they are not in a good place, they cannot come out boldly to say that because of our culture people may think that if I say that I am tired or if I say I need time off, I might be seen as oh I am cruel or I might be, oh it is my responsibility so I don’t need to say it, but sometimes they really need a break.
>
> (HCP1)

Adding to this perspective from the focus group, participants said that sometimes the family caregiver was incapable of continuing with the provision of care because of their health but were unable to say it. Family caregivers were concerned about what society would say when they ignored their cultural expectations. “Sometimes our culture also does not give people room to express themselves about their true feelings, so psychologically they will be uttering all this out and it gets bad" (HCP2). Family caregivers had to comply with the cultural norms, to the detriment of their personal needs.

A Context of Underlying Disparities

Participating caregivers faced numerous struggles often associated with living, working, and social conditions. Underlying disparities highlight the fact that several of their struggles seemed to have their roots in substandard socioeconomic conditions, and unequal access to health care. Underlying disparities are the differences in the individual's socioeconomic status, income level, employment, and geographical location that influence their experiences. The underlying disparities in the lives of family caregivers are discussed under two main sub-themes: a. living in substandard socioeconomic circumstances, and b. unequal access to health care.

Living in Substandard Socioeconomic Circumstances

The socioeconomic situation of the caregiver participants made caregiving more difficult for caregivers as they performed their tasks. Caregiver participants were living with insufficient and unreliable income to support themselves, the care recipient, and significant others. The family caregiver's occupation, monthly earnings, and social life could not be overlooked as they told their stories. The individual family caregivers unveiled the importance of one's socioeconomic situation in contributing to the complexities associated with caregiving. This will be discussed under two sub-themes: a. costs of medical care, and b. housing insecurity.

Costs of medical care. Most family caregivers who participated in this study were earning low or precarious incomes that made it challenging for them to meet their own needs as well as care for their family member. Family caregivers explained how they were struggling with performing their caregiving responsibilities due to their financial situation. A male spousal caregiver participant explained that because of his financial situation any additional money he earned was set aside for his wife's hospital bills, and emergencies. As he explained this further, he said his family member's advanced diagnosis might need immediate medical attention at any time, and without money this was difficult.

> You don't know what is going to happen tomorrow, you don't know what is going to happen next, you understand? … If you don't have money, your loved one is on the bed making noise, what are you going to do? (FCP4)

The poverty situation of some family caregivers was severe, leaving them unable to pay hospital bills, and sometimes even unable to buy food. Participants shared how they had spent all the money they had on their family member's health care, and so did not have enough to support themselves and their family member. A female family caregiver who was caring for her brother said when she had no money to afford the necessities of life and pay the hospital bills, she eventually had to call some friends to beg for money. Although this was embarrassing, she had no option. Speaking further on this she said the situation was so bad that she didn't mind going to the street to beg for money to enable them to survive. Another female family caregiver who was caring for her mother with advanced stage cervical cancer also shared a similar situation:

> Because since last two weeks I have not worked, am home, the money I had is finished, I don't even have money that I will use to work, am just sitting there, I don't know where I will go and get some money from. So am praying if someone will help me and give me something so I can work. (FCP6)

In one situation a male spousal caregiver who was earning approximately 2000 Ghana cedis ($450 CAD) a month said he had to take a loan to be able to pay for his family member's health care services. He took a loan of 30,000 Ghana cedis ($6700 CAD), to be deducted every month from his salary for a period of two and half years.

The financial burden of caregiving also negatively affected the care recipient. Family caregivers mentioned that awareness of the family's economic situation was distressing to the ill family member. A male spousal caregiver said although he was enduring the cost he was paying for the hospital bills, his wife was worried and complained a lot. Speaking further he said he tries to make her feel relaxed. Another female family caregiver also mentioned that her relative sometimes refuses to eat because he was worried about the financial burden on the family caregiver.

When family caregivers were solely responsible for providing physical care and/or financially responsible for the care recipient, they expressed the feeling of distress. A female family caregiver who was caring for her brother said, since she was solely responsible for her brother's care, it was challenging for her to even go out and get a job. She stated that:

> Is a mess, if we were two taking care of him, at least one can go and do something even if it is selling pure water, one can go and sell and the other one will be taking care of him so you can get something to buy food and eat but now I'm the only one here. (FCP16)

There were times when family caregivers would have preferred their family members to be in the hospital for professional care, but their financial situation made this difficult. A male spousal caregiver said because of his family member's deteriorating state of health, he would have preferred her to be in the health care facility. This was not possible because of his financial situation. "Because it got to a point, the way the sickness has become if it was possible, we didn't want her to be in the house but it all bowls down to finances" FCP12. On the other hand, family caregivers who could afford to pay for their relatives to receive care in the health care institution had the opportunity to do so when care at home was not possible.

A female family caregiver participant suggested that a strong financial situation was necessary for providing care for their family member. Adding to this, she mentioned that the cost involved just to get a scan done at the hospital was the equivalent to a month's salary. "If your financials are very strong. Then you can move on because doing one scan is someone's monthly salary" (FCP15).

Health care professional participants also described similar situations where a family caregiver and significant others could not handle the care of their relative who was approaching the end of life. In that situation, the care recipient was sent to the health care institution to be cared for by health care professionals.

> We had a patient recently who took, I mean, we gave her, we kept saying that she had hours to live, hours to days and she stayed with us for weeks, like four weeks or so, … it was really stressful and not talking… it was very tough on all of them and at a point, they had to bring their mother back to the hospital, because they just could not cope with what was going on at home. (HCP1)

The family caregiver participants expressed how expensive it was for them to seek specialist care for their family members. These expenses were financially draining for the family caregivers since they had to pay for the expensive drugs and services out of their pockets. The National Health Insurance Scheme (NHIS) did not pay for the majority of services, making it difficult for some family caregivers to send their family members to the hospital for care when it was warranted. One family caregiver who was a pastor with no fixed monthly earnings noted that the cost of each hospital visit was the equivalent of CAD 350. He said:

> So, because of a challenge last two weeks we did not get money so we did not go but I am praying that Monday or Tuesday I can go and do the lab, and Thursday we can go back to see the doctor. (FCP7)

Disparities in the circumstances of each family caregiver was noteworthy in their experiences. As mentioned by a male spousal family caregiver, they paid cash in advance for every health care service provided, from consultations to purchasing of drugs and other services. No credit payments were accepted in any department including oncology, radiology, and physiotherapy. A family caregiver who was distressed made this statement: “Health insurance is not, is not helping us. Is only B-co (Vitamin B-complex) and paracetamol and this one, the health insurance is not helping” (FCP9).

Encounters at the hospital were very distressing for family caregiver participants because of their financial situation. One female caregiver shared her encounter with doctors when she told them she could not afford the laboratory investigation that was requested for her brother because of her low socioeconomic status. According to her, this was what transpired:

> When I was sent to the dental school to go and do lab when I went I told the doctor that I don’t have money, and they told me if I don’t have money then how will they be able to get the result to help do what is supposed to be done, so for the lab, I have to go, in fact, I stood there and cried because I said I don’t have money. So, one of the doctors even got angry and told me that if I don’t have money, I should take him away because they don’t know what to do. (FCP16)

As she described this incident, she sounded a bit disappointed with the feedback she got but attributed it to her financial situation. Health care professionals also shared their perception of how financially draining it was for the family caregiver when they come to the hospital for health care services. One health care participant said:

> For the finances, is a very big major problem for our family caregivers, with some of them when they pass through, from their treatment to the main sources … if they come and you tell them to pay a consultation fee, they will tell you, we don't have enough money … so there was a case that we have to come together and contribute for even some of them to use as their transport, so this comes to the case that we have to see them without even, without them paying nothing, for the consultation. (HCP7)

The cost involved in caring for a family member diagnosed with cancer was a burden for most family caregivers.

Housing insecurity. The low socioeconomic status of caregiver participants contributed to disparities in the living space of the family caregiver participants, and their care recipients. Housing insecurity creating additional stress was reported by two of the family caregiver participants in this study. Both participants lived in a shared compound type of accommodation, where all tenants had individual rooms but a communal bathroom, toilet, and compound. This type of housing is usually occupied by persons with low socioeconomic status, with limited privacy. A female spousal caregiver participant mentioned that she had to move her family member away from their rented accommodation to an unfinished structure because of the limited privacy, and subsequent comments and reactions from co-tenants.

> The landlord himself, the landlord's child told me that since we have been sending him to the hospital and he is not recovering, now the border is opened so his mother can come and take him to abroad there to treat him. (FCP1)

> Where we were at [Name withheld], is big house, when is late in the night and he is suffering the sound, he makes everybody will hear. You know in the night the atmosphere is quiet so when you say something others will hear. Because of that there was this boy who was our next-door neighbor, now when he sees me, he doesn't greet me, because when is late in the night and he is in pain, the noise he makes he (the boy) can't sleep. When he meets me, he will just pass me by and that frustrates me. (FCP1)

Another female family caregiver participant living in a shared compound accommodation said that they were being evicted from the room they currently occupied. Due to her financial situation, they owed a few months' rent, and despite her pleas with the landlord to give them some time to settle their debts, he refused. This participant said she was currently looking for money to secure another accommodation.

> The landlord has warned me that he doesn't want the month to end, first or second of the next month shouldn't even reach him here, he doesn't want to come and meet him here before he starts moving out, so I am praying that, I will get some money to look for accommodation for him, even if it is kiosk some where I will get it for him so he will have a place to stay, a lot of people leave in kiosk, so even if I get a kiosk at least the price will not be high, so that he will live there like that. So that is my problem. (FCP16)

Another female family caregiver relocated to the capital region anytime her relative needed to seek specialist care services at the teaching hospital.

> So, I was staying with a friend in a, how do you call it, in [name withheld] closer to [Name of institution withheld]. So that was where I was staying, it wasn't comfortable though but there was other accessibility like the kitchen. My main important thing was to get a place for her to sleep and get something good for her to eat. If I didn't have a bed to

> sleep on it wasn’t worrying me so much than she having a place to sleep and having something good to eat. (FCP15)

The comfort of the ill relative was a priority to the family caregiver, over her own comfort.

Unequal Access to Health Care

Family caregivers described limited access to cancer diagnostics, particularly at the early stages of their relatives’ disease. Most family caregivers reported multiple visits to the hospital and other clinics before their family members were finally diagnosed with cancer. The majority of family members reported initial experiences of misdiagnoses that resulted then in late diagnoses. The experience of visiting multiple hospitals and clinics was stressful for family caregivers, and also financially draining. Feelings of disappointment and fear were experienced when they received the news about the late cancer diagnosis.

> Because when the sickness started, it started from last year 2019 March, so when we go to the clinic, they will tell us is typhoid, when we go they tell us is typhoid, you see, so we also took it as typhoid, so we sometimes go for medicine. (FCP6)
>
> Any time we go to the hospital, they say my wife does not have a problem, in fact, she is okay. When we went, we went back to do the lab and we went to see the doctor and that was when the doctor said is cancer in the bones. (FCP7)

After the stress of moving from one hospital to the other, a spousal family caregiver reported how he received the news of the imminent death of his wife. This family caregiver, sharing his story with fear, and disappointment, disclosed how he had to travel to various regions in the country to seek health care for his wife. They kept going back and forth from the capital city to other regions through referrals by various health care professionals. Throughout these times, his family member was in severe pain, which he had to battle with.

> We went there, so after two weeks, then the man said no, what he sees is not a vein issue but something developing as a tumor. So, we should come back to Accra and go to [Name of institution withheld] Hospital. So, we went to [Name of institution withheld] around February (FCP8).

He said: "So, [Name of institution withheld] we did a lot of tests and MRI and scan and they confirmed what the doctor told us that is cancer" (FCP8). The family caregiver said the communication about his wife's poor prognosis lacked sensitivity and concern for privacy. This was what he said:

> [Errmm], what I will say is that [eerrmmm], I don't know but the doctors and the nurses and I think [errrr], everyone has a way of dealing with, even though they are doctors and nurses they are a way of dealing with their issues because, to me, I was very annoyed and sad for the doctor to say somethings in front of the patient. Do you get it? (FCP8).

Some family caregivers said the news of their family member's diagnosis came to them as a shock. It seemed that after visiting various hospitals for months and years, a missed diagnosis was baffling to some of them. A male spousal family caregiver expressed how surprising his wife's late cancer diagnosis was to him, and their family physician.

> Yeah, so when we went to do the scan, the doctor who was there ask the nurses who sent the person that the person they brought in, her cancer has reached stage four. So, the doctor, he himself, in fact, even as at today he/she sometimes comes to the houses, he feels guilty it pains him/her that he/she was not able to diagnose the sickness early, but I don't know when it started. (FCP12)

The issue of lack of transportation to the hospital was also reported by family caregivers. Family caregivers lived far from the teaching hospital where their relatives were seeking specialist care. With few specialists in Ghana, family caregiver participants reported the travel time to the hospital, and the expenditures involved were burdensome. Most family caregivers said they did not have private cars, and used the public transportation system to get to the hospital. They said this was expensive for them because the majority of the time they needed to hire a taxi due to their relative's health condition. A spousal family caregiver reported that:

> We have to alight at [name withheld], and from [name withheld] to [name withheld] then we take another car that will take us to the teaching hospital. [Mmmm.] we always wake, if we are going we always wake up by… at times we wake up by Four, by five o'clock we are on the road. Just to beat the traffic, hold up there are too much traffic before the toll booth you understand. Too much when you are going to Kaneshie too, there is too much of, just to beat it (FCP4).

The travel time to the teaching hospital from the homes of the family caregivers was also reported by family caregiver participants as distressing. This was due to the distance from their home to the hospital, and the traffic situation. A female family caregiver who had her own private vehicle said "The teaching hospital, the fuel sometimes it's above 100 GH cedis (23 CAD), in and out, around 2 hours" (FCP3). In addition, the travel time to the hospital can be about two hours one way, depending on the time of the day. One family caregiver also added that since he had a valid driver's license, he sometimes borrowed a friend's car to take his mother to the hospital, though this was not always possible because his friend also had need of the car. Then he would use an Uber. In addition, when his relative was admitted, he went to the hospital each morning to provide the needed care for her before going to work. In this case, he spent more money and time on transportation. The struggles of family caregivers to access health care for their ill relatives was an integral part of their survival with the care they provided.

Family caregiver participants reported that, for easier accessibility, they were told to seek health care at the nearest hospital whenever they had an emergency. One family caregiver participant mentioned the stress associated with visiting the nearest hospital to their home during emergencies. She said it was expensive, and despite the facility knowing of her husband’s cancer diagnosis history, they still treated him as a new patient with each visit. This was quite frustrating for the family caregiver.

> They know what is wrong with him but they will still ask you and after telling them they will write for you to go and do lab, do this do that. By the time we will return from the hospital we have spent a lot of money and have no money on you (FCP1).

Limited availability of information on the cancer diagnosis, and other services in the health care system was described by some family caregiver participants. This created disparities in the amount of information available to the family caregiver. A male family caregiver said no one provided information to him, so he took the initiative to read more online. He said this helped him to contribute towards the management of his relatives' advanced cancer diagnosis, and care provided at the hospital.

> Because I have read wide. Sometimes when recommendations are been given by doctors and nurses I try to also give them my side which helps one way or the other which makes them sometimes really change their method of doing things sometimes even prescriptions. (FCP5)

A female family caregiver expressed her gratitude to a nurse who provided them with information about how the NHIS could reduce their medical expenditures.

> Like that medicine, initially, when we had no idea that the national health was covering that, we were buying it at 1000 cedis. It was a nurse who told us that the insurance can cater for that medication. (FCP2)

As a way to provide information on access to available services, advanced cancer diagnosis, and early diagnosis and testing, two of the family caregivers made a plea for the creation of public awareness. They were of the view that there was a need for health care personnel, and policymakers to put in more effort to speak to the general public on cancer. “I think everything is alright, but I think with the health system is what I think that, I think like they should publicize it [cancer] small so that we the health people will know more about it” (FCP5). One of the family caregivers stated that he thinks the awareness of cervical cancer should be similar to that of the HIV program. His reason was that he felt cervical cancer his mother was suffering from was deadlier than the HIV infection.

Health care professionals shared their perception of disparities in access to health care. They added that the family caregivers do not have adequate preparation on their caregiving tasks. As mentioned by one HCP: “Those are challenges, information flow so, information flows with respect to what to expect, etc, [errrr] how to do things [Errmm] those are major problems for caregivers” (HCP1). The family caregivers needed to be given the needed information to help them go smoothly through the disease trajectory with their family members.

The underlying disparities associated with caregiving within the Ghanaian context overlapped in some situations. The family caregivers’ socioeconomic circumstances were featured in their unequal access to health care. The context of underlying disparities and socio-cultural influences helped to understand the experiences of the family caregiver as they performed their caregiving tasks through darkness and light. More importantly is the need to note that these underlying disparities could not be separated from the discussion in the next section. These concepts contributed to, and were salient to the experiences of the family caregivers throughout their relative's disease trajectory.

Darkness and Light

The overarching theme describing the family caregiver participants' experiences was darkness and light. Family caregiver participants' experiences occurred within existing socio-cultural influences and a context of underlying disparities. Darkness represents the journey of the family caregiver associated with suffering, pain, and distress while caring for their ill relatives. Amidst this darkness was a brighter part of the family caregiver's experience associated with positive aspects of their experience. This represented the light in the experience of the caregiver participants which included the positive outlook and joy in performing their caregiving responsibilities, trust in God as a source of strength, and the comfort the palliative care unit provided. The overarching theme of Darkness and Light is described under the following sub-themes: a. care that never ends, b. distressing and satisfying health care experiences, c. the pain we endure, d. spirituality, and e. valued relationship.

Care that Never Ends

Participants described feeling distressed because they were responsible to perform caregiving tasks twenty-four hours a day, seven days a week. This was part of the darkness experienced by the family caregivers as they performed these tasks with limited to no training and support. The tasks varied depending on the condition of the care recipient, and the situation at hand. As the care recipient approached the end of life, the responsibilities of the family caregiver participants changed with the need to prepare for their relatives' end-of-life. Family caregivers also reported the types of support they received as caregivers. This sub-theme will be described under: a. intricacy in caregiving expected tasks, and b. living with existing and non-existing support.

Intricacy in Caregiving Expected Tasks. Family caregivers took on multiple responsibilities including supporting the care recipient with activities of daily living, caring for others in the family such as children or elderly parents, managing the symptom relief needs of their sick relatives, and preparing for the end of life.

Activities of Daily Living. Family caregivers performed tasks associated with activities of daily living such as feeding, bathing, cooking, washing of soiled linen, and lifting the care recipient. The experience of performing caregiving tasks increased as the care recipient's advanced cancer progressed. The severity of the care recipient's condition influenced the tasks the family caregiver was expected to perform. It was found that although caregiver participants' performed common caregiving responsibilities, there were variations in their situations. As a female family caregiver said:

> I have to lift him up. Feed him until he is satisfied before I will also eat. Now he cannot get up and go anywhere. I am the one who bath him and do everything. I give him the medications am supposed to give him. He doesn't sleep, he sleeps seconds (FCP1).

Some family caregivers said they had to start their day very early, and did not rest till late at night. Family caregivers reported that they had to wake up as early as 5.00 am. For example, a female family caregiver shared her experience:

> Is too bad, because am the same person who will wake up in the morning, when I wake up at 5:00 am to pray, I will not sleep again, I will wake up and go there to give her medicine, buy food for her, bath her, and sit by her in the afternoon because there is no one to sit by her and chat with her, even when she sleeps I will be sitting by her, In the

> afternoon I will wake her up, look for food for her to eat, at times, she will not even eat the food, I will give her medicine, I will be sitting with her I cannot sleep and I cannot do anything, so it makes me tired, I get tired because, I take it like she is my mother so if I leave her who will do it for her, I don't have anyone to do it for her (FCP6).

In other situations family caregivers had limited caregiving tasks to perform but had to provide emotional support. For example, a male spousal caregiver narrated how he provided emotional support to his wife anytime she was weak. Another female family caregiver said although she kept reassuring her family member, it was sometimes difficult for her to get her relative to settle down psychologically. This was a frustrating situation for the family caregiver.

> She'll be crying and you ask her why and she'll be like she's tired with life and she wants to give up. You have to console her like a baby till she doesn't stop crying. If she doesn't stop, it means you can't do whatever you want to do. So, you always have to be reassuring her that everything will be fine and life will be fine. It's so hectic. Sometimes you get fed up and you're like you're the one suffering and we're to help you so why don't you want us to help you? (FCP2).

Health care professionals shared a similar perception about the darkness experienced by individual family caregivers' as they performed their routines. During our discussion, they said the family caregivers' responsibilities were a very demanding, 24 hours a day, seven days a week responsibility. Family caregivers had limited breaks, hence found it very distressing to fulfill the needs of their family members. Family caregivers who were responsible for the physical care needs of their relatives slept only when the care recipient slept, and needed to wake up early. Focus group participants added that the family caregiver was expected to administer due medications, change diapers, feed their relatives, and also perform other responsibilities. The following is a comment by a focus group participant about how family caregivers feel in the darkness.

> They sometimes think they don't have the confidence to provide the care, but they don't know who to talk to, who to call, and who to talk to so it can be very, is very stressful on them altogether (HCP5).

Caring for Others. Family caregivers had to combine caregiving with their employment and other responsibilities, which added to the darkness of their experiences. Some family caregivers balanced caregiving work with care for their younger siblings. A male spousal caregiver with no support had to combine a full-time job with full-time caregiving, and juggled work and home responsibilities. He prepared his wife's lunch and breakfast, washed all soiled linens and clothes, and ensured her medication was close to her before leaving for work. This was because the relative was bedridden, and all by herself when he was away.

> My work is like 500 meters from the house. So, if I'm at the office, around, we have a one-hour break, so I will rush during the break time to come and check on her. Around 2 pm in the afternoon, I will come and check if the diaper needs changing...So, I wake up early, bathe her then because she is not able to walk, I try to prepare some food for her for breakfast and lunch. Then get all the medications and the things that she may need closer to the bed. Then I will go to work (FCP8).

Another male family caregiver reported he had to perform parental responsibilities to his younger siblings, and care for his mother. He also had to take care of his grandmother who was his mother's responsibility before she became ill. Performing these extra responsibilities and thinking about them was draining for the family caregivers.

Health care professionals concurred with the family caregivers' descriptions of multiple responsibilities which also included providing emotional support to children. For example, a focus group participant shared a story about a male spousal caregiver who was caring for his wife with end-stage cancer, as well as their five children. In addition to these multiple responsibilities, his children wanted to know if their mother was dying. This was a challenge for him to answer because he did not know what to tell them. The palliative care team had to go to their home to help him deal with this situation.

Managing Symptoms. The symptoms that care recipients experienced also framed the situation in which the family caregivers performed their caregiving responsibilities. Symptoms determined the responsibilities, and reactions of the family caregiver as they transitioned across the illness trajectory. A female family caregiver said:

> It wasn't pleasant because I saw my mother growing lean, she was lying down. She was active woman, very active and she was laying down helpless. She looks so pale; she is not somebody who is heavy but you could see that it has really drained her and I just tell her it will be alright (FCP15).

This family caregiver participant said she had to learn how to manage her mother's pain, restlessness, and diet without any professional training. Describing what she did, she said:

> She started taking that powerful tea the leaves I boiled for her the pain started reducing, and I think, and because I changed her diet too. The pain started reducing and the blood when you are there it will come as a dirty blood (FCP15).

Sometimes the circumstances of the care recipients' symptoms overwhelmed the family caregiver's capacity to provide the needed care. A female family caregiver reported that when her auntie was weak, it became difficult to care for her since she did not have the ability to lift her. Describing the situation, she said the care recipient could have easily fallen onto the ground if care was not taken. She said:

> And the days that she's actually weak and she can't get up, and then you have to try and carry her, those ones are actually a challenge because I'm a lady and I don't have strength. Me, I don't have any strength to carry her so sometimes if you're not careful, she'll fall (FCP2).

A male family caregiver said because of his wife's pain, sudden swelling of the limbs, and immobility, he had to be by her most of the time. Speaking further about this situation, he said he was grateful to be in a circumstance of not being expected to report to work at 8.00 am every day. The situation would have been more challenging for him if he had been an employee of an organization.

Family caregivers also found themselves in situations where they were required to take their relatives home immediately after receiving chemotherapy and radiotherapy. Care recipients usually struggled with the side effects of these therapies, and it became the responsibility of the family caregiver to provide the needed supportive care. With limited knowledge on what to expect, two family caregivers emotionally shared how they managed their family member's symptoms at home after receiving chemotherapy. A female family caregiver shared her situation after her mother's initial chemotherapy treatment. She said her mother's vomiting was uncontrollable, and she had to watch her experience this while she provided the needed support. She said:

> Then she started vomiting. She started vomiting, and I said [eeiii], vomiting, vomiting, vomiting and then she was running (passing stool) at the same time. I watched vomiting

> there was nothing I can do. I just watch her, wiping the vomiting, wiping the leak that was coming out. (FCP15)

Caring for a relative with a cancer wound at home can also be very uncomfortable because of the purulent discharge and offensive odor from the wound. A female family caregiver shared her experience while caring for her brother who had a cancer wound. Prior to discharge, they were given a referral letter to the nearest clinic for wound dressing. Unfortunately, the clinic was unable to dress the wound as it lacked the required space and instruments required. Recounting this, she said it was devastating, so they had to travel to the teaching hospital for daily wound dressing. This was expensive for them, and also delayed the wound care until the dressing was soaked with discharge.

Transitions across the illness trajectory were very challenging for family caregivers. HCPs shared their perception that when the care recipient started to exhibit deteriorating symptoms, caregiving became more difficult for family caregivers. During this phase, the family caregivers were unable to understand the care recipients’ non-verbal cues. This made caregiving more distressing for the family caregiver.

Preparing for the End-of-Life. An integral part of the family caregiver participants’ situations was how to prepare themselves, the care recipients, and significant others for when death would finally occur. The circumstances surrounding the preparation for the death of their relatives manifested through the family caregivers' psychological, physical, and spiritual activities, varying according to family caregivers’ knowledge and ability to prepare for end-of-life. Some family caregivers were informed of their family member’s approaching end-of-life, while others were not. In some circumstances, family caregivers refused to believe their family member was approaching the end of life, while others made it a priority to prepare for this phase.

A male caregiver participant said, “Sometimes you sit down or on your way walking back or home you start to even plan how life will be after their death, in my mind anything can happen” (FCP4).

Family caregiver participants disclosed the various ways they prepared for their relatives' end-of-life, although this was a tough experience. A male family caregiver participant said he had started preparing himself, his family members, and significant others by planning a befitting burial for his mother. He had secured a funeral policy and had initiated discussions on the impending death with the care recipient and significant others, so that she could put things in place before she died. His family member had begun to show him the lands she had acquired, and also gave him adequate information on where to find legal documents when death occurred.

> Well, anything unique I will say I’m doing is that, I seems to be more interested in any hiding things, when I say hiding things, daily she turns to tell you what she is doing. I have this here, I have putting this there and there are other maybe very technical things that ideally if she was not well, she might have handled it herself, now I seem to really handle them. (FCP5)

Another male spousal family caregiver shared a similar situation. He said he was prepared for his wife’s impending death and had already prepared her by arranging for reconciliations with the immediate family and others. In addition, he said the children had been prepared, and had been told to spend memorable times with their mother in her final days left with them. Sounding pleased as he shared this, he said he was able to achieve this before she was unable to talk.

> Yeah, so is not her death that I am bothered about, but where she is going after death, that became my challenge, so I started working on it. So, because of that I was able to work

> on that before she couldn’t talk again, so I was happy that I was able to achieve what I wanted to do. The possibility that their mother will go before us is high, therefore, no one should be afraid, we should encourage ourselves, so that anything we are doing we shouldn’t do it as our responsibility but we should do it for love (FCP12).

Family caregiver participants said this eased their ability to prepare with limited regrets for the care recipients impending death.

Also, family caregivers found themselves in a conflict between fulfilling their relatives wish to die at home, and their will to have them receive quality care in an institution. HCPs said family caregivers often asked how long their relatives would be going through the symptoms they experienced.

Living with Existing and Non-existing Support. Family caregivers reported receiving support from family, friends, community, and the health care system, which were spots of light in their dark moments. Disparities in the kind of support received by family caregivers, and the extent of support were important to their caregiving experience. These supports were in various spheres such as financial, emotional, psychological, and physical. In spite of the existing assistance, family caregivers requested additional support. It is worth noting that some family caregivers also reported little to no support from anyone.

The majority of the family caregivers who participated in this study reported that they received some kind of support, mostly financial, from other family members, friends, and the church. Two male family caregivers said they received financial support from their extended family members. With access to such support, they were able to add to what they had to pay for the services their relative received at the hospital. A female family caregiver said they received some financial support from their family physician. She said the doctor usually gave them a refund of the money they paid at the hospital anytime they presented the receipt to him. This he did out of generosity to support them.

Two male family caregivers also reported receiving support from the community. One caregiver participant stated the support was not substantial. “Yes, and I have some siblings, I have siblings in US who have been sending me something every month to add up” (FCP8). The other male caregiver reported that he received a one-time monetary contribution from his network of friends about a year ago. This was the equivalent of $27,000 CAD, which actually helped with the costs of some services his wife received, and also medications.

A female family caregiver received some financial support from friends when she spent all she had on her brother’s hospital bills and had no money left. Churches were also financially supportive to some family caregivers. A male spousal caregiver said that while he received little support from the extended family, he appreciated the financial support provided by the church. Another female family caregiver reported that she received some financial support from the church. A female spousal caregiver said her husband’s relatives had been very supportive, not just financially but also with transportation. She said this was really helpful since she was no longer working.

> Ooh by God’s grace is them ooo, because am not working, so now they do it even food that we will eat is them, they have not abandoned me, is them. I always say God will bless them, they don’t let us go hungry, and they feed us (FCP1).

These supports really helped the family caregivers offload some of the financial burden associated with caregiving. One female family caregiver participants said “The support I got from other people especially some of my friends. If you don’t have that financial assistance. That is where you get depressed” (FCP15).

Some family caregivers reported receiving support from the National Health Insurance Scheme (NHIS), although this was very insignificant in most cases. Health care professionals shared a similar perception, reporting that the insurance coverage does not apply to all services. Though the team was not sure of specific services that were covered, they said the cost for receiving treatment for symptoms such as pain, nausea, and vomiting was covered by the NHIS. This was because the NHIS covers the common uncomplicated symptoms patients usually reported to the health care centres.

In addition to financial support, some family caregivers also received help in providing physical care. A male spousal caregiver said his adult children had been very supportive. He said he was happy the children had not rejected their mother in her deteriorating state, and provided physical help when available to do so. Another male family caregiver said he had an understanding boss which has helped him a lot. The human resource department at his place of employment was aware of his wife’s condition, and was understanding when he reported late for work or called in to take a day off.

Two family caregivers reported having paid someone to help them with caregiving. The church also supported a male spousal family caregiver and care recipient psychologically, and spiritually by visiting every week. A family caregiver reported receiving support from a friend, as she needed accommodation when she brought her family member to receive health care services. She also reported getting emotional, and psychological support from another friend. Adding to the experience of light, she said the support she received from family and friends strengthened her ability to cope with the situation. She said:

> My friends, this my doctor for instance have been a main supportive. He will always call and ask, how is mum doing, what about the medicine, what about the colostomy, what about her this and that and that and that (FCP15).

Other family caregiver participants described not receiving support, which was an aspect of the darkness they experienced. For example, a female family caregiver said her extended family members were not supportive with the care of her mother in anyway. She said none of them had ever given her any money or physical support in the caregiving tasks she performed. In this case it seemed the burden of care was left in the hands of the primary caregiver, who was only 25 years old, and was not working because of her caregiving responsibilities. She said:

> When they come, they will just look at her and leave, they just come and look at her and leave, when we go to the hospital and they request for blood, no one will come and donate, I have to go and look for people to come and donate and I also donate mine before they will give her blood transfusion. FCP6

Similarly, a male spousal family caregiver said he had not received any support from anyone. He said:

> No, no we don't, no one is given us any money or no one is given us anything. No one is giving us anything in fact, no one, no one, friends, church members, no one is giving us anything, no one (FCP7).

Sometimes the availability of the extended family to provide support with the physical care depended on their proximity to the primary caregiver and care recipient. For example, an immigrant male spousal caregiver expressed how he would have received a lot of support from the extended family if he was in his home country. Describing this during our conversation, he said:

> What is there is that, this is another Country, you understand, is not my country where by her sister will come, my wife sister will come and wash and another one will come and clean, another one will come, and may be my own sister will go there too, do you understand. (FCP4)

Another male spousal family caregiver shared negative feelings about the lack of support from his wife's family. He said:

> Aside, another thing is that, as if her family has deserted her, as I said, I am her husband. So, if anything I am supposed to allow the issue. So, at least, as a family member you should have collected someone to come and live with us to take care of her. No one is doing that (FCP8).

In contrast, a male caregiver said he did not want to involve the extended family members in the care of their mother. He said their coming in to help would be an extra burden on him rather than a relief. Unlike the other male family caregiver, he reported that their relationship with the extended family was not strong. Explaining further he said involving the extended family members would not be beneficial to him and the care recipient in any way.

> That is it, we don't have that experience, so we barely try to also [Errmm], really relay any kind of information, as you are going to relay, what are you expecting them? To give you money, which they won't. To come and perform any special exercise for you, which they won't (FCP5).

During the HCP focus group discussions, one of the participants said sometimes the extended family members made it stressful for the primary family caregivers to perform their tasks. She described a story about extended family members stressing the children of the care recipient who were solely responsible for all aspects of care. She explained that the extended family members wanted to make decisions but did not provide any kind of support.

Caregiving with limited support had an influence on the caregivers social and economic lives. Family caregivers reported giving up certain aspects of their lives to provide care, such as having limited social connections, and facing financial constraints. A male family caregiver said caregiving was affecting him financially, affecting his relationship with his fiancée, and also hindering his career. Because of his mother's sickness he had placed on hold all projects he wished to do, his marriage to his long-time fiancé, as well as his wish to upgrade his education. Being in a low middle socioeconomic status he would not achieve all that now because of his financial situation, and being a caregiver. Currently all his finances were going to support his mother's health care, and he failed to envision a positive plan in a new calendar year.

> Oh yeah, I mean, personally, it is financially draining and as an individual you also have a personal plan you want to achieve or attain, sometimes you want to settle down so you want to get a bit of property or something. (FCP5)

Furthermore, caregiver participants also stated that their caregiving responsibilities had affected their ability to go to work. Three male caregiver participants mentioned working for institutions where they were required to report to work at 8:00am, and they were often late. One of them said, in addition to being late for work, he was unable to accept work assignments that required him to go out of town. This was doubly unfortunate because he would have earned some additional cash from such assignments. In some situations, family caregivers had to stop their work in order to provide care for their family member. A female spousal caregiver said she had two teenage children from her first marriage who were her responsibility, and needed to also consider their upkeep. This was challenging because she had stopped her work to care for her husband. Similarly, another female family caregiver caring for her mother said:

> Because am with her every day, we go and come, we go and come, (Up and down, up and down) so I don't get time to work, at times I work on days that we don't go to the hospital, days that we go, I don't work (FCP6).

Family caregivers expressed how their social lives had become sporadic because of limited or no support. For example, a female spousal family caregiver said although she was always with her husband, the good times she had with him were interrupted because of his advanced cancer symptoms. The disruption to a normal social relationship with her husband affected her negatively. A 25 year old female family caregiver also said that caregiving had interrupted her social network. She identified this as an issue with performing the caregiving tasks because she no longer had time for her friends.

An eighteen year old female family caregiver put her education on hold in order to help care for her sick mother. Her father said she needed to stay to help care for their ill relative despite the fact that she had an excellent grade to further her education. Further disclosure of details on this situation revealed that lack of finances also played a part. The care recipient had been supporting the home with her earnings, but things were different after she became sick. The only source of income for the family was the spousal caregiver's earnings, which was not enough to pay for the care recipients health care bills as well as her tertiary education. They both sounded very sad about the situation as they spoke, but mentioned there was no other option for them.

> She completed school last yet and she is not doing anything now, because when I go, her elder sister is a trader so is like she is now the elderly to the one who is twelve years. She

> needs to be at home by her so that if anything she will call and tell us how the situation is. That is the major reason and also finances. So, because of that she is not doing anything, she is at home. Because when I wake up I'm gone and I have been travelling a lot (FCP12).

Two female family caregivers reported that they had relocated from their matrimonial homes in order to be with their family member that needed care. This decision was made due to their low socioeconomic status, since their own homes and community settings were not appropriate for caregiving. One of the female caregiver participants said she lived in a rural setting where access to quality care was impossible, hence her reason for relocating. Sounding desperate and caught in a dilemma, she mentioned needing to be move back with her family, but at the same time was unable to leave her family member.

> I need to go home too to go and see my husband and children small, because this can affect my marriage, … so now that school is about to re-open that is my major problem, my husband too when he wakes up he will have to go to work, he cannot take care of the children to go to school before he goes to work (FCP16).

HCPs shared their perceptions of the impact of caregiving responsibilities on social and economic life. They concurred that the personal lives of family caregivers were usually put on hold because of the caregiving responsibilities they performed. Consequently, some also lost their jobs because they had to skip work and often called in to take the day or week off.

> And so some of them I will say that their socioeconomic status to a larger extent affects the kind of care and then the care giver burden that they experience (HCP7).

In our discussion on non-existence of physical support, a male family caregiver participant suggested that affordable home care services would be very helpful. He compared it to services available in Western countries to support family caregivers in the home. In search for respite support services, another male spousal caregiver said the services of the organization he contacted were too expensive, and their time to deliver care was not convenient. The need for a non-governmental organization to support the family caregivers in any way was expressed by one of the family caregiver participants.

> The only thing we will say here is that, if there is a help from your end. May be some NGO wants to give us help, we shall welcome it. With all respect, we shall welcome it, we shall not refuse anything coming from any NGO with all respect (FCP9).

Family caregiver participants described not wanting to take a break from caregiving, as they did not trust another person to take their place. For example, a health care professional participant said:

> So from that point in time she said never again is she leaving him because she knows how to look after her husband and he has never fallen before, this one time that her sister you know [giggle] was managing affairs, he falls and she can't afford for him to get hurt worse than he already has so she, so she, even though we encouraged her to take a break, she said, she just, she can't trust anyone to look after him well, it gives her more peace of mind to stay (HCP1).

Health care professional participants agreed that family caregivers need a break away from the care recipient for a while, to ease the burden of caregiving. Health care professionals said family caregivers need to be supported as they perform their caregiving responsibilities. They mentioned the need for financial, physical and emotional support.

Distressing and Satisfying Health Care Experiences

The family caregiver's interaction with the formal health care sector was that of darkness and light. In relation to their experiences with the health care system, they described difficult and unpleasant experiences. The darkness was mostly experienced during their interactions with the medical-surgical, oncology, and radiology departments, as well as the laboratories. The family caregivers' experiences with the palliative care unit was light after darkness. Under this sub-theme I describe the darkness and light family caregivers experienced as they interacted with the health care sector. This will be described under: a. hassles in the hospital environment: "It is hell", and b. The safe haven: Palliative care unit.

Hassles in the Hospital Environment: "It is hell". In Ghanaian health care institutions, particularly in the public hospitals, and clinics, it is normal to see family caregivers providing care such as running errands in the hospital, navigating the health care system, and performing other tasks. This experience was part of the darkness family caregivers shared. A male family caregiver participant reported that he needed to be at the hospital full time when his mother was admitted. In addition, he said he became a personal nurse because of some of the procedures and tasks he was performing. He said he spent most of his day by his mother in the hospital and learned a lot of procedures through observation, and actually performed these tasks by himself, even though some of these tasks were considered nursing procedures, such as managing drainage tubes. When I asked why he did that, he said the nurses do not attend to them as quickly as expected because of the nurse-patient ratio. Commenting on this he said confidently:

> And the nurses of course when you look at the ratio the patient and the nurses available you will have to do some of the things by yourself. There have been several times whereby, I know how a drip is supposed to fall, I learnt all those things upon caring for her at the hospital, I know how a drip is supposed to fold okay (FCP5).

Other family caregivers shared the responsibilities they had to take up when their family member was admitted to hospital. Some family caregivers said it was necessary for them to sleep at the hospital. One male family caregiver shared the hassle he went through to ensure that his family member got the blood transfusion they needed. Sharing this experience, he said that he went to various hospitals to get the appropriate blood to be transfused, which was distressing. Another male family caregiver reported that he was expected to support the health care professionals with care provision, lifting and transferring his relative from one place to the other when necessary. Below two family caregivers describe what they experienced when their relative was admitted:

> When I go to the hospital in the morning I will not come back home till evening. Till evening 9pm, at 9pm in the evening if I go to bed, by 5am I will wake up bath, pray and go to the hospital, because I will go there before people start coming there to see her, I will go and bath her, dress her bed and give her food (FCP6).
>
> Sometimes when you go to the hospital and she is admitted, because of that you have to stay in the hospital, you can't come home. You'll have to sleep there (FCP2).

Health care professionals shared their perceptions of the strain placed on family caregivers by the complications of navigating the health care system.

> Caregivers suffer from communication stress where they are not being communicated to very well and when you, the system also does not help them well because if they bring patients to the clinic, they will be ask to go here, go to this lab, go and do this, run around, they do all sort of errands and at the same time they have to bear the stress of a caregiving, and it actually have a very bad impact on that patient. (HCP3)

This added to the physical and psychological strains of family caregivers' experiences. The stress that they experienced in the hospital sometimes influenced their willingness to seek health care services for themselves when needed. A focus group participant shared an experience with a family caregiver who visited the palliative care unit with her mother diagnosed with advanced cancer of the breast. The family caregiver complained of their distressing experiences at other departments in the health care system. After their discussion about the care recipient, the health care provider decided to teach the family caregiver on the need to visit the hospital for routine clinical breast examination for herself. This family caregiver expressed she was not ready for another displeasing experience with the hospital, so did not show interest.

Waiting time at the hospital was also seen by some family caregivers as stress inducing. it was not unusual for families to wait anywhere from two to seven hours to be attended to at the hospital, depending upon the health care service required. A male family caregiver said that, whenever he took his wife to the hospital to receive blood, they stayed for approximately four hours. Another male spousal caregiver mentioned how long it took his family member to be seen by the specialist when they went to the teaching hospital. "The stress of going to the teaching hospital is a big hassle when you are there, you can be there 6:00 o'clock AM and they will answer you by 3:00 o'clock PM" (FCP4).

Another family caregiver shared her experience on how long it took them to get an appointment date. Considering that the purpose of the visit was only to be scheduled for the next available appointment date, she felt the duration of stay was too long. This female family caregiver explained that it took seven hours to get an appointment at the radiotherapy unit. After waiting so long, she expressed her anger and frustration to the receptionist. For all her efforts, they were given an appointment with a specialist in 3 months. This was unacceptable because her relative was without treatment or medication for her severe pain for that period of time. “So, there was no pain killer there was nothing to the patient, not even a doctor to see her and say oh okay we will try and do this for you, you understand what I am saying?” (FCP15).

The hassle in the hospital was an additional stress to what family caregivers experience with provision of care in their homes.

The Safe Haven: Palliative Care Unit. In the current study the palliative care unit was the final referral point for patients and their family caregivers. In contrast to their experiences of darkness described above, family caregivers’ time with the palliative care unit was described as an experience of light. From their first day at the palliative care unit family caregivers felt comfortable, relaxed, and hopeful despite the deteriorating state of their family member.

Family caregivers described the differences in services received in the palliative care unit with those in the other departments. For example, they mentioned how the health care professionals at the palliative care unit devoted time to speak to and communicate with them. Family caregivers expressed disappointment with late referrals to the unit, described their relationships with the palliative care team, and gave recommendations about the palliative care unit based on their experiences. This sub-theme was discussed under the following: a. The light came too late b. Increased satisfaction with care c. Relationship with the health care professionals, and d. The safe haven needs help.

The Light Came Too Late. Family caregivers, and their relatives were referred to the palliative care unit when the care recipient was approaching end-of-life. This was a disappointment to family caregivers, particularly after experiencing the services from the palliative care team. A female family caregiver said this was the first time she had ever heard of palliative care. Another male spousal family caregiver said the time of referral from the chemotherapy and radiotherapy department was too long. Although he was happy they were referred to the unit, their previous experiences had been devastating.

> So, when we went to the unit. In fact, that place they made things clear to us than the Korle-Bu when they were taking care of us. In fact, me, I was suggesting that, that should have been a starting point than taking the person there when the person is about to die (FCP12).

He passionately recommended that family caregivers and their family members be referred to the palliative care unit early in the course of the patient's disease trajectory. He said if someone could speak to the authorities to make the palliative care unit the first point of contact it would be well appreciated.

Health care professionals also commented on the challenges to improving the referral system for the palliative care unit. Lack of awareness of the aims of palliative care on the part of health care professionals and the public was identified as a significant challenge. Before coming to the palliative care unit, family caregivers often understood that their family members would receive curative treatment, and were disappointed when they understood that the unit would control their family member's symptoms, and improve their quality of life, but not provide curative care. One health care participant identified that there needed to be a change in the perception about early palliative care through the training of all health care professionals in the various universities and colleges.

Increased Satisfaction with Care. Family caregivers also shared their experiences of how the palliative care unit had helped them, and their family member. The palliative care unit provided them with services which counteracted their unpleasant experiences from previous departments. A spousal family caregiver was happy to share that his family member who was bed ridden could now walk, talk, and do things by herself after their visit to the palliative care unit. He said:

> She can eat, she can cook, she can bath herself, before she cannot bath herself, formally she cannot do anything, she is on the bed 24 hours but now she is trying to do exercise everyday like she is trying to cook, she is trying to do whatever, whatever. (FCP7)

Another male spousal caregiver shared how excited he was on their first visit to the palliative care unit. His wife was given medication for pain relief, and they received counselling, decreasing their anxiety and stress. A female family caregiver participant said the experience of being able to contact the palliative care unit via phone for assistance, and consultation at any time was very helpful. Adding to this, a male family caregiver reported there was no issue with long waiting hours to be seen by the health care professionals, like in other departments. Some family caregivers said they did not pay for the services they received at the palliative care unit, and sometimes the team provided support by purchasing their relatives' medication when they could not afford it.

Health care professionals noted that palliative care services were more accessible to patients. Palliative care staff made visits to new referrals who were admitted to various wards in the teaching hospital to provide psychological support, and allow access to the team at any time. The HCPs reported that they were also reviewing home visit services with the aim of increasing accessibility, and availability of palliative care services for their patients and family caregivers. Currently, they provided telephone consultations where family caregivers needed to obtain medications to manage symptoms, as well as providing information on private home care services to contact for respite support.

Relationship with the Health Care Professionals. The majority of family caregivers described having strong relationships with the palliative care team, providing a positive experience that was light to family caregivers. A male family caregiver said the way the members of the team smile when they talk to them was very hospitable. Others described the health care professionals as "very outstanding", "nice", and "excellent". One male spousal family caregiver expressed his gratitude for the services provided.

A female caregiver said she commends the palliative care team for the excellent work they were doing, and how the warm reception she received made her feel welcome and relaxed. "That was my first time going there and the reception I got there was amazing, I just relaxed and was looking at them honestly. So honestly, they are doing well, seriously, seriously" (FCP15).

The Safe Haven Needs Help. Considering the services provided there, family caregivers identified that the unit needed help from the authorities. Though this topic was not part of my research questions, it was a salient feature in participants' experiences. Two of the family caregivers noted that the palliative care unit should be relocated to a larger, better ventilated place. They felt the unit deserved a conducive infrastructure to serve a lot more people.

> But with the palliative, I said they are doing massively well and they don't deserve to be in that corner. Yes, small corner they really need a very open ventilated space. Yeah, I told her that this is not the place that they have to be (FCP15).

Health care professionals added to the recommendations made by the family caregivers for early diagnosis, infrastructure, and space. They noted that they were not involved with management level decision making about the unit, but were clear that access to palliative care services could be improved. They identified awareness raising, and increasing knowledge among health care professionals on the need for palliative care in the health care system, as strategies for increasing awareness. In addition, health care professionals highlighted using the media as a channel for family caregivers to share their positive experiences with the palliative care unit.

> Can we integrate, it, it's going to take [emmm] it is going to take a lot of work from those of us who work within palliative care and also maybe, the families, the families of the patient who have received palliative care, have benefited from it should begin to make noise about their experience and as they have spoken to you right now about how they envisage their care. (HCP3)

Health care professionals added that if family caregivers would share their experiences publicly, they could send a message to policy makers for the integration of early palliative care.

The Pain we Endure

Family caregivers' experiences influenced their lives both positively and negatively. The negative influences of social and economic strain, and physical and psychological distress constituted the darkness experienced by family caregivers. Participants described how their lives was adversely impacted as a result of caregiving, including feeling pain themselves as they observed their relative's pain. In spite of their suffering, family caregivers also reported the positive influence of caregiving where their experience engendered a personal transformation on the family caregiver. This sub-theme is discussed under a. physical and psychological impact of caregiving, b. personal transformation

Physical and Psychological Impact of Caregiving. The findings of this study revealed that family caregivers lacked sleep, experienced health issues, and also overlooked their own health conditions in order to support the care recipient. The negative health implications of insufficient sleep was generally overlooked by family caregivers. A male spousal family caregiver said he started growing lean when his wife's condition got worse, because he was unable to sleep well. He said he ignored all the changes in his body, and didn't bother to go to the hospital to seek health care.

> That time I grew slim, I grew slim when people, any friend sees me they say oh [FCP7] you have grown slim and I will say yeah is normal, you know. But they all saw that is because of what I was passing through (FCP7).

A female caregiver participant said she stayed up at night to sing for her mother who found that it helped her to sleep. Her brother, also a family caregiver, noted that she had no option than to do according to their mother's wish, no matter how distressing it was for her. Two male spousal caregiver participants noted that their family members' pain and inability to sleep also compromised their own sleep.

A 70 years old male family caregiver who spent his days doing errands around the hospital, and lifting and transferring his family member said was experiencing pains in his knees, but he did not attribute the pain to the tasks he was performing.

> Oh [errrr] as for that [errrr], to be honest with you me I have leg problem, knee, my right knee, my right knee. Yes, and this thing, the pain is still there but I have been going to the hospital apart from that there is no any other issue. (FCP9)

Family caregivers were also affected psychologically because of caregiving. A male spousal family caregiver said caregiving was psychologically draining since he had to also think about other responsibilities, and personal issues, in addition to being there for the care recipient. Caring for his family member was causing a delay of his marriage to his long-time fiancée. Although the lady was not complaining about the delay in their getting married, he felt that keeping her waiting for too long might have a negative effect on her ability to give birth in future. “It is also psychologically and emotionally draining. Because I mean [errrm] though she is not shouting, she is not doing anything, but it affects you okay” (FCP5).

One female family caregiver said her job suffered whenever she had to be out of town with her family member to seek health care, which in turn affected her psychologically. She was worried about losing clients, but hid her anxiety and left her employees to sort things out. A male family caregiver said when his mother was in the hospital he started his day with the sight of her blood, since he was at the hospital every morning before work to help care for her. “Is quite psychological because with many things that you are seeing, sometimes blood in the morning and that is how you start your day” (FCP5).

Family caregivers reported feeling anxious and unsure of what would happen next to the care recipient. Admission of their family member to hospital was particularly psychologically traumatizing for family caregivers. A male spousal family caregiver said he was not psychologically stable whenever he was away from his wife in hospital, thinking about what was happening to her, and if she was receiving the care she needed.

As well, they lived in fear, and uncertainty as they witnessed their relatives experience symptoms associated with their cancer diagnosis such as pain, bleeding, inability to communicate verbally, and immobility. These were dark moments for family caregivers and some participants reported that they were often in tears. A female spousal family caregiver said she worried a lot as a caregiver because she could see her family member’s condition deteriorating. Casting her mind back to the strong man she had married, it was troubling to see her husband unable to move. Two female caregivers described the emotional distress they experienced with their family members’ advanced cancer diagnosis. They said they cried a lot when they saw their loved one in their current condition, unable to do anything, and bedridden.

“I can just be sitting there and be thinking. When she is cry I also cry. I feel bad. When am at work I will be crying … I never knew my mother can get that sickness” (FCP6).

Health care professionals agreed that family caregivers experienced psychological and emotional distress in the face of their family members’ deteriorating health. One HCP participant said the emotional attachment to the care recipient sometimes increased the difficulty for the family caregiver to go through their experience of caregiving. Health care professionals also agreed that family caregivers masked their own symptoms in order to continue performing their caregiving tasks. One HCP said: “When some of them fall sick, they have blood pressure issues and all that, they don’t look after themselves and it becomes … really tough” (HCP2). When family caregivers ignored their own routine checkups, and medications, they were at risk of develop complications, sometimes becoming patients themselves, and even experiencing sudden death.

Personal Transformation. Along with the stress associated with caregiving, the experience also added some positive aspects to the life of family caregivers. Two participants mentioned how being a family caregiver had changed them as a person. For example, a male family caregiver said performing the caregiving responsibilities had changed him, and groomed him for the future. It had made him appreciate life, and had given him a different viewpoint about what life is about. He said, “You don’t know what tomorrow will bring so you have to show love to others” (FCP5). Another female family caregiver said caregiving had had a positive impact and made her develop a different outlook about life. She noted that life is short so a person had to be ready to help others.

> I feel like, you realized that life is really like short and then when you go out and you meet people, you don’t know what someone is going through so you always have to like

> help, be there for others because if they really open their mouths to tell you what they are going through. I think it has made a positive impact in my life though. (FCP2)

One family caregiver reported that her caregiving experience had made her less judgmental about people she met, and felt empathetic for persons who are diagnosed with advanced diseases.

Spirituality

Some family caregivers tried to find meaning in life amidst their current state of uncertainty, and fear. In some situations, they considered their relationship with something superior as a source of hope and strength, helping them to cope during the disease trajectory, and the approach of death. The experience of practicing spirituality was the brightest part of the experience for most family caregivers. On the other hand, for some family caregivers, spirituality had a negative impact if they were looking forward to a miracle cure for their family member. These experiences are discussed below.

Adjusting to the New Life, and Coping. Family caregivers had to adapt to providing care, and their family member's advanced cancer diagnosis. The majority of family caregiver participants who believed in a higher power said their trust in God, reading the bible, and prayers had been their strength throughout the disease trajectory. Some mentioned how the care recipient asked them not to be worried but to rely on God. A female family caregiver said such words from her husband caused her to keep praying for him to get better. A male family caregiver said there was nothing he could do but to rely on God.

> Oh, what do you want me to do, you cannot do anything but we always put everything in prayer, we pray, you understand. That is, it, only God, sister, it is only God. Is moving my wife, is only God that is moving my wife. Is only God, I will not lie to you, is only God (FCP4).

Some family caregivers believed that everything happens for a reason. Based on their religious affiliation, they mentioned that some things happen as a test, and it was important to know that what they were passing through was temporal. A male spousal caregiver said he gets his courage from God. “[Errrr] the courage, I will say is by God. Because in anything when you don’t put yourself in God you cannot do” (FCP12).

A male spousal family caregiver participant said he had been working on developing his inner strength, encouraging himself to remain strong to support his wife. He noted that the initial stages of the disease were a struggle for him, but he had tried to overcome the fear, and emotional weakness through the years. He added that to survive that experience, he told himself he would be victorious, and everything would be okay.

> Then I have to forget everything and cope with it. For now, [errmm] I am okay, somebody will say you do not know when you will go and the type of sickness and the way you will go, so for now, everything is okay. (FCP8)

Health care professional participants confirmed what family caregivers said about their spiritual practice. They said when family caregivers cannot do anything more for their family members and witness the deteriorating symptoms, they resort to prayers, irrespective of their religious beliefs. The practice of spirituality made it easier for family caregivers to go through the disease trajectory, and also when death finally occurs. A male spousal family caregiver spoke about how prayer and his belief in God helped him to prepare for his wife’s impending death.

> Me from now my prayer is that God should look at her sickness and how the family is suffering and if she has to pass on she should pass on; [if he has to call her he should call her] so that the pain that she is going through will go away. (FCP12)

In contrast, for some family caregivers the practice of spirituality through intuitive reasoning, and belief in a supreme being developed into denial of their family members approaching death. A female spousal family caregiver said during their last visit to the hospital, the doctor informed her that her husband was nearing death. She said this was the first time she had heard this, although her husband and other family members already knew about it. Ever since, whenever she was alone the thought of losing him made her talk to herself. She kept denying that he was dying anytime soon. As I probed further on this, she said although her husband's symptoms were not improving, and he was deteriorating by the day, she still believed her prayers were going to change something. "When am alone I will be talking to myself, no that will not happen, when I say it will not happened then I support it with prayers, after praying I will just be sitting there" (FCP1).

Similarly, a male spousal family caregiver said although he was informed about his wife's impending death, he was looking for a miracle cure from a supreme authority. He said "I do not believe what the doctor said. I think God is going to do wonders, and she is going to walk again, the doctor has said it but I do not believe it" (FCP8). Health care professional also shared their perception on this saying that the family caregiver's religion and spirituality posed a challenge for them to sometimes accept that their family member was at the end of life. This was stressful for the individual caregiver, particularly when they were looking forward to a miracle which never materialized.

Valued Relationship

This sub-theme focuses on the valued relationship between the family caregiver and the care recipient. What the care recipient meant to the family caregiver, and the lineage they shared brought some joy to the experience of the family caregiver. Also, where there were split responsibilities amongst multiple family caregivers, the experience was different. I will discuss this under: a. reciprocity and b. we all perform our unique responsibilities.

Reciprocity. Reciprocity encompasses how much caregiver participants valued the relationship they had with the care recipient and saw the need for reciprocity during this time of their lives. The connection between the family caregiver and the care recipient contributed to the enthusiasm of caregiving, as expressed by participants. A female spousal family caregiver passionately expressed how she valued her family member. He was all that she had, which was why she was caring for him. The love she had for her husband could never make her leave his side in his current situation. She also said her husband had been very supportive of her in the past and believed this was the best way to show her appreciation. In addition, she said no one could care for her husband the way she did, so she was unwilling to leave the responsibility for another person. As she shared her emotions on this, it was clear she enjoyed performing her responsibilities as a caregiver.

> He is important to me in all things, I value him in everything, in my life, and he is my everything. There are times that if he had not been there for me I don’t know where I would have been by now. It is from my heart that is why am doing it for him. Is because of the love I have for him, that is the work am doing for him. (FCP1)

Another male spousal caregiver recalled the previous good times he had with his wife. He valued these experiences in their relationship, and this was the reason he would never abandon his responsibilities as a caregiver. He said: “I have to cope with it because I walk with the person, when there was sweetness we all enjoyed so why this situation I have to ignore her, no, no, no” FCP7.

In some situations, caregiver participants were motivated by reciprocity to care for the care-recipient. Role reversal in a parent's caregiving was reported by three multiple family caregivers who were caring for their mother. One of them said it was their responsibility to take care of their mother, who was diagnosed with cancer of the heart, because she took care of them when they were young. "She passes through labor and once she has brought us on this earth and we are all grownups and there is something wrong with her, is our responsibility to cater for her" (FCP9). Health care professionals added their perception of family caregivers providing care because of their relationship with the care recipient, or the past positive impact the care recipient had played in their lives. Family caregivers valued the relationships they had with their family members, as well as their previous times together, and recognized the need for reciprocity.

We all Perform our Unique Responsibilities. In situations where the care was shared between multiple caregivers the burden of care was seen to be lightened. A family caregiver said that because her daughter was available during the day to provide the physical care for her sister, it made it easier for her to be away to work during the day. Similarly, three siblings who participated in this study were multiple caregivers caring for their aged mother who was diagnosed with advanced cancer. They said they each performed different responsibilities as caregivers. The care recipient was living with one of them, and she was responsible for the physical care. The other two contributed to the financial care, and also called every morning to ensure their mother was okay. In addition, anytime their family member was going to the hospital all three caregivers went. A female family caregiver also said she had given financial responsibility to her brothers while she performed the physical care for their mother. "I have brothers I gave them their responsibilities, where they can work and get me money to support" (FCP15).

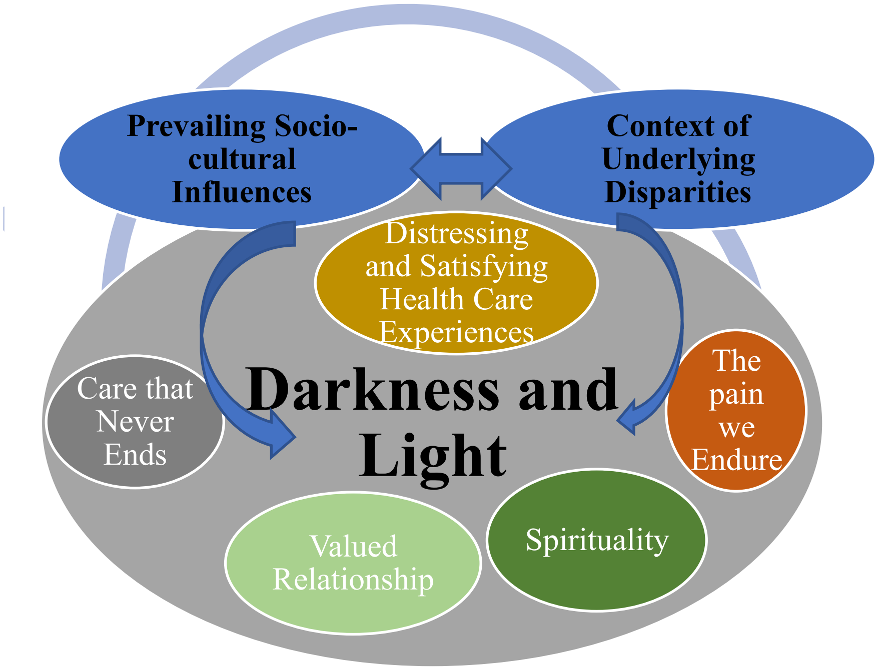
Health care professionals confirmed what was said by family caregivers, and also added that in some cases where there are many people involved in the caregiving, there could be communication issues. Health care professionals also stated that in the Ghanaian context, the likelihood of having multiple caregivers was not unusual, but even with many people involved with the care recipient, there was always one primary caregiver who was responsible for the care provision. It was mentioned that the relationship between the family caregiver and the care recipient also determined the burden of care they had to take up.

Summary of Findings

Figure 1 illustrates the findings of this study. Darkness and light was the main theme, with the sub-themes of care that never ends, distressing and satisfying health care experiences, the pain we endure, spirituality, and valued relations. The themes are interconnected and describe the experiences of family caregivers in the context of underlying disparities and prevailing socio-cultural influences.

Figure 2

Themes Under Study Findings



The complexities associated with caregiving were highlighted in diverse ways in this study. Family caregivers disclosed how their circumstances contributed to their caregiving experiences, and also to how these experiences affected them. Caregiver participants mentioned the influence of sociocultural power on the decisions they made as they cared for their family members. The context of disparities in the socioeconomic circumstances of the family caregiver, and the existing inequality in the health care system were also emphasized.

Interactions within the health care system where family caregivers were burdened with extra responsibilities, were poorly informed of the plan of care, and were faced with unacceptable wait times and costs highlighted the role played by deficiencies in the health care system in how family caregivers perceived their experiences. There was a noticeable distinction between caregiver participants’ experiences at the palliative care unit, and at other departments in the hospital. Family caregivers also expressed that financial support was their greatest need, with the need for physical support being the second greatest.

Family caregiver’s experiences were reported as darkness with light. Their responsibilities were demanding, and encompassed juggling multiple aspects of caregiving and of their personal lives; however, spirituality and the valued relationship with the care recipient were perceived as sources of hope, and strength to continue performing their caregiving tasks. This contributed to the enthusiasm of some family caregivers to provide care.

Chapter Five: Discussion

The purpose of this study was to explore the experiences of family caregivers of persons living with advanced cancer in Ghana. In this chapter, I discuss the main findings of this research and compare them to the literature, identifying similarities and differences. The findings were novel because little knowledge concerning the experiences of family caregivers in Ghana had previously been generated.

To begin, I discuss the context of disparities in which the caregivers experience occurs, as well as the influence of socio-cultural power on caregiving within the African context. Then I discuss the main finding which reflected the caregivers experience in the overarching theme of *darkness and light.* This is followed by discussion of family caregiver's dealing with multiple caregiving responsibilities. The impact of caregiving on the family caregiver, and the experience of interacting with the health care system will also be discussed. I conclude with a discussion of the influence of spirituality and family ties as a source of strength and motivation.

Living in a Context of Disparities

The participants' experiences of caregiving occurred within the context of multiple disparities including low socioeconomic status, housing insecurity, and barriers in access to health care services. Similarly, a study by Murray et al. (2003) in Kenya found that family caregivers of low socioeconomic status were living in substandard housing facilities with limited basic amenities such as running water, and indoor toilets, making it challenging for family caregivers to perform their roles efficiently (Murray et al., 2003). Housing insecurity is identified a social determinant of health that contributes to severe inequalities in cancer care particularly in low- and middle-income countries (LMICs) (Vacccarella et al., 2019). In an Australian study, unemployed and underemployed people were found to live in poor housing conditions (Baker et al., 2016) which has a negative impact on the general mental and physical health of these populations (Baker et al., 2016). The health of the family caregiver participants was not examined in this study. There is a need for future studies to understand how poor or uncomfortable housing affects the health of family caregivers.

Another disparity identified in this study was that most care recipients presented with late diagnoses after multiple visits to hospital. Late diagnoses are common in most LMICs because of limited access to health care and health care inequality (Rivera-Franco & Leon-Rodriguez, 2018; Vacccarella et al., 2019). Early detection and treatment of cancer could save an estimated 2.4 to 3.7 million lives worldwide annually, with most of these persons living in LMICs (de Souza et al., 2016). This could also generate a global economic benefit of an extra US$400 billion per year (de Souza et al., 2016). Inequality in accessing health care results in many patients in developing countries such as Ghana to have limited survival period after their initial diagnosis (Vacccarella et al., 2019).

Social inequalities in health refers to differences that are systematic, socially produced, unnecessary, and avoidable and they are considered unjust and unfair (Whitehead & Dahlgren, 2006). In resource poor countries, it is important to note that a highly privileged minority has an advantage over the poor majority in accessing cancer care because they are able to afford the care (Vacccarella et al., 2019). This indicates the existence of inequalities amongst a country’s population based on an individual’s income and socioeconomic status (Vacccarella et al., 2019). This doctoral study demonstrates that participants’ socioeconomic status made it difficult for family caregivers to afford cancer care services for their ill relatives.

The family’s geographic location also created unequal access to health care because of the centralisation of specialist services in the Ghanaian health care system. This has been reported in the literature in other developed and developing countries such as Australia, India, and the United States (Ambroggi et al., 2015; Vacccarella et al., 2019). In Uganda, patients living further away from cancer diagnostic centres or hospitals reported with late stage diagnoses (Galukande et al., 2014). Similarly, Dickens et al. (2014) found in their South African study that the majority of female breast cancer patients who lived 20 km or more from the diagnostic centre presented with late stage cancer diagnosis. In this study, data were not collected on the participants' distance to cancer care centres, so it is unknown whether Dickens et al. (2014)'s finding would apply to these participants. However, future research should be conducted to explore how the family caregiver's geographical location to the health care centre contributes to late diagnosis.

The financial strain incurred by family caregiver participants included the high cost of transportation to and from the hospital. Kusi et al. (2020) reported that family caregivers in their study shared similar experiences. They needed to hire a taxi to send their ill relatives to the hospital for treatment, which was financially draining for them (Kusi et al., 2020). In this study, participants also reported multiple transportation issues and long distances to the hospital. The longer the distance, the more money they had to spend accessing health care for their ill relatives, adding to the financial burden experienced.

The impact of the cost of cancer care on persons with low socioeconomic status who are already living in deprivation can be devastating (Gardiner et al., 2020). Out-of-pocket payment for cancer care and treatment is common in health care systems of LMICs (Vacccarella et al., 2019). In a Ghanaian study, family caregivers of breast cancer patients complained of being financially drained because they had to pay for their relative's cancer treatment with cash (Kusi et al., 2020). In a study by Kusi et al. (2020) family caregivers mentioned that the National

Health Insurance Scheme (NHIS) in the country did not cover most of the cancer treatments received by their ill relatives.

Ghana was among a few sub-Saharan African countries to reduce the out-of-pocket payment of health care services in an effort to make health care affordable and accessible to all (Aikins et al., 2021). Yet Aikins et al. (2021) found there is still a need for major improvements as the majority of cancer care was not funded as part of this initiative to reduce out-of-pocket costs. In that study, stakeholders highlighted that for the NHIS to be positioned under the Universal Health Coverage, cancer care needed to be included in the benefit package (Aikins et al., 2021). In Ghana currently, family caregivers of cancer patients pay out of pocket for hospital services such as consultations, and laboratory investigations, and for medications. (Kusi et al., 2020).

Participants reported late access to palliative care after multiple experiences with other departments in the hospital. They expressed the wish to have interacted with the palliative care unit in the initial stages of the diagnosis and were unhappy with the late referrals. A study conducted in the Netherlands found that patients experiencing homelessness who were at the end of life also had late access to palliative care (de Veer et al. 2018). Similarly, in this study, family caregivers who experienced unstable housing situations were devastated with late access to palliative care. Some of the factors contributing to late access in people experiencing homelessness in the Dutch study included difficulty among professionals to recognize the palliative care needs amongst people experiencing homelessness, the hesitation felt by professionals towards persons experiencing homelessness, and the limited specialized palliative care services for this population (de Veer et al. 2018). Similarly, in this study, health care professionals in the medical and surgical departments identified the need for access to palliative care late in the disease trajectory, contributing to the late referrals experienced by family caregivers.

The issue of late access to palliative care exists in both high and low income countries, and amongst various types of populations as reported in this study and others. In France, a study assessed an existing database for the number of cancer patients who had access to palliative care from the time of diagnosis to death (Janah et al., 2019). Janah et al. (2019) reported that access to palliative care was always late in the disease trajectory of cancer patients (Janah et al., 2019). It seems health care professionals in other departments in Ghana, such as the medical and surgical departments, are hesitant to refer patients and their relatives to the palliative care team during the initial diagnosis. Health care professional participants suggested that late referral could be due to misconceptions about the aims of palliative care, or the appropriate time to refer. Further research to understand the cause of the hesitation to early referral to the palliative care unit from other departments is needed.

Access to early palliative care can have a positive impact on both patients and their family caregivers throughout the disease trajectory (PalliativeCare Australia, 2017). This includes managing patients' symptoms, addressing the psychosocial and spiritual challenges for both patients and their families, and helping family caregivers to set care goals and take part in transition planning (PalliativeCare Australia, 2017). In Canada, a retrospective cohort study was done to examine how early access to palliative care is associated with reduced late life acute hospital use (Qureshi et al., 2019). The study found that palliative patients who had early access to palliative care spent fewer days in an acute care setting, and experienced an increased use of community-based services when they were approaching the end of life (Qureshi et al., 2019). The World Health Organization (WHO) has stated that "early palliative care reduces unnecessary hospital admission and the use of health services" (WHO, 2020). For countries to improve access to early palliative care globally, the WHO recommends policymakers and stakeholders must: a) develop a national health insurance policy to integrate palliative care services at all levels of care, b) train more palliative care professionals, add palliative care to the curriculum of health care professionals, and train volunteers, and c) ensure continuous availability of essential palliative care medications, particularly opioids (WHO, 2020). These recommendations by the WHO (2020) are congruent with what was found in this doctoral study to be essential to improve access to a national palliative care program in Ghana. There is a need for a well-integrated national palliative care program at all levels of care, inclusion of cost of cancer care in Ghana's health care insurance program, and palliative care education for all health care professionals.

The existence of health inequalities globally and amongst people in the same country is troubling. However, policy makers and stakeholders have a role to play to bridge the inequality gap between the various social-economic classes. As mentioned by the WHO, the political and socioeconomic forces in a country determine the conditions in which the people live and die (WHO, 2008). Thus, there is urgent need for governments to act on the social determinants of health to improve the lives of their citizens, with the aim of attaining health equity (WHO, 2008). In the end, improving access to early palliative care for all can be accomplished in countries with policies in place to achieve health equity.

The Influence of Socio-cultural Power on Caregiving within the African Context

The socio-cultural perspective of the family caregiver is an essential aspect of their lives that influences their caregiving experiences. Participating caregivers described a lack of support from their extended family members. This is similar to findings from a study in Botswana that reported that caregiving was left solely to an individual family caregiver (Kangethe, 2009). In

Africa, support from extended family members and the community is well recognised and valued amongst the people of the same clan, or kinship (Gykeye, 1996). This African value has changed in recent times, where the provision of physical care for ill relatives is left in the hands of an individual primary caregiver (Kangethe, 2009). African scholars attribute this change to the influence of Western cultures (Dyaji & Kajom, 2018). In Nigeria, westernisation and colonization have led to the abandonment of local cultures and traditions (Odinye & Odinye, 2012). The perception of Western culture to be more appropriate or ideal by native Nigerians, during and after the British colonial era, has generated both positive and negative consequences (Odinye & Odinye, 2012). Adopting the nuclear family system instead of the extended family system may contribute to the lack of family support found in this study.

Another factor that affected the lack of support from other family members in this doctoral study was that some participants had relocated to the urban setting from a neighbouring country or a rural community in Ghana. The busy work schedule of family members and families living far from one another likely contributes to the ability of other family members to support the provision of care. The lack of family support has been reported in other African countries (Kangethe, 2009; Murray et al., 2003). In Uganda, family caregivers of persons living with HIV/AIDS and other terminal illnesses reported experiencing distress due to lack of support from their community and other family members (Kangethe, 2009). Family caregivers in the study by Kangethe (2009), although not mentioning the reason for the limited support, expressed the need for assistance from other family members in providing care for their ill relatives.

Although support from other family members can help reduce the stress experienced by family caregivers, this can also be an individual preference. In this doctoral study, family caregivers did not always want the support of other family members. This was unusual from a

Ghanaian socio-cultural perspective where support from the extended family is valued. However, the reason for this is not well understood and more research is needed in this area.

Most participants in this study were females who described having caregiving expectations associated with their gender. This finding was similar to studies conducted in other African countries (Githaiga, 2016; Githiaga & Swartz, 2017; Murray et al., 2003; Kangethe, 2009; Muliira et al., 2019; Oyegbile & Brysiewicz, 2016). Caregiving responsibilities are perceived to be the role of females in the African culture. Women are usually unpaid home caregivers due to cultural norms and values (Gardiner et al., 2020). In Africa, female children learn from a young age to be caregivers in the home (Dilworth-Anderson & Gibson, 2002; Kusi et al., 2020; Agyeman-Dua et al., 2019). Female caregivers are liable for economic, domestic, health care, spiritual, and social responsibilities as they perform their roles (Agyeman-Dua et al., 2019). This perception of caregiving being a female role is a form of gender inequality which places female family caregivers at a disadvantage as compared to male family caregivers. In this doctoral study, female family caregivers reported sacrificing their matrimonial homes, immediate families, education, and jobs to be with their ill relatives. On the other hand, the male family caregivers rarely gave up their jobs or matrimonial homes to be by their ill relatives' throughout the day. The female family caregivers' personal lives were interrupted in various ways. The need to explore further the influence of gender on the experiences of family caregivers is highly suggested.

In African and Ghanaian culture, refusing to provide care means abandoning a key responsibility as was reported by some participants in this study. Family caregivers of prostate cancer patients in Ghana also mentioned that they were enthused to care for their fathers because, culturally, the father is identified as the spiritual leader (Salifu et al., 2021). In other words, the fathers are identified as the head of the family, and thus, it is important to ensure their fathers, and spouses receive appropriate care (Salifu et al., 2021).

The cultural expectations of caregiving from the family member to an ill relative was well represented in this study. Ignoring the individual's culture when interacting with family caregivers in Africa and Ghana could cause communication gaps in care provision. With family caregivers feeling motivated to care for their ill relatives because of their ties, culture, and past relationship, health care professionals can assess the family caregivers to know how best they can be supported.

Although there is acknowledgement of the common views, and shared traditions amongst family caregivers, there is a need to also recognise the differences in individual cultures within Ghana. Health care professionals need to recognize the uniqueness amongst cultures when interacting with family caregivers, to avoid generalizing them to one predominant culture. Health care professionals must also encourage family caregivers in their roles, and make them feel the importance of their roles within the care team. This can increase the strength that already exists, and improve their quality of life. Further study to explore in-depth the impact of culture on caregiving is suggested.

Darkness and Light

The overarching theme of darkness and light represents the negative and positive experiences of family caregivers. For example, this study found that caregiving was never ending, and family caregivers had both distressing and satisfying experiences interacting with the health care system. Being a family caregiver had an impact on their lives positively, and negatively. Caregiving experiences created panic, and fear for the family caregiver. However, family caregivers also experienced joy, reward and satisfaction in providing care to their ill relative. Other studies on family caregivers have focused on the negative aspects of caregiving (Muliira et al., 2019; O'Neil et al., 2018; Salifu et al., 2021; Vahidi et al., 2016). A few studies have focused on the positive (Kusi et al., 2020; Oyegbile & Brysiewicz, 2016). However, participants in this study described the interacting nature of both positive and negative experiences, which encompassed the theme of darkness and light.

Dealing with Multiple Caregiving Responsibilities

Findings from this study show that the responsibilities of family caregivers continued 24 hours a day and seven days a week. Often family caregivers performed multiple roles such as working full time, and caring for other family members, in addition to caring for their ill relative. They found it challenging to juggle all of these multiple roles and responsibilities. This is the case for caregivers in various parts of the world. Studies in Africa (Muliira et al., 2019; Murray et al., 2003), Asia (Leow & Chan, 2017) and Europe (van Roij et al., 2019) show that family caregivers often play concurrent roles as caregivers, spouses, parents, daughters, sons, grandchildren, siblings, and full-time employees. These studies illustrate that performing multiple roles can be distressing for caregivers (Leow & Chan, 2017; Muliira et al., 2019; Murray et al., 2003; van Roij et al., 2019), and in some cases can generate role tension (Nemati et al., 2017). In this doctoral study, family caregivers expressed a similar concern of working full time, and caring for other family members, in addition to caring for their ill relatives. This added to the burden experienced by family caregivers who were already struggling with caring for people with advanced cancer all by themselves.

In Norway, the burden of care has increasingly become the responsibility of family caregivers, with a larger number of persons diagnosed with cancer who need long term care at home (Stenberg et al., 2014). A review by Girgis et al. (2013) reported that the burden experienced by family caregivers entails economical, physical, and psychosocial spheres. Similar to the findings in this doctoral study, several studies in LMICs report that family caregivers of persons diagnosed with advanced cancer and end-stage renal disease performed a variety of tasks such as feeding patients, lifting, administering medication, and bathing (Kusi et al., 2020; Muliira et al., 2019; O'Neil et al., 2018; Oyegbile & Brysiewicz, 2016; Vahidi et al., 2016). In Nigeria, family caregivers of persons diagnosed with end-stage renal disease expressed that their roles were never ending (Oyegbile & Brysiewicz, 2016). In this doctoral study, family caregivers were burdened with the provision of care and wondered when the tasks they performed would ever stop. The feeling of uncertainty of what would happen next was what family caregivers experienced daily as they performed the caregiving activities.

Family caregivers also had to look after their ill relatives in the hospital, and perform additional tasks such as running errands, and helping with transfers. Similarly, in Kenya, Muliira et al. (2019) found that family caregivers were required to perform caregiving tasks for their ill relatives diagnosed with advanced cancer when they were admitted to hospital. Family caregivers in the study by Muliira et al. (2019) requested that the hospital authorities assist with caring for their ill relatives while they are admitted to the hospital, to ease the family caregiving burden.

One of the contributing factors to the burden of caregivers who participated in this doctoral study is the lack of support and resources from the Ghanaian health care system. The reality is that the Ghanaian health care system does not address the needs of family caregivers of persons living with advanced cancer (Salifu et al., 2021). This gap was palpable in the experiences of family caregivers in this doctoral study, similar to the research on the family caregiving experiences of persons living with HIV/AIDS and advanced cancer in other sub-

Saharan African countries such as Botswana (Kangethe, 2009) and Uganda (Muliira et al., 2019). This was also true of community support services. For example, in Botswana, family caregivers had access to a community based palliative care program but reported that the health care personnel rarely visited their homes to provide needed services (Kangethe, 2009). This resulted in a lack of caregiving support and low motivation which negatively affected the family caregivers (Kangethe, 2009). In this doctoral study, although family caregivers reported limited support from other departments in the hospital, they described receiving an impressive amount of support from the palliative care team. This is contrary to what was found by Kangethe (2009).

Another contributing factor to the caregiving burden is the limited resources in the health care system, such as medication and other medical supplies, in most African countries. (Atobrah & Adomako Ampofo, 2016; Ntizimira et al., 2014; O'Neil et al., 2018). Ghanaian family caregivers of patients with prostate cancer experienced challenges caring for their relatives at home in the context of limited resources (Salifu et al., 2021). This included situations where access to medications to manage their relatives' pain was limited, and thus caregivers had to rely on herbal medications as alternatives to manage their relative's pain (Salifu et al., 2021). Murray et al. (2003) reported that family caregivers in Kenya felt burdened because of a lack of drugs, and limited knowledge about their relative's cancer diagnosis. In Western countries, where resources may be more readily available, access to support such as respite services, funds, and medical supplies from the health care system have been reported by family caregivers. (Hendriksen et al., 2019; Sparla et al., 2016); yet inequities in accessing caregiver benefits such as the Compassionate Care Benefit have been reported in Canada (Giesbrecht et al. 2012). Being able to access supports from the health care system strengthens family caregivers, and encourages them to cope psychologically (Sparla et al., 2016).

In contrast to the limitations in the health care system, participating caregivers in this study described their experiences of receiving valuable support from their attending palliative care team. Nonetheless, resources were limited even within the palliative care unit. For example, there were restraints with space and infrastructure to accommodate the family caregivers, and their ill relatives. The unit lacked resources to do home visits, and provide family caregivers with medical supplies. In order to provide the needed support, the palliative care team had to use their own personal resources or funds. This was different from what was found in a Nigerian study where family caregivers had access to resources from a home-based palliative care program (Omoyeni et al., 2014) that included physical, emotional, psychological, and financial support (Omoyeni et al., 2014).

In addition to having a palliative care out-patient unit, the Ghanaian health care system needs a home-based palliative care program to assist the palliative care team identify specific needs of family caregivers and their ill relatives, and support them in the community on a regular basis. Most African countries lack a well integrated national palliative care program in their health care systems (African Palliative Care Association, 2017). Even in countries that do have such comprehensive programs, such as Kenya (Murray et al., 2003) and South Africa (O'Neil et al., 2018), there are gaps in the provision of services. These study findings suggest the need for a well-integrated palliative care service in Ghana, and for the provision of community based services and resources to family caregivers of people with advanced cancer.

In this doctoral study, participants expressed that although they do not want to abandon their obligations, they need support while caring for their ill relative for the sake of their physical and mental health. In Ghana where health care professionals, including the palliative care professionals, rarely have adequate resources, it is challenging to support family caregivers with respite care (Salifu et al., 2021). When supports are limited, the health of family caregivers suffers. For example, a study in Korea showed that family caregivers of terminally ill cancer patients did not receive adequate support, they experienced impaired mental state that triggered suicidal thoughts (Im Song et al., 2010). This is justification for research into the best ways to support family caregivers caring for their ill relatives.

The Impact of Caregiving on the Family Caregiver

Study findings showed that the experiences of caregiving had both positive and negative effects on family caregivers. Caregiving responsibilities influenced the participants financially, physically, and psychosocially. The impact of caregiving on the family caregiver puts them in a situation of being "hidden patients", who are barely noticed by health care professionals (Reinhard et al., 2008, p.343). The degree of distress experienced by family caregivers determined the severity of physical and mental impact of caregiving on their overall health. This finding is supported by a study from Saudi Arabia where family caregivers of adult cancer patients who experienced high levels of stress were found to have worse physical and mental health than those with low level stress. (Saimaldaher & Wazqar, 2020). Various studies in LMICs, as well, have shown similar findings (Elmore, 2014; Irfan et al., 2017; Kangethe, 2009; Muliira et al., 2019; van Deventer & Wright, 2017). Family caregivers of HIV/AIDS patients in a study conducted in Zimbabwe complained of physical exhaustion, and health issues including psychosomatic complaints due to their caregiving role (van Deventer & Wright, 2017). In Pakistan, family caregivers of persons diagnosed with chronic illnesses mentioned that their caregiving role had an unpleasant impact on their lives (Irfan et al., 2017) because it interfered with daily routines such as their eating, sleeping, and exercising habit, and affected their psychological, physical, social, and work life (Irfan et al., 2017).

Family caregivers in this study mentioned how the tasks they performed affected their ability to have quality sleep. This finding is similar to other studies on caregivers. For example, Wong et al. (2020) in a Chinese study found that caregiving responsibilities affected the sleep quality of family caregivers of persons living with advanced cancer. They further stated that in spite of this, most family caregivers chose not to take sleep medication. The importance of sleep in ensuring good health and overall quality of life has been highlighted by studies in high income countries (Leow & Chan, 2017; Mukherjee et al., 2015). Studies have also shown that if an individual lacks adequate rest and sleep, they experience cognitive problems, limited concentration, and may in the long-term develop diabetes, and hypertension (Mukherjee et al., 2015). In this doctoral study, family caregivers experienced these health problems but they gave them minimal attention because their focus was on the care recipient.

Participating caregivers in this doctoral study mentioned how witnessing their relatives experience of symptoms related to advanced cancer was emotionally and psychologically traumatizing. This was similar to findings of studies conducted in Ghana (Salifu et al., 2021), and Zimbabwe (van Deventer & Wright, 2017). Salifu et al. (2021) found that family caregivers felt helpless and worried when they saw their relatives experience symptoms of advanced prostate cancer. Similarly, in Zimbabwe family caregivers of chronically ill HIV/AIDS patients reported they felt depressed, helpless, and worried seeing their ill relatives experience advanced symptoms of the disease (van Deventer & Wright, 2017). Such experiences affected the mental state of the family caregiver (van Deventer & Wright, 2017); therefore, it is important for health care professionals to assess the mental state of family caregivers to provide needed support. Referrals to experts such as the clinical psychologist must be done immediately when necessary to minimize the severity of the problem.

Another important finding of this study related to the financial strain experienced by family caregivers because of their caregiving role. Caring for a person with cancer has been found to be financially draining for family caregivers in other studies both in developed (Gardiner et al., 2020; Gott et al., 2015; Saimaldaher & Wazqar, 2020) and developing countries (Kusi et al., 2020). This was because of the cost involved in cancer care received by their ill relatives (Gardiner et al., 2020; Gott et al., 2015; Kusi et al., 2020; Saimaldaher & Wazqar, 2020). In Ghana, Kusi et al. (2020) found that the cost involved in caring for a person diagnosed with breast cancer was very high and draining for most family caregivers. Similar to this study, Kusi et al (2020) identified costs as including consultation, medications, extensive therapies, laboratory investigations, and blood transfusions. Indirect costs of caregiving, such as the loss of a job, and time spent looking after their relative (Gardiner et al., 2020; Gott et al., 2015) add to the financial strain of already burdened caregivers.

Similar findings were also reported in a New Zealand study where the financial impact of caregiving on family caregivers caused serious consequences such as borrowing money, lack of availability of food to feed the entire family, and moving to a less expensive home (Gott et al., 2015). The availability of financial supports from the government in countries such as Australia, Canada, Ireland, New Zealand, United States of America, and United Kingdom alleviates some of the financial impact experienced by family caregivers (Gardiner et al., 2019). The development of programs by the Ghanaian government to support family caregivers with the cost of cancer care for their ill relatives can reduce the financial strain they experience.

Although most family caregivers reported negative impacts of the caregiving experience on their lives, this doctoral study found caregiving had positive impacts as well. Participants mentioned how their caregiving responsibilities were rewarding as they received praise and gratitude from their ill relatives. Family caregivers learned how to be patient in life, and also how to empathize with persons diagnosed with advanced cancer. Other research in African countries has reported positive outcomes for caregivers. For example, in Nigeria, a study found that family caregivers of end-stage renal disease patients reported a positive impact in that the role was rewarding, and also granted them the opportunity to get closer to their ill relatives (Oyegbile & Brysiewicz, 2016). Those findings correspond with some of the positive impacts of caregiving found in this doctoral study.

One finding unique to this study was that family caregivers reported reading about their ill relatives' cancer diagnosis to understand the treatment regimen, and disease prognosis. This information seeking was not found by Oyegile and Brysiewicz (2016). Caregiver participants in this research observed that knowing more about the disease process and treatment moved them to develop a more positive attitude towards performing their caregiving responsibilities. Positivity towards performing the caregiving role helps with the mental and physical health of the individual (Elmore, 2014). Developing a positive rather than a negative attitude towards performing the responsibility of caregiving, can be beneficial to family caregivers in maintaining their quality of life (Kivima¨ki et al., 2005). Most importantly with good mental and physical health, family caregivers will likely be better able to look after their ill relatives. This finding may indicate the significance of patient and caregiver education in improving their caregiving experiences and quality of life. However, this requires future research to understand the relationship between health education, positive attitude to caregiving, and the quality of life of family caregivers.

Interacting with the Health Care System

Study findings in this doctoral study showed that family caregivers had distressing experiences with the health care system, including communication gaps, long waiting times for services and specialist consultations, and caring for their ill relatives when admitted to hospital. Health care professionals did not provide participants with information regarding their ill relative's prognosis, and information on the cancer diagnosis. In some cases, health care professionals in surgical and medical departments communicated in a way that hurt the feelings of family caregivers.

In this study, poor communication between family caregivers and health care professionals was reported in various departments throughout the health care system. Similarly, a South African study found that family caregivers of cancer patients experienced gaps in communication with health care professionals (Maree et al. 2018). The resulting limited understanding of their relative's disease process, and treatment plan created fear, doubt, and uncertainty, and increased distress in providing care (Maree et al. 2018). In Iran, family caregivers of adult cancer patients reported a communication gap in their interaction with health care professionals, which was expressed as a need (Hashemi et al. 2017). Family caregivers in this Iranian study mentioned that health care professionals ignored their lack of understanding about the cancer diagnoses, and were not empathetic. They further stated that health care professionals did not take time to listen to them, or to clarify their worries and misunderstanding about their relatives' illness (Hashemi et al., 2017). In contrast, participants in this doctoral study reported how the palliative care team payed attention to their needs when they interacted with them. This gave family caregivers an assurance they had someone to whom they could express their worries and challenges.

Exchange of information between the health care professional and family caregivers of cancer patients has been reported in a United States study to be very critical for quality cancer care (Mazor et al., 2013). Family caregivers and persons diagnosed with cancer mentioned that lack of information about the cancer diagnoses and disease progression created fear, anxiety, and uncertainty (Mazor et al., 2013). Effective communication with health care professionals helps family caregivers to identify their responsibilities, and decreases the experience of stress (Schaad et al., 2015). In a UK study, effective communication between health care professionals and family caregivers of frail adults, such as being consulted during their relatives' stay at the hospital, was reported to provide support to family caregivers (Caswell et al., 2015), and gave them greater confidence that their work is being appreciated, and someone was available to listen (Caswell et al., 2015).

Findings from this doctoral study showed some family caregivers wanted to know more about their relative's cancer diagnosis and prognosis, but health care professionals did not properly communicate this information. Lack of information concerning what is actually happening to their ill relative can create feelings of despair among family caregivers (Maree et al. 2018). In a New Zealand study, family caregivers of persons 80 years and older described how their role was made difficult because of limited information and support from the health care system when their relatives were at the end of life (Williams et al., 2018). In Nigeria, family caregivers of persons diagnosed with end stage kidney disease reported they were not informed about their relatives' condition (Oyegbile & Brysiewicz, 2016). Family caregivers felt they were not being treated fairly, as they were responsible for providing care but had little sound information on which to base caregiving decisions and actions (Oyegbile & Brysiewicz, 2016). The issues surrounding this limited sharing of information need to be addressed. Family caregivers are part of the care team, and it is essential for the health care system to consider their welfare as well.

In this doctoral study, family caregivers appreciated communication with members of the palliative care team. Participants mentioned that staff of the palliative care unit had enough time to listen to them, and gave them enough information about their relatives' health condition. This is similar to other studies in which palliative care teams have been recognized for their effective communication (Caswell et al., 2015; Washington et al., 2019). In the United States of America, family caregivers of cancer patients expressed how happy they were with their communication with palliative care nurses (Washington et al., 2019). In Washington et al.'s (2019) study, family caregivers said the palliative care nurse listened attentively to their worries, and shared information about their relatives' condition with them (Washington et al., 2019). This made them feel they were being recognised as part of the care team, since they were the main caregivers for their ill relatives (Washington et al., 2019). Family caregivers value sharing information about the care recipient. However, Caswell et al. (2015) found that when the prognosis of frail adults was stated bluntly to family caregivers, their experience of feeling distressed increased. This can be why some health care professionals hesitate to provide details about the patient condition and prognosis. Notwithstanding, findings from this doctoral study showed the need to improve communication processes, and assess family members' informational needs.

Family caregivers who participated in this doctoral study reported that when their ill relative was admitted to hospital, they were required to spend most of their time at the hospital in order to ensure that appropriate care was given, and to be available to buy medication, look for blood to be transfused, and pay for services. This required that they get to the hospital very early and leave very late, or in some cases sleep in the hospital.

A study from Iran reported that family caregivers of cancer patients described the unavailability of shelter or space where they could rest while staying at the hospital as a great concern (Hassankhani et al., 2019). They felt they were not recognised by the health care system for the vital roles they played (Hassankhani et al., 2019). This was similar to findings from this doctoral study, as participants reported no place of comfort to wait even though they were needed to respond quickly to various circumstances. In a Norwegian study, family caregivers of cancer patients said although they were identified as part of the health care team, their welfare was barely taken into consideration by the health care system (Ekstedt et al., 2014).

Waiting times during out-patient hospital visits, and long waits to be seen by specialists was another unbearable experience for family caregivers in this study. Lengthy waiting times for access to health services is not uncommon throughout the world. For example, in a study conducted in Vietnam, the waiting time for patients to see a consultant in a national hospital was approximately 30 minutes to 5 hours or more (Nguyen et al., 2018). Waiting time depended on the services the patients were receiving during each visit, and the days of the week that patients visited the hospital (Nguyen et al., 2018). Patients who needed laboratory testing, and diagnostic imaging were found to stay longer in the hospital (Nguyen et al., 2018). In Hong Kong waiting time for specialist outpatient consultation in the public hospital for new referral cases could be up to144 weeks (Tsui & Fong, 2018). The long waiting time was due to reasons such as the progress of the patient’s disease, or availability of material and human resources (Tsui and Fong, 2018). However, Tsui and Fong (2018) also mentioned the existence of a triage system that considers the severity of the patient’s presenting symptoms to allow emergency cases to be seen early. Considering how participants in this study complained about how they had to wait for months for their relatives in severe pain to be seen by a specialist, the Ghanaian health care system could also adopt a triage system.

Health care professionals interact with family caregivers and their ill relatives during their shifts in every department. The need to address the issue of poor communication between the health care professionals, and family caregivers and patients must be an agenda for all departments in the hospital. Good communication skills must be one of the key skills instilled in every profession, particularly those trained to interact with persons that seek health care (Chichirez & Purcărea, 2018). The family caregiver's role as part of the caregiving team needs to be recognised and appreciated by other members of the team. This would increase the visibility of family caregivers within the care team. There is a need to design strategies to reduce waiting times in the hospital, and for specialist appointments to reduce the stress family caregivers experience.

Spirituality and Family Ties: Family Caregivers Sources of Strength

The findings of this study showed that family caregivers had sources of strength that gave them the ability to endure watching the pain and suffering of their ill family member as they performed their caregiving roles. The study found spirituality to be a source of strength for family caregivers, and their valued relationships with their ill relatives to be a source of motivation.

Spirituality as a Source of Strength. Most family caregivers who participated in this study identified that reliance on God, and prayers kept them performing their tasks when the situation was tough. Williams et al. (2013) mentioned that family caregivers relied on faith in God, and prayers to cope with the caregiving experience. The term spirituality can have distinct meanings depending on how it is used. Spirituality in a broader perspective can represent the connection of the individual body and soul to something bigger than oneself, or a supreme being (Scott, 2020). The individual can describe it as sacred or transcendent. Spirituality is guidance for every human, and a root of power and energy (Swinton & Pattison, 2010). This power often develops after an experience of suffering, and gives a person a renewed approach to appreciating life and death, resulting in personal and spiritual growth (Ando et al., 2010; Deal, 2011). In this doctoral study, participants described their suffering, and their ability to overcome it through spiritual and personal growth. They described how spirituality, and personal growth made them embrace the challenges associated with daily caregiving irrespective of the difficulties.

Spirituality can be practiced through a connection with religious denominations or groups, meditations, or connecting with nature and art (LaMeaux, 2022). Participants in this study mentioned practicing spirituality through their religious affiliations with the church or mosque which strengthened them in performing their caregiving responsibilities. Family caregivers felt that caring for the sick was part of their religious practice. Irrespective of one’s religious affiliation, the positivity of spirituality in a person’s life is commonly recognized. For example, Rassool (2000) mentioned that in Islamic teachings spirituality gives meaning and purpose in life. Similar views are seen in other faith traditions such as Christianity, Judaism, and Buddhism where trust in a supreme force or being brings meaning to life's experience (Scott, 2020). In this study, family caregivers reported how their practice of spirituality had made them appreciate life. Family caregivers accepted their difficult experiences, and attributed them to a test from God that they needed to pass. Therefore, they asserted they would never give up on their caregiving responsibilities.

Similar to the findings from this study, Penman and Ellis (2015) in Australia mentioned that the practice of spirituality amongst family caregivers of people with life limiting conditions provided support, comfort, peace, and strength. Other studies in non-African countries have also found that religious practices, such as praying, are acts of spirituality that enhance satisfaction in life, and help participants to endure challenges when they arise (Ferrell & Baird, 2012; Hodge & Sun, 2012). In this study, the practice of spirituality was found to be the main source of strength for family caregivers. Their relationship with the supreme being gave them passion in performing their caregiving role.

Family caregivers relied on their spiritual practice to cope with caregiving tasks, and overcome their fears and uncertainty. Similarly, in other studies, family caregivers of advanced cancer patients who identify spirituality as a way to cope with the tasks they perform rise above both their known and unknown fears, as they experience their caregiving trajectory (Leow & Chan, 2017; Penman & Ellis, 2015). Egan et al. (2011) stated that a person with a strong spiritual outlook is better able to cope with difficulties, and is often more resilient. In an Iranian study, persons who were very spiritual or religious and used spirituality to cope with their challenges in life received benefit to their health and wellbeing (Akbari & Hossaini, 2018). The spiritual wellbeing of cancer patients in another Iranian study was also reported to improve their quality of life (Nia et al., 2021). Future research should focus on examining the association of spirituality and quality of life of family caregivers of persons living with advanced cancer.

In this doctoral study, family caregivers reported having a positive experience when performing their role. Family caregivers in this study were optimistic about the tasks they performed, and derived satisfaction in their role. Similarly, other studies have reported that family caregivers had a positive view about their responsibilities (Hudson, 2006), and experienced a change in their worldview (Mok et al., 2003).

The Relationship between Family Caregiver and Patient: A Source of Motivation. The valued relationship between the family caregiver and the care recipient was also found to be a source of strength for participants in this study. Family caregivers appreciated the love and good times they shared with the care recipient, and this became a source of motivation for providing care. Family caregivers' reciprocity and connectedness with the care recipient contributed to the reasons why family caregivers performed the caregiving tasks in several other studies (Atobrah & Adomako Ampofo, 2016; Githaiga, 2016; Kusi et al., 2020; Leow & Chan, 2017; Oyegbile & Brysiewicz, 2016). Reciprocity is an exchange between two or more people, where every individual party involved benefits from the interaction (Lewis, 2015). This is usually perceived as a social norm, which becomes a noticeable expectation (Lewis, 2015).

In this study, I found reciprocity to be a source of strength for family caregivers. The family caregivers mentioned that they felt the need to perform their caregiving responsibilities because of what their ill relative had done for them in the past. This finding is similar to the findings of two Ghanaian studies. Family caregivers of breast cancer patients (Kusi et al., 2020) and prostate cancer patients (Salifu et al., 2021) stated that they were motivated by the good deeds their ill relatives had shown them in the past, and caring for them was a form of repayment (Kusi et al., 2020; Salifu et al., 2021). The past relationship between family caregivers and care recipients creates a bond which makes it difficult to refuse providing care when needed (Salifu et al., 2021). In this study family caregivers felt motivated to provide care because of the ties they had with their ill relatives.

Summary of Discussion

This study of experiences of family caregivers of persons living with advanced cancer in Ghana informs the importance of supporting the family caregivers. The study findings shine light on the family as an integral part of care provision in the Ghanaian context. Understanding the experiences of care provision, needs, and responsibilities of family caregivers is essential to providing comprehensive and quality palliative care. The study findings show that the family caregiver’s responsibilities include performing caregiving tasks both in the home and in health care institutions. The family caregiver experience is part of and shapes their personal lives. Most of the family caregivers in this study were related to the care recipient by blood and perceived the need to care for them as an obligation.

This research also suggests that the context of existing disparities contributed to the distress family caregivers experienced. Challenges placed upon the family caregivers by the Ghanaian health care system were also revealed in the study; however, the benefits of palliative care were clearly recognized by family caregivers. The limited support provided to family caregivers by the health care system, and social and family networks added to the stress experienced by participants. As the care recipient’s condition advanced, the caregiving tasks became intense, making the family caregiver's experience more stressful. Study findings pose the need for healthcare providers to recognize the responsibilities of the family caregiver and provide the needed support to individual family caregivers.

The negative impact of caregiving on the family caregivers in this study was extensive, but family caregivers also mentioned positive influences of caregiving on their lives. Spirituality, and the relationship between the family caregiver and their ill family member were their main sources of strength. This unique study about the experiences of family caregivers of persons living with advanced cancer provides valuable knowledge that can inform the development of a program to support family caregivers in Ghana.

Limitations of the Study

Findings of this study present a novel perspective of the experiencs of family caregivers of persons living with advanced cancer in a low middle income country like Ghana where resources and palliative care services are limited. The study was not without limitations. The initial plan for the research was to conduct face-to-face interviews in the participants' homes, or at the clinic. However, due to the COVID-19 pandemic, I had to conduct telephone interviews with family caregivers who participated in this study. Conducting telephone interviews might result in missing non-verbal cues from the participant's facial expression, which could add to their verbal responses. All the same, during our conversations, I paid attention to expressions such as moaning, sighing, and tone of voice to gather additional cues about their experiences.

In addition, while listening to their stories, I felt a range of emotions, that required discussion with my supervisors prior to analysis of the data. To reduce this limitation throughout the study process, I maintained a reflective journal to explore my personal biases, opinions, and feelings throughout the study.

Another limitation is the geographical location of the research. Participants who took part in this study lived in the southern part of Ghana. Family caregivers living in other parts of Ghana might have a different experience because of their location.

Finally, the sample characteristics of family caregivers who participated in this study could also be a limitation. Most of the family caregivers who participated in the study were within the low and middle socioeconomic status. Therefore, findings in this study might not be transferrable to family caregivers with high socioeconomic status in a similar context.

Chapter Six: Study Implications and Conclusion

In this study, the findings indicate that family caregivers’ experiences while caring for their ill relatives were difficult; however, the overarching theme of the findings shows their experiences were that of *darkness and light*. Family caregivers experienced needless suffering and pain with limited support which affected their lives in diverse ways, but also related experiences of growth and resilience. In this chapter, implications for practice, policy development, education, and research are suggested. This will be followed by a reflection of my experience conducting this doctoral study, and a conclusion for the entire study.

Implications for Practice

Caring for a family member diagnosed with advanced cancer at home is challenging. Family caregivers' experiences when providing care for ill relatives indicated the need for support from stakeholders and the entire health care team. The support needs of family caregivers included physical, psychological, financial, and spiritual spheres suggesting that a family-centred approach is needed. Stakeholders and health care professionals should make all possible efforts to implement family-centred strategies to ensure the family caregiver and the care recipient are supported psychologically, financially, spiritually, and physically by a multidisciplinary team.

Family caregiving experiences are influenced by socioeconomic status, cultural and personal values, and the intensity of the care recipient’s needs. Findings suggest that health care professionals should conduct a multidimensional assessment of the needs of individual family caregivers when they interact with them. This would help health care professionals to identify the specific needs of each family caregiver and support them accordingly.

Family caregiver participants suggested that they felt ill prepared, and had not received training to care for their ill relative. Provision of training in physical tasks associated with caregiving may assist in this. For example, health care providers can develop written educational materials in various languages on how to do physical tasks. These materials could be given to family caregivers who can read to educate them on how to perform the caregiving tasks. In addition, health care providers can provide training sessions for family caregivers when they are waiting for appointments with their relatives at the hospital. This would also give family caregivers an opportunity to support and learn from each other. Stakeholders can also use videos to demonstrate to family caregivers how to care for their ill relatives at home. However, these videos would need to be translated into the various Ghanaian languages to serve the purpose within the Ghanaian context.

In addition, decision makers or management in the hospitals should make available adequate resources to have dedicated personnel care for persons with advanced cancer on admission. This would ease the family members involvement in caring for their relatives while in the hospital. Management of health care institutions should put in place strategies such as prioritizing the care of people with advanced cancer for appointments and diagnostics due to their frail health status. This would reduce the wait times during out-patients visits to see a specialist.

The study findings also suggest that caregiving had a psychological and a financial impact. Creating awareness of the stress experienced by family caregivers in providing care for their ill relatives should be a priority in every department at the hospital. Health care providers should consider early referral to the clinical psychologists for family caregivers who show severe psychological distress. Stakeholders could advocate with policy makers for financial support for cancer care on behalf of family caregivers. Stakeholders and health care professionals have a responsibility to identify and collaborate with non-governmental organizations (NGOs) willing to support family caregivers financially. Health care professionals should provide family caregivers with accurate information on existing government and NGO supports for financial and social assistance.

The findings also suggest the need for health care professionals to communicate effectively and sensitively with the family caregiver. Health care professionals must be respectful and ensure privacy when discussing sensitive topics about their ill relatives’ condition. This requires proper knowledge and communication skills to discuss the topic successfully. Health care professionals must be offered advanced education on communicating with family caregivers. Study findings suggest that advance care planning was not discussed between health care professionals and patients and their family caregivers. This can be a difficult discussion (Githaiga & Swartz, 2017); however, it can provide vital information for both family and health care professionals as they plan appropriate care throughout the illness trajectory. Health care professionals should also ensure that it is culturally safe to have a discussion on advance care planning and be aware of potential repercussions if family and patient beliefs are not respected.

Findings also suggest the need for health care professionals to understand the influence of culture on family caregivers' experiences in order to interact with family caregivers in a culturally acceptable manner. Health care professionals should bear in mind the uniqueness of each family caregiver's cultural and personal values and beliefs when interacting with them. It is also important for health care professionals to assess the sources of strength of each family caregiver and provide the needed support. In situations where the family caregiver is struggling to cope with caregiving, health care professionals should assist them to identify positive coping strategies and refer them to the appropriate experts if needed.

Implications for Policy Development

Policymakers have an enormous responsibility to ensure the role of the family caregiver is recognized and supported, by recognizing the responsibilities of the family caregiver and considering their needs when developing policies related to palliative care and oncology. The WHO (2020) suggests various strategies for policy makers to improve access to palliative care. Study findings indicate the need to integrate the cost of cancer care into the National Health Insurance Scheme to reduce the financial burden on family caregivers. The scheme must accommodate all the costs involved in care received by cancer patients (Aikins et al., 2021) such as consultation, medications, diagnostic investigations, and hospital admissions.

Findings show that family caregivers, particularly those with low socioeconomic status, need ongoing financial support from the government. Programs should include income assistance, access to health care supplies and medication, transportation, and safe housing.

Access to palliative care needs to be expanded to serve a larger population, according to the findings of this study. The palliative care unit needs access to a larger space to provide the care needed by the patients and their family caregivers. In addition, policymakers can implement a national palliative care program that would ensure the delivery of palliative care in primary, secondary, and tertiary levels of care. In particular, the program developed to operate at the primary level must include supporting family caregivers in their homes and follow-up, continuous home visits, and monitoring by a palliative care team. Policymakers can take action to support the development and implementation of effective palliative care programs running in all regions in the country that are available, affordable, and accessible. Findings suggest the need for increased and expedited access to cancer diagnostic centres to reduce the issues of late diagnosis of cancer patients. This would decrease the burden on the family caregiver to travel long distances and do multiple hospital visits.

Findings show there are long waiting periods to see a specialist after a referral. Management of various hospitals should develop policies that ensure shorter waiting periods for patients to see a specialist. In addition, more cancer centres must be established to make specialists more accessible and reduce wait periods.

The need for early referrals from other departments to the palliative care unit was also indicated in this study. Heads of the oncology, surgical, and medical departments should emphasize the need for early referral to the palliative care unit during their weekly meetings or briefs with the health care professionals. Also, the study findings indicate the need to create awareness of the importance of early access to palliative care to patients and family caregivers. Television, radio, and social media platforms can be used to create awareness of health care professionals and the general public. Management heading the various institutions must create a system where health care providers at the various departments can have continuous collaboration with the palliative care team.

Implications for Health and Nursing Education

Family caregivers are key players in palliative care, and their position as part of the health care team must be indicated in the health professional curricula. In Ghana, nursing and medical training programs do not currently have a stand-alone course in palliative care. It is recommended that stakeholders integrate a course in palliative care into the training programs for nurses and medical doctors in both private and public accredited universities. The course must include content that describes the experiences of family caregivers and how best to support them as part of the health care team.

Study findings suggest that health care professionals need to interact with family caregivers throughout the disease trajectory. Thus, health care trainees should acquire the knowledge and skill to communicate effectively with family caregivers. The palliative care course must include effective communication, and how to engage family caregiver discussions on advance care planning. Students in nursing and medical schools must also be prepared to communicate in a culturally sensitive manner, and identify the importance of spirituality to the family caregiver experience. In addition, student nurses need to learn about how to prepare family caregivers to provide the needed care for their relatives at home to reduce the stress family caregivers experience. Findings also suggest the need for students to learn about the use of recommended tools to assess the burden of family caregivers.

Workshops or in-service training sessions about supporting family caregivers should be offered for health care professionals currently working in departments caring for persons in need of palliative care. The provision of continuing education sessions on effective communication, providing culturally sensitive care, assessing family caregiver burden, and coping strategies should be provided regularly to all staff who interact with family caregivers of persons in need of palliative care. The study findings strongly suggest crucial training of health care professionals at all levels of the health care system on the benefits of palliative care and the need to support the family caregiver's role.

In a resource-poor country such as Ghana, available funding for the training of health care professionals in areas of family caregiving can be sought from palliative care organizations both internationally and locally. Through collaboration with international universities and educators, an educational program can be organized for health care professionals who are currently practicing. There is a need for specialist palliative care nurses to design a unique home based palliative care program for patients and family caregivers to support their needs.

Implications for Research

This study focused on exploring the experiences of family caregivers of persons living with advanced cancer receiving services through a palliative care unit in a large urban area of Ghana. Further research should be done in various times during the illness trajectory to identify similarities and variations in the experiences of family caregivers at both the initial and later stages of illness. Findings suggest late referrals to the palliative care unit frequently occur. Future studies to explore the reasons for late referrals are recommended.

Spirituality was found to be a source of strength for family caregivers in this study. Further study to understand how spirituality plays a significant role in providing hope and the ability to withstand the caregivers' stress is suggested.

Study findings also indicate that the socioeconomic status of the family caregiver has an influence on their experience. An in-depth understanding of how the disparities amongst family caregivers of different socioeconomic status influence their experience was not established in this study. Therefore, future studies to understand the differences or similarities in the experiences of family caregivers with different socioeconomic status is also suggested. Additionally, research to identify how the socioeconomic status of the family caregiver influences the experience from the patient’s perspective is recommended.

Future studies using different methodologies such as an ethnography or action research are also recommended. Also, in light of the cultural diversity within and among countries in the

African region, studies targeting different cultures and ethnicities in Africa can be conducted to further understand culture and caregiving in Africa.

In this particular study, healthcare professionals in the palliative care unit were involved in two focus group discussions. Future studies are recommended to identify the perception of health care professionals in other departments such as oncology and radiotherapy on the experiences of family caregivers of persons living with cancer. This would generate an understanding of the family caregivers' experiences from the perspective of the health care professionals when visiting these departments.

Reflection on My Experience Conducting this Doctoral Study

Conducting this doctoral study was a great learning journey for me in which I acquired new knowledge about the experiences of family caregivers, the research process, and how to maintain my position as a researcher. Prior to conducting this work, I was of the view that caregiving experiences were the same for all family caregivers. However, as I interviewed my participants, I understood that although there were similarities in the responsibilities of family caregivers, the intensity of care needed by ill relatives varied. Also, it was concerning to learn that family caregivers felt a lack of sensitivity among health care professionals in departments other than the palliative care unit. Additionally, the traditional Ghanaian cultural values of support from the extended family members was not experienced by all participants, and some indicated that they did not want the help of extended family. This was surprising to me and increased my awareness of the changing and dynamic nature of Ghanaian culture and society.

Conducting this study helped me gain insight into how the socioeconomic disparities amongst family caregivers contributed to their caregiving experiences. I was able to understand to what extent family caregivers' socioeconomic status contributed to their struggles with housing, paying for health care services, and livelihood due to their relatives' cancer diagnoses. This was also another novel knowledge I acquired after interpreting my findings.

Listening to family caregiver participants share their stories in my study was saddening. I felt disturbed to hear family caregivers had to go through the experience of caregiving with limited support from health care professionals, and the government. Hearing family caregivers talk about multiple hospital visits and late diagnoses that were financially draining was very worrying and heart breaking. After a series of meetings with my supervisors and doing reflective journaling after every conversation with family caregiver participants, I was able to recover from my emotional involvement, and continue data collecting. I also learned to control my feelings and to maintain my position as a researcher. By doing this, I was able to focus on the purpose of the work which was to obtain information to solve a clinical problem. As I interacted with my participants, I felt enthusiastic about using findings from my doctoral study to improve the experiences of this vulnerable group. This was an appreciable learning process for me as a novel researcher.

Conducting this doctoral study using ID added to my knowledge of conducting qualitative research to gain an in-depth understanding of a clinical problem. ID allowed me to go beyond describing my findings and interpreting what my participants shared to better understand the experiences of the family caregivers. I learned how to do this through constant deliberations with my supervisors, and continuously referring to how Thorne (2016) explained the process of conducting ID research. Doing this helped me to engage in constant reflection on the data collected from the field, and make meaning of the data by asking myself questions such as: "what am I seeing"? and "why am I seeing this"? I enjoyed using the ID for this research because it was flexible, and I was able to identify solutions to a clinical problem with this method.

The initial plan for this doctoral study was to have in-person interactions with my participants; however, this had to change because of the COVID-19 pandemic protocols. Protocols were put in place by the University of Alberta and Korle-Bu Teaching Hospital Ethics Research Board for all research involving face-to-face interactions to be put on hold. I felt disappointed because I had put my doctoral study on hold for about six months before proceeding with data collection. I discussed proposed changes to my study with my supervisors and sent study amendments to the Research Ethics Boards. Making amendments to my doctoral research proposal gave me the opportunity to learn how to conduct research using other communication strategies. I learned how to conduct telephone interviews, and have zoom online discussions ensuring participant privacy, confidentiality, and anonymity. This experience has made me develop new skills I can use for future research in case of a crisis, or the need to conduct research that does not require in-person interactions.

Conclusion of the Study

The study findings present a novel and needed perspective of the experiences of family caregivers of persons living with advanced cancer in a developing country like Ghana, where resources and palliative care services are limited. The study reported the experiences of family caregivers that illustrate the vital role they play in caring for their ill relatives throughout the disease trajectory. The study is one of its kind that I know of, describing and interpreting the experiences of family caregivers of persons with advanced cancer. In Ghanaian culture, the family plays an integral role in caregiving, especially with persons in need of palliative care. Findings in this study show the multiple struggles, pains, and stresses experienced by family caregivers of which the majority were of low socioeconomic status. Despite the challenges family caregivers faced, spirituality was their major source of strength, and a valued family tie and relationship was a source of motivation. Family caregivers accepted the responsibilities of caregiving and endured the stress they experienced. Study findings strongly support the positive impacts of palliative care on the family caregivers’ experiences and their terminally ill relatives. The findings of this doctoral study show that the experiences of the family caregivers inform policy makers, stakeholders and the health care system. To end, I will say the family caregiver deserves the recognition of all health care professionals, irrespective of their race, culture, religious affiliation, and socioeconomic status.

References

African Palliative Care Association (2017). *Palliative care in Africa: Delivery*. Retrieved from https://www.africanpalliativecare.org/awareness/palliative-care-in-africa-delivery/

Agyemang-Duah, W., Mensah, C. M., Peprah, P., Arthur, F., Addai, B., & Abalo, E. M. (2019). Informal health care: Examining the role of women and challenges faced as caregivers in rural and urban settings in Ghana. *Journal of Public Health*, *27*(3), 321-327. https://doi.org/10.1007/s10389-018-0953-1

Aikins, M., Tabong, P. T. N., Salari, P., Tediosi, F., Asenso-Boadi, F. M., & Akweongo, P. (2021). Positioning the National Health Insurance for financial sustainability and Universal Health Coverage in Ghana: A qualitative study among key stakeholders. *Plos One*, *16*(6), e0253109. https://doi.org/10.1371/journal.pone.0253109

Akbari, M., & Hossaini, S. M. (2018). The relationship of spiritual health with quality of life, mental health, and burnout: The mediating role of emotional regulation. *Iranian Journal of Psychiatry*, *13*(1), 22–31. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5994229/

Ambroggi, M., Biasini, C., Del Giovane, C., Fornari, F., & Cavanna, L. (2015). Distance as a barrier to cancer diagnosis and treatment: Review of the literature. *The Oncologist*, *20*(12), 1378-1385. https://doi.org/10.1634/theoncologist.2015-0110

Ando, M., Kawamura, R., Morita, T., Hirai, K., Miyashita, M., Okamoto, T., & Shima, Y. (2010). Value of religious care for relief of psycho-existential suffering in Japanese terminally ill cancer patients: The perspective of bereaved family members. *Psycho-Oncology*, *19*(7), 750-755. https://doi.org/10.1002/pon.1625

Anngela-Cole, L. & Busch, L. (2011). Stress and grief among family caregivers of older adults with cancer: A multicultural comparison from Hawaiʻi. *Journal of Social Work in End-of-Life & Palliative Care*, *7*. 318–337. https://doi.org/10.1080/15524256.2011.623460

Atobrah, D. & Adomako Ampofo, A. (2016). Expressions of masculinity and femininity in husbands' care of wives with cancer in Accra. *African Studies Review*, *59* (1), 175-197. https://doi.org /10.1017/asr.2016.2

Baker, E., Lester, L. H., Bentley, R., & Beer, A. (2016). Poor housing quality: Prevalence and health effects. *Journal of Prevention & Intervention in the Community*, *44*(4), 219-232. https://doi.org/10.1080/10852352.2016.1197714

Binka, C., Nyarko, S. H., Awusabo-Asare, K., & Doku, D. T. (2018). "I always tried to forget about the condition and pretend I was healed": Coping with cervical cancer in rural Ghana. *BMC Palliative Care*, *17*(1), 24. https://doi.org /10.1186/s12904-018-0277-5

Birks, M., Chapman, Y., & Francis, K. (2008.). Memoing in qualitative research: Probing data and processes. *Journal of Research in Nursing*, *13*(1), 68–75. https://doi.org/10.1177/1744987107081254

Bunt, H. & Du Plessis, D. (2015). What patients want: A qualitative study of palliative care experiences of HIV and AIDS patients and their families. *African Journal for Physical, Health Education, Recreation and Dance*, 348-359. Retrieved from http://eds.b.ebscohost.com/eds/pdfviewer/pdfviewer?vid=1&sid=1c119ddb-3ded-405e-9b7d-9c4285b4ed45%40sessionmgr104

Byrne, M. (2001). Research corner. The concept of informed consent in qualitative research. *AORN Journal, 74*(3), 401-403 403p. https://doi.org /10.1016/S0001-2092(06)61798-5

Canadian Cancer Society. (2022). *Advanced cancer*. Retrieved February 18, 2022, from https://cancer.ca/en/living-with-cancer/advanced-cancer

Caswell, G., Pollock, K., Harwood, R., & Porock, D. (2015). Communication between family carers and health professionals about end-of-life care for older people in the acute hospital setting: A qualitative study. *BMC Palliative Care*, *14*(1), 1-14. https://doi.org/10.1186/s12904-015-0032-0

Center for Disease Control and Prevention. (2019, August 12). *Global health Ghana*. https://www.cdc.gov/globalhealth/countries/ghana/default.htm

Chichirez, C. M., & Purcărea, V. L. (2018). Interpersonal communication in healthcare. *Journal of Medicine and Life*, *11*(2), 119-122. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6101690/pdf/JMedLife-11-119.pdf

CIDA. (2009). *Ghana country strategies*. https://www.international.gc.ca/development-developpement/assets/pdfs/countries-pays/Ghana-Country-Strategy-2009.pdf

Collins, A., McLachlan, S.-A., & Philip, J. (2017). How should we talk about palliative care, death and dying? A qualitative study exploring perspectives from caregivers of people with advanced cancer. *Palliative Medicine*, *32*(4), 861–869. https://doi.org/10.1177/0269216317746584

Cooke, A., Smith, D., & Booth, A. (2012). Beyond PICO the SPIDER tool for qualitative evidence synthesis. *Qualitative Health Research*, *22*(10), 1435-1443. https://doi.org/10.1177/1049732312452938

de Souza, M. T., da Silva, M. D., & de Carvalho, R. (2010). Integrative review: What is it? How to do it? *Einstein (16794508)*, *8*(1), 102-106. https://doi.org/10.1590/S1679-45082010RW1134 de Souza, J. A., Hunt, B., Asirwa, F. C., Adebamowo, C., & Lopes, G. (2016). Global health equity: Cancer care outcome disparities in high-, middle-, and low-income countries. *Journal of Clinical Oncology*, *34*(1), 6-14. https://dx.doi.org/10.1200%2FJCO.2015.62.2860

de Veer, A. J., Stringer, B., Van Meijel, B., Verkaik, R., & Francke, A. L. (2018). Access to palliative care for homeless people: Complex lives, complex care. *BMC Palliative Care*, *17*(1), 1-11. https://doi.org/10.1186/s12904-018-0368-3

Deal, B. (2011). Finding meaning in suffering. *Holistic Nursing Practice*, *25*(4), 205-210. https://doi.org/10.1097/HNP.0b013e31822271db

Dickens, C., Joffe, M., Jacobson, J., Venter, F., Schüz, J., Cubasch, H., & McCormack, V. (2014). Stage at breast cancer diagnosis and distance from diagnostic hospital in a periurban setting: A South African public hospital case series of over 1,000 women. *International Journal of Cancer*, *135*(9), 2173-2182. https://doi.org/10.1002/ijc.28861

Dilworth-Anderson, P., & Gibson, B. E. (2002). The cultural influence of values, norms, meanings, and perceptions in understanding dementia in ethnic minorities. *Alzheimer Disease and Associated Disorders*, *16*(2), S56–S63. https://doi.org /10.1097/00002093-200200002-00005

Downing, J., Powell, R. A., & Mwangi-Powell, F. (2010). Home-based palliative care in Sub-Saharan Africa. *Home Healthcare Nurse*, 28(5), 298-307. https://doi.org/10.1097/NHH.0b013e3181dbf2b6

Duggleby, W., Tycholiz, J., Holtslander, L., Hudson, P., Nekolaichuk, C., Mirhosseini, M., ... & Swindle, J. (2017). A metasynthesis study of family caregivers' transition experiences caring for community-dwelling persons with advanced cancer at the end of life. *Palliative Medicine*, *31*(7), 602-616. https://doi.org/10.1177%2F0269216316673548

Dyaji, D. M., & Kajom, D. H. (2018). The influence of civilization in eroding family values system in Nigeria: Religion as the panacea. *International Journal of Social Sciences and Conflict Management*, *3* (1), 1-9. https://casirmediapublishing.com/wp-content/uploads/2019/09/Pages-145-153-2018-3052.pdf

Edwin, A. K., Johnson McGee, S., Opare-Lokko, E. A., & Gyakobo, M. K. (2016). A structured approach to end-of-life decision making improves quality of care for patients with terminal illness in a teaching hospital in Ghana. *American Journal of Hospice & Palliative Medicine*, *33*(2), 144–149. https://doi.org /10.1177/1049909114557350

Egan, R., MacLeod, R., Jaye, C., McGee, R., Baxter, J., & Herbison, P. (2011). What is spirituality? Evidence from a New Zealand hospice study. *Mortality*, *16*(4), 307-324. https://doi.org/10.1080/13576275.2011.613267

Ekstedt, M., Stenberg, U., Olsson, M., & Ruland, C. M. (2014). Health care professionals' perspectives of the experiences of family caregivers during in-patient cancer care. *Journal of Family Nursing*, *20*(4), 462-486. https://doi.org/10.1177%2F1074840714556179

Elmore, D. L. (2014). The impact of caregiving on physical and mental health: Implications for research, practice, education, and policy. *The challenges of mental health caregiving* (pp. 15-31). Springer, New York, NY.

Embassy of the Republic of Ghana, the Hugue (n.d.). *What is the official language in Ghana?* http://www.ghanaembassy.nl/index.php/faqs-mainmenu-25/121-what-is-the-official-language-of-ghana.html

Ferrell, B. R., & Baird, P. (2012, November). Deriving meaning and faith in caregiving. *Seminars in Oncology Nursing* (Vol. 28, No. 4, pp. 256-261). WB Saunders. https://doi.org/10.1016/j.soncn.2012.09.008

Food and Agricultural Organisation (2015). *The state Food and agriculture: Social protection and agriculture breaking the cycle of rural poverty*. http://www.fao.org/3/a-i4910e.pdf

Funk, L. M., & Stajduhar, K.I. (2009). Interviewing family caregiver: Implications of the caregiving context for the research interview. *Qualitative Health Research*, *19* (6). 859-867. https://doi.org/10.1177/1049732309334105

Galukande, M., Mirembe, F., & Wabinga, H. (2014). Patient delay in accessing breast cancer care in a sub-Saharan African Country: Uganda. *British Journal of Medicine and Medical Research*, *4*(13), 2599. https://doi.org/10.9734/BJMMR/2014/7293

Gardiner, C., Taylor, B., Robinson, J., & Gott, M. (2019). Comparison of financial support for family caregivers of people at the end of life across six countries: A descriptive study. *Palliative Medicine*, *33*(9), 1189-1211. https://doi.org/10.1177%2F0269216319861925

Gardiner, C., Robinson, J., Connolly, M., Hulme, C., Kang, K., Rowland, C., ... & Gott, M. (2020). Equity and the financial costs of informal caregiving in palliative care: A critical debate. *BMC Palliative Care*, *19*, 1-7. https://doi.org/10.1186/s12904-020-00577-2

Ghanney, E. C., Mensah, D., Addo, E., & Meier, D. (2015). Palliative care education and training workshop for caregivers of patients with cancer in Ghana. *Annals of Global Health*, *81*, 28. https://doi.org/10.1016/j.aogh.2015.02.575

Giesbrecht, M., Crooks, V. A., Williams, A., & Hankivsky, O. (2012). Critically examining diversity in end-of-life family caregiving: implications for equitable caregiver support and Canada's Compassionate Care Benefit. *International Journal for Equity in Health*, *11*(1), 1-13. https://doi.org/10.1186/1475-9276-11-65

Girgis, A., Lambert, S., Johnson, C., Waller, A., & Currow, D. (2013). Physical, psychosocial, relationship, and economic burden of caring for people with cancer: A review. *Journal of Oncology Practice*, *9*, 197–202. https://ascopubs.org/doi/pdf/10.1200/JOP.2012.000690

Githaiga, J. N. (2016). Culture, role conflict and caregiver stress: The lived experiences of family cancer caregivers in Nairobi. *Journal of Health Psychology*, *22*(12), 1591–1602. https://doi-org//10.1177/1359105316631199

Githaiga, J.N., & Swartz, L. (2017). Socio-cultural contexts of end-of-life conversations and decisions: Bereaved family cancer caregivers' retrospective co-constructions. *BMC Palliative Care*, *17*, 1–8. https://doi.org/10.1186/s12904-017-0222-z

GLOBACAN. (March 2021). Ghana. Retrieved February 18, 2022, from https://gco.iarc.fr/today/data/factsheet/populations/288-ghana-fact-sheet.pdf

Gobah, F.K., & Zhang, L. (2011). The national health insurance scheme in Ghana: Prospects and challenges: a cross-sectional evidence. *Global Journal of Health Science*, *3*(2), 90-101. https://doi.org/10.5539/gjhs.v3n2p90

Gott, M., Allen, R., Moeke-Maxwell, T., Gardiner, C., & Robinson, J. (2015). 'No matter what the cost': A qualitative study of the financial costs faced by family and whānau caregivers within a palliative care context. *Palliative Medicine*, *29*(6), 518-528. https://doi.org/10.1177%2F0269216315569337

Guba, E. G., & Lincoln, Y. S. (2000). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (2nd Eds.), *Handbook of qualitative research* (pp. 163-188). Thousand Oaks, CA: Sage.

Gyekye, K. (1996). *African cultural values: An introduction*. Sankofa Publishing Company.

Gyekye, K. (2013). *Philosophy culture and vision: Africa Perspectives*. Sub-Saharan Publishers.

Hackett, J., Godfrey, M., & Bennett, M. I. (2016). Patient and caregiver perspectives on managing pain in advanced cancer: A qualitative longitudinal study. *Palliative Medicine*, *30*(8), 711–719. https://doi.org /10.1177/0269216316628407

Hannon, B., Zimmermann, C., Knaul, F. M., Powell, R. A., Mwangi-Powell, F. N., & Rodin, G. (2016). Provision of palliative care in low- and middle-income countries: Overcoming obstacles for effective treatment delivery. *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology*, *34*(1), 62-68. https://doi.org/10.1200/JCO.2015.62.1615

Hashemi-Ghasemabadi, M., Taleghani, F., Yousefy, A., & Kohan, S. (2016). Transition to the new role of caregiving for families of patients with breast cancer: A qualitative descriptive exploratory study. *Supportive Care in Cancer*, *24*(3), 1269-1276. https://doi.org/10.1007/s00520-015-2906-3

Hassankhani, H., Eghtedar, S., Rahmani, A., Ebrahimi, H., & Whitehead, B. (2019). A qualitative study on cancer care burden: experiences of Iranian family caregivers. *Holistic Nursing Practice*, *33*(1), 17-26. https://doi.org/10.1097/HNP.0000000000000309

Hendriksen, E., Rivera, A., Williams, E., Lee, E., Sporn, N., Cases, M. G., & Palesh, O. (2019). Manifestations of anxiety and coping strategies in patients with metastatic lung cancer and their family caregivers: A qualitative study. *Psychology & Health*, *34*(7), 886–899. https://doi.org/10.1080/08870446.2019.1579909

Hodge, D. R., & Sun, F. (2012). Positive feelings of caregiving among Latino Alzheimer's family caregivers: Understanding the role of spirituality. *Aging & Mental Health*, *16*(6), 689-698. https://doi.org/10.1080/13607863.2012.678481

Hospice and Palliative Care: Resolution to Action. (2016). *Differentiating care for diverse communities.* http://www.thewhpca.org/images/resources/advocacy/Kampala_Declaration_on_Palliative_Care_Final.pdf

Hudson, P. L. (2006). How well do family caregivers cope after caring for a relative with advanced disease and how can health professionals enhance their support? *Journal of Palliative Medicine*, *9*(3), 694-703. https://doi.org/10.1089/jpm.2006.9.694

Hunt, M. R. (2009). Strengths and challenges in the use of interpretive description: Reflections arising from a study of the moral experiences of health professionals in humanitarian work. *Qualitative Health Research*, *19*(9), 1284-1292. doi: 10.1177/1049732309344612

Im Song, J., Shin, D. W., Choi, J. Y., Kang, J., Baik, Y. J., Mo, H., Park, M.H., Choi, S.E., Kwak, J.E., & Kim, E. J. (2011). Quality of life and mental health in family caregivers of patients with terminal cancer. *Supportive Care in Cancer*, *19*(10), 1519-1526. https://doi.org/10.1007/s00520-010-0977-8

Irfan, B., Irfan, O., Ansari, A., Qidwai, W., & Nanji, K. (2017). Impact of caregiving on various aspects of the lives of caregivers. *Cureus*, *9*(5). https://doi.org/10.7759/cureus.1213

Janah, A., Gauthier, L. R., Morin, L., Bousquet, P. J., Le Bihan, C., Tuppin, P., & Bendiane, M. K. (2019). Access to palliative care for cancer patients between diagnosis and death: A national cohort study. *Clinical Epidemiology*, *11*, 443-455. https://dx.doi.org/10.2147%2FCLEP.S198499

Jones, S., Torres, V., & Arminio, J. (2013). *Negotiating the complexities of qualitative research in higher education*. (2nd Ed.). New York: Routledge. https://doi.org/10.4324/9780203123836

Kangethe S. (2009). Critical coping challenges facing caregivers of persons living with HIV/AIDS and other terminally Ill persons: The case of Kanye care program, Botswana. *Indian Journal of Palliative Care*, *15*(2), 115–121. https://doi.org/10.4103/0973-1075.58456

Kitchenham, A. (2010). Diaries and Journals. In A. J. Mills, G. Durepos, & E. Wiebe (Eds.), *Encylopedia of Case Study Research* (pp. 300-302). Thousand Oaks, CA: SAGE Publications

Kivimäki, M., Vahtera, J., Elovainio, M., Helenius, H., Singh-Manoux, A., & Pentti, J. (2005). Optimism and pessimism as predictors of change in health after death or onset of severe illness in family. *Health Psychology*, *24*(4), 413. https://psycnet.apa.org/doi/10.1037/0278-6133.24.4.413

Knaul, F. M., Farmer, P. E., Krakauer, E. L., De Lima, L., Bhadelia, A., Kwete, X. J., Arreola-Ornelas, H., Gomez-Dantes, O., Rodriguez, N. M., Alleyne, G. A. O., Connor, S. R., Hunter, D. J., Lohman, D., Rodbruch, L., Madrigal, M. del R. S., Atun, R., Foley, K. M., Freuk, J., Jamison, D. T., … Lancet Commission Palliative Care. (2018). Alleviating the access abyss in palliative care and pain relief-an imperative of universal health coverage: the Lancet Commission report. *LANCET*, *391*(10128), 1391–1454. https://doi.org/10.1016/S0140-6736(17)32513-8

Kusi, G., Boamah Mensah, A. B., Boamah Mensah, K., Dzomeku, V. M., Apiribu, F., & Duodu, P. A. (2020). Caregiving motivations and experiences among family caregivers of patients living with advanced breast cancer in Ghana. *PloS One*, *15*(3), e0229683. https://doi.org/10.1371/journal.pone.0229683

LaMeaux E.C. (2022). GAIM: 5 ways to put spirituality into practice. Retrieved February 18, 2022, from https://www.gaiam.com/blogs/discover/5-ways-to-put-spirituality-into-practice

Landman, C., & Yates, H. (2017). Africanity and research: A case study in rural South Africa. *HTS Theological Studies*, *73*(4), 1-9. http://dx.doi.org/10.4102/hts.v73i4.4775

Lempert, L. B. (2007). Asking questions of the data: Memo writing in the grounded. *The Sage Handbook of Grounded Theory*, 245-264. https://dx.doi.org/10.4135/9781848607941.n12

Leow, M. Q., & Chan, S. W. (2017). The challenges, emotions, coping, and gains of family caregivers caring for patients with advanced cancer in Singapore: A qualitative study. *Cancer Nursing, 40*(1), 22-30. https://doi.org/10.1097/NCC.0000000000000354

Lewis, S. C. (2015). Reciprocity as a key concept for social media and society. *Social Media+ Society*, *1*(1). https://doi.org/10.1177%2F2056305115580339

Lincoln, Y. S, & Guba, E. G. (1985). *Naturalistic inquiry.* Beverly Hills, CA: Sage Publications.

Maree, J. E., Moshima, D., Ngubeni, M., & Zondi, L. (2018). On being a caregiver: The experiences of South African family caregivers caring for cancer patients. *European Journal of Cancer Care*, *27*(2), e12801. https://doi.org/10.1111/ecc.12801

Mazor, K. M., Firneno, C., Lemay, C. A., Beard, R. L., Alexander, G. L., Arora, N. K., Gaglio, B., Greene, S. M., Robinson, B. E., Roblin, D. W., Walsh, K., Street Jr., R. L., & Gallagher, T. H. (2013). Patients' and family members' views on patient-centered communication during cancer care. *Psycho-Oncology*, *22*(11), 2487-2495. https://doi.org/10.1002/pon.3317

McIlfatrick, S., Hasson, F., McLaughlin, D., Johnston, G., Roulston, A., Rutherford, L., & Kernohan, W. G. (2013). Public awareness and attitudes toward palliative care in Northern Ireland. *BMC Palliative Care*, *12*(1), 34-40. https://doi.org/10.1186/1472-684X-12-34

Merriam, S. B. (2009). *Qualitative research: A guide to design and implementation.* (2nd ed.). San Francisco: Jossey-Bass.

Merriam, S. B. & Tisdell. E.J. (2016). *Qualitative research: A guide to design and implementation.* (4th Edition). San Francisco: Jossey-Bass Plublishers.

Mok, E., Chan, F., Chan, V., & Yeung, E. (2003). Family experience caring for terminally ill patients with cancer in Hong Kong. *Cancer Nursing, 26*(4), 267-275. https://journals.lww.com/cancernursingonline/Fulltext/2003/08000/Family_Experience_Caring_for_Terminally_Ill.00003.aspx?casa_token=gesDndNS9eIAAAAA:3hr-8NtJMfKjesc8HYOz2X5zZvO6-2M2d2AYX9LRykY6Hg2kCMxbQO3RMH7gTx5RW6EGyoZkQvEtHzDtWZidzdRh6dn9uo4

Mok, E., & Chiu. C.P. (2004). Nurse-patient relationships in palliative care. *Journal of Advanced Nursing*, *48*(5), 475-483. https://doi.org/10.1111/j.1365-2648.2004.03230.x

Mok, E., & Chiu. C.P. (2004). Nurse-patient relationships in palliative care. *Journal of Advanced Nursing*, *48*(5), 475-483. https://doi.org/10.1111/j.1365-2648.2004.03230.x

Montgomery, R.J.V., Kwak, J., & Koloski, K.D. (2016). Theories Guiding Support Services for Family Caregivers. In. V.L. Bengtson, & R.A. Settersten (3rd Eds), *Handbook of Theories of Aging* (pp. 443-462). New York: Springer Publishing Company.

Montoro-Rodriguez, J., Kosloski, K., & Montgomery, R. J. V. (2003). Evaluating a practice-oriented service model to increase the use of respite services among minorities and rural caregivers. *Gerontologist*, *43*(6), 916–924. https://doi.org/10.1093/geront/43.6.916

Morse, J. M., & Field, P. (1995). *Qualitative research methods for health professionals* (2nd Ed.). Thousand Oaks, CA: Sage Publications.

Mosher, C., Adams, R., Helft, P., O'Neil, B., Shahda, S., Rattray, N., … Champion, V. L. (2015). Family caregiving challenges in advanced colorectal cancer: patient and caregiver perspectives. *Supportive Care in Cancer*, *24*(5), 2017–2024. https://doi.org/10.1007/s00520-015-2995-z

Mukherjee, S., Patel, S. R., Kales, S. N., Ayas, N. T., Strohl, K. P., Gozal, D., & Malhotra, A. (2015). An official American thoracic society statement: The importance of healthy sleep. Recommendations and future priorities. *American Journal of Respiratory and Critical Care Medicine*, *191*(12), 1450-1458. https://doi.org/10.1164/rccm.201504-0767ST

Muliira, J. K., Kizza, I. B., & Nakitende, G. (2019). Roles of family caregivers and perceived burden when caring for hospitalized adult cancer patients: Perspective from a low-income country. *Cancer Nursing*, *42*(3), 208-217. https://doi.org/10.1097/NCC.0000000000000591

Murray, S. A., Grant, E., Grant, A., & Kendall, M. (2003). Dying from cancer in developed and developing countries: Lessons from two qualitative interview studies of patients and their carers. *BMJ (Clinical Research Ed.)*, *326*(7385), 368. https://doi.org/10.1136/bmj.326.7385.368

National Cancer Institute (n.d.). Cancer Research. Retrieved from https://www.cancer.gov/research/key-initiatives

National Institution of Aging. (2017). *What are palliative care and hospice care?* Retrieved January 20, 2020, from https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care#palliative

Nemati, S., Rassouli, M., Ilkhani, M., & Baghestani, A. R. (2017). Perceptions of family caregivers of cancer patients about the challenges of caregiving: A qualitative study. *Scandinavian Journal of Caring Sciences*, *32*(1), 309-316. https://doi.org/10.1111/scs.12463

Nguyen, S. T. T., Yamamoto, E., Kariya, T., Saw, Y. M., Hamajima, N., Nguyen, M. T. N., Le, H. B., & Nguyen, C. D. (2018). Waiting time in the outpatient clinic at a national hospital in Vietnam. *Nagoya Journal of Medical Science*, *80*(2), 227. https://doi.org/10.18999/nagjms.80.2.227

Nia, H. S., Lehto, R. H., Seyedfatemi, N., & Mohammadinezhad, M. (2021). A path analysis model of spiritual well-being and quality of life in Iranian cancer patients: A mediating role of hope. *Supportive Care in Cancer*, *29*, 6013-6019. https://doi.org/10.1007/s00520-021-06172-2

Ntizimira, C. R., Nkurikiyimfura, J. L., Mukeshimana, O., Ngizwenayo, S., Mukasahaha, D., & Clancy, C. (2014). Palliative care in Africa: A global challenge. *Ecancermedicalscience*, *8*(474–494), 1–4. https://doi.org/10.3332/ecancer.2014.493

O’Neil, D. S., Blinderman, C. D., Jacobson, J. S., Neugut, A. I., Prigerson, H. G., Mmoledi, K., Sobekwa, M., Ratshikana-Moloko, M., Cubasch, H., Joffe, M., Ruff, P., Tsitsi, J. M., Omoshoro-Jones, J. A. O., Wong, M. L., Blanchard, C. L., & Sackstein, P. E. (2018).

Informal caregiver challenges for advanced cancer patients during end-of-life care in Johannesburg, South Africa and distinctions based on place of death. *Journal of Pain and Symptom Management*, *56*(1), 98–106. https://doi.org/10.1016/j.jpainsymman.2018.03.017

Odinye, I. & Odinye, I. (2012). Western influence on Chinese and Nigerian cultures. *OGIRISI: A New Journal of African Studies*, *9*, 108-115. http://dx.doi.org/10.4314/og.v9i1.5

Ojimadu, N.E., & Okwuonu, C.G. (2015). Understanding the concept and challenges of palliative care medicine: a review of a centre in a tertiary hospital in South-East Nigeria. *International Journal of Medicine and Biomedical Research*, *4(2),* 86-90. doi: 10.14194/ijmbr.4.2.4

Omoyeni, N. E., Soyannwo, O. A., Aikomo, O. O., & Iken, O. F. (2014). Home-based palliative care for adult cancer patients in Ibadan—A three year review. *Ecancermedicalscience*, *8* (420), 1-7. https://dx.doi.org/10.3332%2Fecancer.2014.490

Onyeneho, C.A., & Ilesanmi, R.E. (2021). Burden of care and perceived psycho-social outcomes among family caregivers of patients living with cancer. *Asia-Pacific Journal of Oncology Nursing*, *8* (3), 330-336. https://doi.org/10.4103/2347-5625.308678

Opoku, S. Y., Benwell, M., & Yarney, J. (2012). Knowledge, attitudes, beliefs, behavior, and breast cancer screening practices in Ghana, West Africa. *The Pan African Medical Journal*, *11*, 28-39. https://doi.org /10.11604/pamj.2012.11.28.548

Oyegbile, Y.O., & Brysiewicz. (2016). Family caregiver's experiences of providing care to patients with end-stage renal disease in South-West Nigeria. *Journal of Clinical Nursing*, *26,* 2624-2632. https://doi.org/10.1111/jocn.13689

PallitaiveCare Australia. (July 6, 2017). The economic benefits of early access to palliative care and end-of-life care. Retrieved February 18, 2022, from https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2017/07/PCA019_Economic-Research-Sheet_6a_Early-Access.pdf

Partridge, A. H., Seah, D. E., King, T., Leighl, N. B., Hauke, R., Wollins, D. S., & Von Roenn, J. H. (2014). Developing a service model that integrates palliative care throughout cancer care: the time is now. *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology*, *32*(29), 3330-3336. https://doi.org/10.1200/JCO.2013.54.8149

Penman, J., & Ellis, B. (2015). Palliative care clients' and caregivers' notion of fear and their strategies for overcoming it. *Palliative & Supportive Care*, *13*(3), 777-785. https://doi.org/10.1017/S1478951514000571

Puplampu, G. L., Olson, K., Ogilvie, L., & Mayan, M. (2014). Feature: Attracting and retaining nurses in HIV care. *Journal of the Association of Nurses in AIDS Care*, *25*, 253–261. https://doi.org/10.1016/j.jana.2013.01.002

Qureshi, D., Tanuseputro, P., Perez, R., Pond, G. R., & Seow, H. Y. (2019). Early initiation of palliative care is associated with reduced late-life acute-hospital use: A population-based retrospective cohort study. *Palliative Medicine*, *33*(2), 150-159. https://doi.org/10.1177%2F0269216318815794

Rassool, G. H. (2000). The crescent and Islam: Healing, nursing and the spiritual dimension. Some considerations towards an understanding of the Islamic perspectives on caring. *Journal of Advanced Nursing*, *32*(6), 1476-1484. https://doi.org/10.1046/j.1365-2648.2000.01614.x

Reilly, R., Micklem, J., Yerrell, P., Banham, D., Morey, K., Stajic, J., … Brown, A. (2018). Aboriginal experiences of cancer and care coordination: Lessons from the Cancer Data and Aboriginal Disparities (CanDAD) narratives. *Health Expectations*, *21*(5), 927–936. https://doi.org/10.1111/hex.12687

Reinhard, S. C., Given, B., Petlick, N. H., & Bemis, A. (2008). Supporting family caregivers in providing care. *Patient safety and quality: An evidence-based handbook for nurses*. (pp. 342-363). https://www.ncbi.nlm.nih.gov/books/NBK2665/

Rivera-Franco, M. M., & Leon-Rodriguez, E. (2018). Delays in breast cancer detection and treatment in developing countries. *Breast Cancer: Basic and Clinical Research*, *12*, 1-5. https://doi.org/10.1177%2F1178223417752677

Røen, I., Stifoss-Hanssen, H., Grande, G., Brenne, A.-T., Kaasa, S., Sand, K., & Knudsen, A. K. (2018). Resilience for family carers of advanced cancer patients-how can health care providers contribute? A qualitative interview study with carers. *Palliative Medicine*, *32*(8), 1410–1418. https://doi.org/10.1177/0269216318777656

Saimaldaher, Z. A. H., & Wazqar, D. Y. (2020). Relationships between caregiving stress, mental health and physical health in family caregivers of adult patients with cancer: Implications for nursing practice. *Scandinavian Journal of Caring Sciences*, *34*(4), 889-898. https://doi.org/10.1111/scs.12795

Salifu, Y., Almack, K., & Caswell, G. (2021). ‘My wife is my doctor at home’: A qualitative study exploring the challenges of home-based palliative care in a resource-poor setting. *Palliative Medicine*, *35*(1), 97-108. https://doi.org/10.1177%2F0269216320951107

Santos, H. P. O., Jr, Black, A. M., & Sandelowski, M. (2015). Timing of translation in cross-language qualitative research. *Qualitative Health Research*, 25(1), 134–144. https://doi.org/10.1177/1049732314549603

Schaad, B., Bourquin, C., Bornet, F., Currat, T., Saraga, M., Panese, F., & Stiefel, F. (2015). Dissatisfaction of hospital patients, their relatives, and friends: Analysis of accounts collected in a complaints center. *Patient Education and Counseling*, *98*(6), 771-776. https://doi.org/10.1016/j.pec.2015.02.019

Scott E. (November 27, 2020). What is Spirituality? Verywell Mind. Retrieved November 20, 2021, from https://www.verywellmind.com/how-spirituality-can-benefit-mental-and-physical-health-3144807

Sepúlveda, C., Marlin, A., Ullrich, A., & Yoshida, T. (2002). Palliative care: The world health organization's global perspective. *Journal of Pain and Symptom Management*, *24*(2), 91–96. https://doi.org/10.1016/S0885-3924(02)00440-2

Sherman, D. W., McGuire, D. B., Free, D., & Cheon, J. Y. (2014). A pilot study of the experience of Family caregivers of patients with advanced pancreatic cancer using a mixed methods approach. *Journal of Pain and Symptom Management*, *48*(3), 385-399. https://doi.org/10.1016/j.jpainsymman.2013.09.006

Smith, C., Olson, K., Hale, L. A., Baxter, D., & Schneiders, A. G. (2011). How does fatigue influence community-based exercise participation in people with multiple sclerosis? *Disability & Rehabilitation*, *33*(23/24), 2362–2371. https://doi.org/10.3109/09638288.2011.573054

Sparla A, Flach-Vorgang S, Villalobos M, Krug K, Kamradt M, Coulibaly K, Szecsenyi J, Thomas M, Gusset-Bährer S, & Ose D. (2016). Individual difficulties and resources - A qualitative analysis in patients with advanced lung cancer and their relatives. *Patient Preference & Adherence*, *10*, 2021–2029. https://doi.org/10.2147/PPA.S110667

Sparla, A., Flach-Vorgang, S., Krug, K., Kamradt, M., Coulibaly, K., Szecsenyi, J., Ose, D., Villalobos, M., Thomas, M., & Gusset-Bährer, S. (2017). Reflection of illness and strategies for handling advanced lung cancer - a qualitative analysis in patients and their relatives. *BMC Health Services Research*, *17*, 1–9. https://doi.org/10.1186/s12913-017-2110-x

Squires, A. (2009). Methodological challenges in cross-language qualitative research: A research review. *International Journal of Nursing Studies*, *46*, 277–287. https://doi.org /10.1016/j.ijnurstu.2008.08.006

Stake, R. E. (1995). *The art of case study research.* Thousand Oaks, California: Sage Publications.

Stenberg, U., Cvancarova, M., Ekstedt, M., Olsson, M., & Ruland, C. (2014). Family caregivers of cancer patients: Perceived burden and symptoms during the early phases of cancer treatment. *Social Work in Health Care*, *53*(3), 289-309. https://doi.org/10.1080/00981389.2013.873518

Sujatha, R., & Jayagowri, K. (2017). Assessment of palliative care awareness among undergraduate healthcare students. *Journal of Clinical & Diagnostic Research*, *11*(9), 6-10. https://doi.org/10.7860/JCDR/2017/29070.10684

Sussman, J., Barbera, L., Bainbridge, D., Howell, D., Yang, J., Husain, A., Librach, L. S., Viola, R., & Walker, H. (2012). Health system characteristics of quality care delivery: a comparative case study examination of palliative care for cancer patients in four regions in Ontario, Canada. *Palliative Medicine*, *26*(4), 322–335. https://doi.org/10.1177/0269216311416697

Swinton, J., & Pattison, S. (2010). Moving beyond clarity: Towards a thin, vague, and useful understanding of spirituality in nursing care. *Nursing Philosophy*, *11*(4), 226-237. https://doi.org/10.1111/j.1466-769X.2010.00450.x

Syed A, Almas A, Naeem Q, Malik U., & Muhammad, T. (2017). Barriers and perceptions regarding code status discussion with families of critically ill patients in a tertiary care hospital of a developing country: Across-sectional study. *Palliative Medicine*, *31*(2), 147-157. https://doi.org/10.1177/0269216316650789

Thorne, S. E., Kirkham, S. R., & MacDonald-Emes, J. (1997). Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing & Health*, *20*(2), 169-177. https://doi.org/10.1002/(SICI)1098-240X(199704)20:2<169::AID-NUR9>3.0.CO;2-I

Thorne, S. E., Reimer Kirkham, S., & O'Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods*, *3*(1), 1. https://doi.org/10.1177/160940690400300101

Thorne, S. E. (2008). *Interpretive description*. Walnut Creek, CA: Left Coast Press.

Thorne, S. (2016). *Interpretive Description: Qualitative Research for Applied Practice* (2nd Ed.). New York, United States: Routledge.

Trading Economics. (2022). *Ghana indicators*. Retrieved February 18, 2022, from https://tradingeconomics.com/ghana/indicators

Tsui, Y. M., & Fong, B. Y. (2018). Waiting time in public hospitals: case study of total joint replacement in Hong Kong. *Public Administration and Policy*, *21 (*2), 120-133. https://doi.org/10.1108/PAP-10-2018-009

United Nations. (n.d.). *Department of Economic and Social Affairs*. Retrieved November 20, 2021, from https://sdgs.un.org/goals/goal3

United Nations Girls Child Initiative. (n.d). *Ghana: Background*. Retrieved February 20, 2019, from http://www.ungei.org/infobycountry/ghana.html

United Nations Development Program. (2020). *Human development report*. Retrieved November 20, 2021, from https://hdr.undp.org/en/content/latest-human-development-index-ranking

Vacccarella, S., Lortet-Tieulent, J., Saracci, R., Conway, D. I., Straif, K., & Wild, C. P. (2019). *Reducing social inequalities in cancer: Evidence and priorities for research.* The International Agency for Research on Cancer, France.

Vahidi, M., Mahdavi, N., Asghari, E., Ebrahimi, H., Ziaei, J.E., Hosseinzadeh, M., Hossein, N.A. & Kermani. I.A. (2016). Other side of breast cancer: Factors associated with caregiver burden. *Asian nursing research*, *10*(3), 201-206. https://doi.org/10.1016/j.anr.2016.06.002

van Deventer, C., & Wright, A. (2017). The psychosocial impact of caregiving on the family caregivers of chronically ill AIDS and/or HIV patients in home-based care: A qualitative study in Zimbabwe. *Southern African Journal of HIV Medicine*, *18*(1), 7. https://doi.org/10.4102/sajhivmed.v18i1.718

van Roij, J., Brom, L., Youssef-El Soud, M., van de Poll-Franse, L., & Raijmakers, N. J. H. (2019). Social consequences of advanced cancer in patients and their informal caregivers: A qualitative study. *Supportive Care in Cancer: Official Journal of the Multinational*

Association of Supportive Care in Cancer, *27*(4), 1187–1195. https://doi.org/10.1007/s00520-018-4437-1

Washington, K. T., Craig, K. W., Parker Oliver, D., Ruggeri, J. S., Brunk, S. R., Goldstein, A. K., & Demiris, G. (2019). Family caregivers' perspectives on communication with cancer care providers. *Journal of Psychosocial Oncology*, 37(6), 777-790. https://doi.org/10.1080/07347332.2019.1624674

Whitehead, M., & Dahlgren, G. (2006). Concepts and principles for tackling social inequities in health: Levelling up Part 1. *World Health Organization: Studies on social and economic determinants of population health*, *2*, 1-34. http://www.enothe.eu/cop/docs/concepts_and_principles.pdf

Wiencek, C., & Coyne, P. (2014). Palliative Care Delivery Models. *Seminars in Oncology Nursing*, *30*, 227–233. https://doi.org/10.1016/j.soncn.2014.08.004.

Williams, A., Duggleby, W., Eby, J., Cooper, R. D., Hallstrom, L. K., Holtslander, L., & Thomas, R. (2013). Hope against hope: Exploring the hopes and challenges of rural female caregivers of persons with advanced cancer. *BMC Palliative Care*, *12*(1), 1-10. http://www.biomedcentral.com/1472-684X/12/44

Williams, L. A., Moeke-Maxwell, T., Wiles, J., Black, S., Trussardi, G., Kerse, N., & Gott, M. (2018). How family caregivers help older relatives navigate statutory services at the end of life: A descriptive qualitative study. *Palliative Medicine*, *32*(6), 1124-1132. https://doi.org/10.1177%2F0269216318765853

Wong, C. L., Choi, K. C., Lau, M. N., Lam, K. L., & So, W. K. W. (2020). Caregiving burden and sleep quality amongst family caregivers of Chinese male patients with advanced cancer: a cross-sectional study. *European Journal of Oncology Nursing*, *46*, 101774. https://doi.org/10.1016/j.ejon.2020.101774

Woo, K. (2019). *Polit & Beck Canadian essentials of nursing research*. (4th Edition). Philadelphia: Wolters Kluwer

World Health Assembly. (2014, May 24). *Sixty-seventh world health assembly: Strengthening of palliative care as a component of comprehensive care throughout the life course*. http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf

World Health Organisation. (August 27, 2008). *Closing the gap in a generation: Health equity through action on the social determinants of health - Final report of the commission on social determinants of health*. Retrieved November 18, 2019, from https://www.who.int/publications/i/item/WHO-IER-CSDH-08.1

World Health Organization & Worldwide Palliative Care Alliance. (2014, January). *Global atlas of palliative care at the end of life.* https://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf

World Health Organization (2015). *Palliative care*. Retrieved August 19, 2019, from http://www.euro.who.int/en/health-topics/noncommunicable-diseases/cancer/policy/palliative-care

World Health Organization. (2016). *Planning and implementing palliative care services: A guide for programme managers*. Switzerland. http://apps.who.int/iris/bitstream/10665/250584/1/9789241565417-eng.pdf

World Health Organization. (2017, February). *10 Facts about cancer*. Retrieved August 19, 20219, from http://www.who.int/features/factfiles/cancer/en/

World Health Organization. (2019a). *What is health financing for universal coverage*? Retrieved November 20, 2020, from https://www.who.int/health_financing/universal_coverage_definition/en/

World Health Organization. (2019b, January 24). *Universal health coverage (UHC)*. Retrieved November 20, 2019, from https://www.who.int/en/news-room/fact-sheets/detail/universal-health-coverage-(uhc)

World Health Organisation. (August 5, 2020). *Palliative care*. Retrieved July 25, 2019, from https://www.who.int/news-room/fact-sheets/detail/palliative-care

World Health Organisation. (February 2, 2022). *Cancer*. Retrieved February 19, 2022, from https://www.who.int/news-room/fact-sheets/detail/cancer

World Health Ranking. (2018). *Ghana life expectancy*. Retrieved from https://www.worldlifeexpectancy.com/ghana-life-expectancy

Worldwide Hospice Palliative Care Alliance. (2016, August 25). *African misters of health adopt Kampala declaration on palliative care*. Retrieved August 20, 2019, from http://www.thewhpca.org/latest-news/item/african-ministers-of-health-adopt-kampala-declaration-on-palliative-care

World Population Review. (2022). *Ghana population*. February 18, 2022, from https://worldpopulationreview.com/countries/ghana-population

Wu, H., & Volker, D.L. (2011). Humanistic nursing theory: Application to hospice and palliative care. *Journal of Advanced Nursing*, *68*(2), 471-479. https://doi.org/10.1111/j.1365-2648.2011.05770.x

Young, J., & Snowden, A. (2016). A systematic review on the factors associated with positive experiences in carers of someone with cancer. *European Journal of Cancer Care*, *26*(3). 1-18. https://doi.org/10.1111/ecc.12544

Appendix A

Recruitment Script for Palliative Care Nurse

Title of Study	**Exploring the Experiences of Family Caregivers of Persons Living with Advanced Cancer in Ghana**
Principal Investigator	Bisi Adewale (PhD student) Faculty of Nursing University of Alberta adewale@ualberta.ca Phone: +1(587)3416657 +233266507628
Co-Supervisors	Dr. Anna Santos Salas, Faculty of Nursing, University of Alberta. avs@ualberta.ca Dr. Wendy Duggleby, Faculty of Nursing, University of Alberta. wduggleb@ualberta.ca

A student of the University of Alberta, Faculty of Nursing in Canada is doing a research for her Doctor of Philosophy Degree in Nursing.

I am helping her to find participants for her study which is looking into the experiences of family caregivers of persons living with advanced cancer. She will be interviewing you on the telephone for 45-60 minutes and you will be asked questions about your experiences with caring for the person living with advanced cancer. She will be engaging you in at least two interviews.

If you are interested in being part of this study, I will like to have your verbal consent to give her your contact details so she can contact you for further explanation about the research. Your refusal to take part in the study will not affect the services you receive from this unit.

Thank You.

Appendix B

Demographic Data form of Family Caregivers of Persons Living with Advanced Cancer

Title of Study	**Exploring the Experiences of Family Caregivers of Persons Living with Advanced Cancer in Ghana**
Principal Investigator	Bisi Adewale (PhD student) Faculty of Nursing University of Alberta adewale@ualberta.ca Phone: +233266507628
Co-Supervisors	Dr. Anna Santos Salas, Faculty of Nursing, University of Alberta. avs@ualberta.ca Dr. Wendy Duggleby, Faculty of Nursing, University of Alberta. wduggleb@ualberta.ca

I am a student of the University of Alberta, Faculty of Nursing. I am conducting this research as part of the requirement for the Doctor of Philosophy Degree in Nursing.

As explained in the information sheet, this telephone interview will last for 45-60 minutes and you will be asked questions pertaining to your experiences with caring for the person living with advanced cancer. The information you provide is very important for the completion of this project. It is anticipated that information gathered will help develop a program to support the family caregivers to improve the implementation of palliative care in Ghana. Before we begin our discussion on your experience, I will like to take some demographic data about you and your relative receiving care.

Participant's No: ………

Participants Age: ……..

Participants Gender: ....

Care recipient's Gender: ………………

Care recipients Age: ………………….

Diagnosis of Care recipient: …………………………………….

Date of diagnosis ………………………………………………..

Date of Diagnosis of advanced cancer …………………………..

What is your current marital status? …………………………….

What is your highest level of education? ………………………..

What is your current employment?

If employed, which of the following best describe your monthly income: below 200GHC, 300-500GHC, 600-900GHC, and 1000GHC and above? ……………………………………..

How are you related to the person living with advanced cancer? ………………………...

What do you know about your relative's condition? ……………………………………...

How long have you been a family caregiver to this person? ……………………………...

Appendix C (Google Form)

Demographic Data Form for Health Care Professionals Participating in Focus Group

Title of Study	**Exploring the Experiences of Family Caregivers of Persons Living with Advanced Cancer in Ghana**
Principal Investigator	Bisi Adewale (PhD student) Faculty of Nursing University of Alberta adewale@ualberta.ca Phone: +233266507628
Co-Supervisors	Dr. Anna Santos Salas, Faculty of Nursing, University of Alberta. avs@ualberta.ca Dr. Wendy Duggleby, Faculty of Nursing, University of Alberta. wduggleb@ualberta.ca

I am a student of the University of Alberta, Faculty of Nursing. I am conducting this research as part of the requirement for the Doctor of Philosophy Degree in Nursing.
As explained in the information sheet, this Zoom focus group will last for 60-90 minutes and you will be asked questions pertaining to your perception on the experiences of family caregivers of person living with advanced cancer. The information you provide is very important for the completion of this project. It is anticipated that information gathered will help develop a program to support the family caregivers to improve the implementation of palliative care in Ghana. Before we begin our focus group discussion on what your perception is on their experiences, I will like to know a little bit more about you and your position in the palliative care team.

Participant's No: ....

Professional designation: ……………………………..

Level of education: ……………………………………

How long have you been practicing as a health care professional? ……………...

How long have you been practicing as a palliative care professional?

What is your position in the palliative care team? ……………………………………………

Are you working full time or part time at the Palliative Care Out-Patients Unit?
…………………………………………………………………………………..

Appendix D
Consent form and Information Letter for Family Caregivers

Title of Study	**Exploring the Experiences of Family of Persons Living with Advanced Cancer in Ghana**
Principal Investigator	Bisi Adewale (PhD candidate) Faculty of Nursing University of Alberta adewale@ualberta.ca Phone: +233266507628
Co-Supervisors	Dr. Anna Santos Salas, Faculty of Nursing, University of Alberta. avs@ualberta.ca Dr. Wendy Duggleby, Faculty of Nursing, University of Alberta. wduggleb@ualberta.ca

Background to the Study

Studies have shown family members to look after their sick relatives, all over the world. In countries with fewer resources, the experiences of family members who care for their sick relatives is different from countries with resources. The experiences of those who look after a sick person in Ghana are very important. We know very little about this. Understanding their experience will help the government of Ghana to know how best to support family caregivers like yourself.

Purpose of the Study

Families of persons diagnosed with cancer provide most of the care needed by their relatives in Africa. This study will look at the experiences of family members looking after their relatives with cancer in Ghana. We want to understand what you go through when looking after your sick relative. We hope the findings of this study will help inform the Ghanaian health care system on the way forward to support the families of persons looking after their relatives who are sick. This study is part of my doctoral study at the University of Alberta.

Procedures

We will ask you to take part in this study at your own free will. First, I will ask you questions about yourself and the person you are caring for such as age, gender, what the doctor told you is happening to your relative medically. Then we will ask you to take part in at least two telephone talks with myself. This will last about 45-60 minutes at a time that is okay for you. If you agree to take part, I will record our talk directly on the mobile phone that will be used for the interview. I can turn the recorder on the phone off at any time. Should you wish to turn the recorder off, I will write notes with your agreement. In this talk, we will ask you to tell me about what you go through when looking after your sick relative. When I ask you the questions, you can talk about any of the things you go through when looking after your sick relative. You are also free to tell us other things which you think will let us know about what you are going through whiles looking after your sick relative. We will also ask you during our talk to tell us what you know about support that exist and those that you need when looking after your sick relative. The questions will be about what you go through when looking after your sick relative.

Benefits

There are no expected direct benefits to participants in the study. However, through our talk about what you go through when looking after your sick relative we will understand what it is like for you on a daily basis performing this role. We also hope that what we find in this study will increase the support family members looking after their sick relative receive in Ghana. We are grateful for the time you will give to us understand what you go through when looking after your relative.

Risks

Being in this study is your choice. You may feel emotionally distressed or fatigued when sharing your story. You may also feel fatigued for being on the phone for 45-60 minutes. In case this happens, we will offer to end the interview and reschedule it for another day. Also, if you need to speak to someone about the way you feel, we will offer you to contact your relatives palliative care nurse. Finally, you may feel unsure of how safe if is to do a phone interview. In order for our discussion to be secured, all measures to keep your information safe will be done as described under the confidentiality and anonymity section.

Compensation

We will give you an amount of $25 as a way of saying thank you for taking part in the study when we finish our talk. If you can only do one interview you will still receive this amount. You will receive no additional compensation even if you participate in a second interview.

Confidentiality and Anonymity

The talk will take place at a place of your choice so that what we talk about can be private. We will keep everything you say private, except when professional codes of ethics or the law requires reporting. The mobile phone that will I will be using for the interviews is dedicated purposely for this study. Also the researcher will be doing the interviews in a private room in the researchers' home. We will keep audio files and written material resulting from our talk in a locked filing cabinet in Bisi Adewale's supervisor's research area. We will keep your information safe in a computerized system, which only Bisi Adewale and Bisi's supervisors can have access. If we have our talk in Twi, a person who speaks and writes both English and Twi will have access to the audio files for a while. We will remove your name from all the records. We will give a number to each file, record, and to any other material that results from you taking part in this study. All hard copies of data collection documents will be safely transported by Bisi Adewale after data collection when returning to Alberta. We will keep audio files and paper you sign to agree to take part in this study voluntarily for at least five years after the study is finished. We will keep the paper you sign separate from audio files.

We will take the necessary steps to keep you and what you say safe. Study findings may not relate to one person that took part but to a number of them. We will use all the information collected from persons taking part in this study only for this study. Information about this study will be reported using direct quotes from our talk. . Stories may be prepared putting together direct quotes from a talk.

Voluntary Participation

Your taking part in this study is not a duty. Your taking part in this study is at your own will.

Freedom to withdraw: Even if you enter the study, you do not have to answer any questions or discuss any subject during our talk if you do not want to. You may withdraw from the study at any time by telling Bisi. Taking part in this study or dropping out will not affect your receiving services from the palliative care outpatient unit in any way.

Future use of data: We may report findings from this study in conferences or published material. Your name will not appear in any report. We may also use information collected in this study in future studies. Before doing so, we will request permission from the appropriate ethics committee.
For Further information: If you have any questions about the study, please contact me on phone via [cell phone to be used for study purpose only] or e-mail at adewale@ualberta.ca.

The plan for this study has been reviewed by a Research Ethics Board at the University of Alberta and the Ethics Board at the Korle-bu Teaching Hospital. If you have questions about your rights or how research should be conducted, you can call +1 (780) 492-2615 and/or + 233 (302) 739510. This office is independent of the researchers.

Please keep a copy of this letter for reference.

Consent Statement

The study has been explained to me. I had the chance to ask question, which were answered. If I have any other questions, I know whom to contact. I agree to take part in the study described above and will be given a copy of this form after I sign it.

____ ______________

Participant's Name (printed) Date

____ ______________

Name (printed) and Signature of Person Obtaining Consent Date

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate. The person taking part in this study has a copy of this consent form.

____ ______________

Name of Researcher Date

Appendix E (Google Form)
Consent form and Information Letter for Health Care Professionals (Email message can be found at the end as Appendix K)

Title of Study	**Exploring the Experiences of Family of Persons Living with Advanced Cancer in Ghana**
Principal Investigator	Bisi Adewale (PhD student) Faculty of Nursing University of Alberta adewale@ualberta.ca
Co-Supervisors	Phone: +233266507628 Dr. Anna Santos Salas, Faculty of Nursing, University of Alberta. avs@ualberta.ca Dr. Wendy Duggleby, Faculty of Nursing, University of Alberta. wduggleb@ualberta.ca

Background to the Study

Family caregivers of palliative patients have been found in studies both in the developed and developing countries to assume a caregiving role. In settings where resources are limited, experiences of the roles performed by family caregivers vary comparatively to resource adequate settings. There is the need to further understand the experience of the family caregivers of palliative care patients, especially in Ghana where implementation of the services is limited. This will guide us towards the development of a program which will support the family caregivers in performing their roles in Ghana.

Purpose of the Study

Studies have shown that families of persons diagnosed with cancer are expected to shoulder majority of the care giving in Sub Saharan Africa. The goal of this study is to explore the experience of family caregivers of palliative cancer patients in Ghana. A related goal is to have an in-depth understanding of the lived experience of the family caregivers of palliative cancer patients in Ghana. The findings of this study is anticipated to inform the Ghanaian health care system on the way forward to support the family caregivers of palliative care patient as a whole. This study is also part of the requirement for my doctoral study at the University of Alberta.

Study Procedures

You will be invited to voluntarily participate in a focus group recorded conversation online via Zoom with other palliative care team members and the researcher. At the beginning of the focus group you will be asked to tell us about yourself such as your age, gender, position at the clinic. The focus group will last about 60-90 minutes. With your consent the conversation will be recorded directly on Bisi's research computer and not the cloud.

In addition to the audio recording, notes will be taken by a student palliative care nurse specialist with your consent. In this conversation Bisi Adewale will invite you to talk about your perception on the experiences of family caregivers of persons living with advanced cancer. You may wish to talk about a particular experience as a member of the palliative care team based on the questions you are asked during the discussion.

You are also free to share with us other experiences which you think will best inform us about the circumstances of family caregiver of persons living with advanced cancer. You will also be asked during the discussion to share your knowledge on existing and needed supports for a family caregiver of persons living with advanced cancer. The nature of the questions will be about your perception on the experiences of family caregivers of persons living with advanced cancer.

Benefits

There are no anticipated direct benefits to participants in the study. However, through our discussion on the experiences of family caregivers of persons living with advanced cancer we will gain an insight on their daily experiences whiles performing their roles. We also hope that the results of this study will improve the implementation of palliative care services in Ghana. We truly appreciate the time you will give to help us further understand the experience of family caregivers of persons living with advanced cancer.

Risks

Being in this study is your choice. You may be concerned with the security of data being shared online. You are still entitled to this compensation even if you withdraw early in the study. The researcher has made provision to ensure the security of data that will be collected online, and this has been described under the confidentiality section.

Compensation

At the end of the focus group you will receive a small contribution of CAD 25.00 as a way of saying thank you. No additional compensation will be provided related to your participation in this study.

Confidentiality

All persons participating in this focus group must pledge to abide by the confidentiality rules of this discussion. All information will be held private, except when professional codes of ethics or the law requires reporting. We will keep audio files and written material in a secure server at the University of Alberta. Hard copies will be stored in a filing cabinet in Bisi Adewale's supervisor's research area. The PI will encrypt the device that will be used to store the data collected using the University of Alberta Information Security Technology system. This will keep the information secured and safe from being accessed by a third party. We will delete your name from all the records. We will assign a number to each file, transcript, and to any other material that results from your participation in this study. All hard copies of data collection documents will be safely transported by Bisi Adewale after data collection when returning to Alberta. We will keep audio files and consent forms for at least five years after the study is completed. Consent forms will be stored separate from audio files.

Steps to safeguard anonymity will be taken. Research findings may not relate to one particular participant but to a number of them. All the data collected with participants will be used for this study. Data will be reported using direct quotes from the discussion with participants, however there will be no identifying information. Stories may be prepared combining direct quotes from this discussion. Although we cannot guarantee that others from the group will maintain the confidentiality of what is discussed, we ask that you keep confidential what is said during the focus groups.

Voluntary Participation

You are under no obligation to participate in this study. Your participation in this study is completely voluntary.

Freedom to withdraw: Even if you enter the study, you do not have to answer any questions or discuss any subject in the conversations if you do not want to. You may withdraw from the study at any time by telling the researcher. Taking part in this study or dropping out will not in affect you in anyway.

Future use of data: We may report findings from this study in conferences or published material. Your name will not appear in any report. We may also use information collected in this study in future studies. Before doing so, we will request permission from the appropriate ethics committee.

For Further information: If you have any questions about the research, please contact me on phone via [cell phone to be used for study purpose only] or e-mail at adewale@ualberta.ca.

The plan for this study has been reviewed by a Research Ethics Board at the University of Alberta and Ethics Board at the Korle-bu Teaching Hospital. If you have questions about your rights or how research should be conducted, you can call +1 (780) 492-2615 and /or + 233 (302) 739510.

This office is independent of the researchers.

Informed Consent

I have read this form and the research study has been explained to me earlier, through an online presentation by the PI. Yes/No

I have been given the opportunity to ask questions via phone. Yes/No

My questions have been answered. Yes/No

If I have additional questions, I have been told whom to contact.

Yes/No

By Clicking on Submit, you provide your consent to participate in the study.

____________________________________ ________________

Name of Researcher Date

Appendix F
Interview Guide for Family Caregivers

Title of Study	**Exploring the Experiences of Family of Persons Living with Advanced Cancer in Ghana**
Principal Investigator	Bisi Adewale (PhD student) Faculty of Nursing University of Alberta adewale@ualberta.ca Phone:+233266507628
Co-Supervisors	Dr. Anna Santos Salas, Faculty of Nursing, University of Alberta. avs@ualberta.ca Dr. Wendy Duggleby, Faculty of Nursing, University of Alberta. wduggleb@ualberta.ca

As explained in the information sheet, this interview will last for 45-60 minutes and you will be asked questions pertaining to your experiences with caring for the person with advanced cancer. The information you provide is very important for the completion of this project. It is anticipated that information gathered will help develop a program to support the family caregivers to improve the implementation palliative care in Ghana.

1. Can you describe how a typical day is for you as a family caregiver of a person living with advanced cancer?

Probes:

- Does performing this role daily create any inconveniences for you in a way?
- What does a good day look like for you?
- What does a bad day look like for you?

2. Are there any challenges you have been experiencing as a family caregiver for a person living with advanced cancer? What might they be?

Probes:

- Does performing your roles affect your job?
- Do you receive any help from other family members?
- How are you able to manage your time as a family caregiver?
- What are the challenges regarding finances, accommodation, transportation, and family support with the care of your relative.

3. Do you know of any support services available to you as a family caregiver for a person living with advanced cancer?

Probes:

- Do you have an idea of any support services from the hospital, or health care professional located at the Community based Health Planning and Services (CHPS)?
- Are there any support services available to you from other family members and the community (district health, church, neighbours, and friends)?
- Do you know of any NGO that provides support services such as the Reach for Recovery**?**

4. How accessible are these support services to you as a family caregiver for a person living with advanced cancer?

Probes:

- Do you have access to information on these support services easily?
- How far do you have travel to access these services?
- Are these services free or at a fee?

5. What does your experience of caregiving for your family member mean to you?

Probes:

- Is your culture linked to the role you are performing in anyway?
- What do you think about this responsibility personally?

6. Is there anything else you would want to say?

Thanks for participating in the study.

Appendix G
Guide for Focus Group Discussion

Title of Study	**Exploring the Experiences of Family of Persons Living with Advanced Cancer in Ghana**
Principal Investigator	Bisi Adewale (PhD student) Faculty of Nursing University of Alberta adewale@ualberta.ca Phone: +233266507628
Co-Supervisors	Dr. Anna Santos Salas, Faculty of Nursing, University of Alberta. avs@ualberta.ca Dr. Wendy Duggleby, Faculty of Nursing, University of Alberta. wduggleb@ualberta.ca

As explained in the information sheet, this focus group will last for 60-90 minutes and you will be asked questions based on your perspectives on the experience of the family caregivers of persons living with advanced cancer. Your knowledge is very important for the completion of this project. It is anticipated that information gathered will help develop a program to support the family caregivers to improve the implementation of palliative care in Ghana.

Discussion questions

1. What initiated the implementation of the Palliative Care Outpatients Unit at the Korle-Bu Polyclinic?

2. In your views what do you think a typical day will be like for the family caregivers of persons living with advanced cancer?

Probes:

- What are some of the routines they are expected to perform?
- Do you think the roles they perform affect their personal lives in anyway?

3. Take a moment to recollect. What are the challenges you perceive family caregivers of persons living with advanced cancer face in general?

Probes:

- Do you think family caregiver experience any psychosocial challenges?
- Are there any financial and spiritual challenges family caregivers are likely to experience?

4. What services do you perceive are available to family caregivers of persons living with advanced cancer? From experience how accessible are these services?

Probes:

- Does the hospital have any support services available for family caregivers?
- Are family caregivers in anyway supported by health care professional at the CHPS compound?

- Do family caregivers receive any form of support from other family members, community, neighbours, and NGO's?

5. What are the support and services needed for family caregivers?

6. In your views, in what ways do you think the local or family culture influences the roles of being a family caregiver?

Probes:

- What is the impact of social or cultural expectations?
- In what ways do individual family caregivers' cultural value and norm dictate their responsibilities in providing care?

7. Is there anything else anyone would like to say?

Appendix H
Confidentiality Agreement

Title of Study	**Exploring the Experiences of Family Caregivers of Persons Living with Advanced Cancer in Ghana**
Principal Investigator	Bisi Adewale (PhD student) Faculty of Nursing University of Alberta adewale@ualberta.ca Phone: +233266507628
Co-Supervisors	Dr. Anna Santos Salas, Faculty of Nursing, University of Alberta. avs@ualberta.ca Dr. Wendy Duggleby, Faculty of Nursing, University of Alberta. wduggleb@ualberta.ca

I ………………………………………….. have been asked by Bisi Adewale to assist with study activities.

I agree to –

1. Keep all the research information shared with me confidential by not discussing or sharing the research information in any form or format (e.g., disks, tapes, transcripts) with anyone other than the Researcher.

2. Keep all research information in any form or format (e.g., disks, tapes, transcripts) secure while it is in my possession.

3. Return all research information in any form or format (e.g., disks, tapes, transcripts) to the Researcher when I have completed the research tasks.

4. After consulting with the Researcher, erase or destroy all research information in any form or format regarding this research project that is not returnable to the Researcher (e.g., information stored on computer hard drive).

5. Other (specify).

……………………………………….. …………………………………… ……………………………..

(Print Name) (Signature) (Date)

Researcher
…………………………………………… ………………………………………..
…………………..
(Print Name) (Signature)
(Date)

The plan for this study has been reviewed for its adherence to ethical guidelines and approved by Research Ethics Board REB 1 at the University of Alberta and the research Ethics board at the Korle-Bu Teaching Hospital. For questions regarding participant rights and ethical conduct of research, contact the University of Alberta Research Ethics Office at +1 (780) 492-2615 or the Korle-bu Teaching Hospital Research Ethics office at + 233 (302) 739510.

Appendix I
Email Message to Health Care Professionals

Title of Study	**Exploring the Experiences of Family Caregivers of Persons Living with Advanced Cancer in Ghana**
Principal Investigator	Bisi Adewale (PhD student) Faculty of Nursing University of Alberta adewale@ualberta.ca Phone: +233266507628
Co-Supervisors	Dr. Anna Santos Salas, Faculty of Nursing, University of Alberta. avs@ualberta.ca Dr. Wendy Duggleby, Faculty of Nursing, University of Alberta. wduggleb@ualberta.ca

Dear Colleague,

My name is Bisi Adewale a Ph.D. Nursing Student at the University of Alberta. I would like to invite you to participate in my doctoral study titled: **Exploring the Experiences of Family Caregivers of Persons Living with Advanced Cancer in Ghana**. If you would like to take part in this study, please review the consent form by clicking on the link provided below.

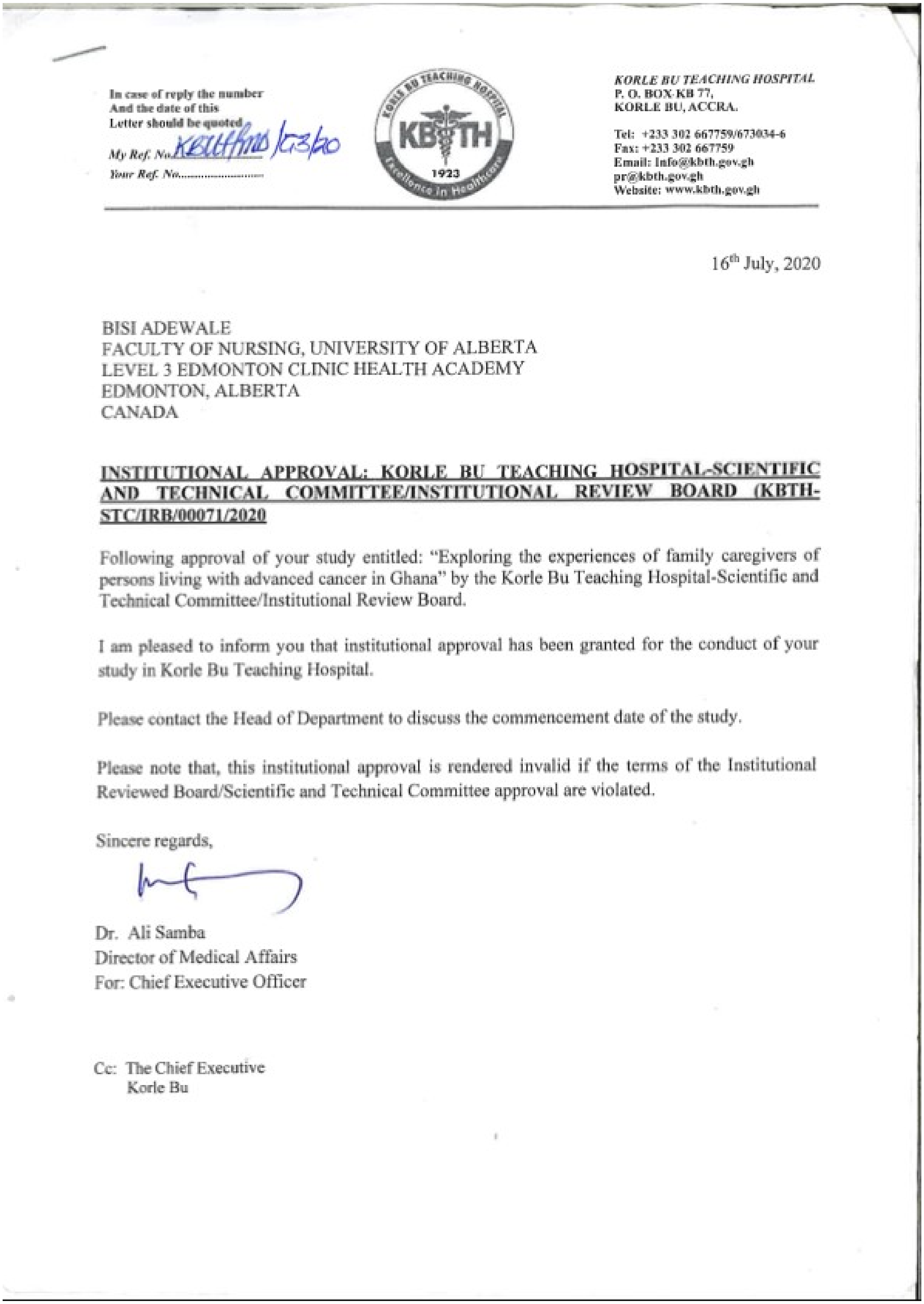
This link will take you to a secure Google form hosted by the University of Alberta Google Suite. This form contains the information letter and informed consent. At the end of the form, you will have an option to submit the form. This will indicate you have consented to participate in the study.

Should you wish to discuss the study before consenting, please feel free to contact me at your earliest convenience via email at adewale@ualberta.ca or via phone at +233-266-507628.

Thank you in advance for your time, and voluntarily accepting to participate.

Regards

Bisi



In case of reply the number
And the date of this
Letter should be quoted
My Ref. No. KBTH/IMS/ 3/20
Your Ref. No.........................

KORLE BU TEACHING HOSPITAL
P. O. BOX KB 77,
KORLE BU, ACCRA.

Tel: +233 302 667759/673034-6
Fax: +233 302 667759
Email: Info@kbth.gov.gh
pr@kbth.gov.gh
Website: www.kbth.gov.gh

16th July, 2020

BISI ADEWALE
FACULTY OF NURSING, UNIVERSITY OF ALBERTA
LEVEL 3 EDMONTON CLINIC HEALTH ACADEMY
EDMONTON, ALBERTA
CANADA

INSTITUTIONAL APPROVAL: KORLE BU TEACHING HOSPITAL-SCIENTIFIC AND TECHNICAL COMMITTEE/INSTITUTIONAL REVIEW BOARD (KBTH-STC/IRB/00071/2020

Following approval of your study entitled: "Exploring the experiences of family caregivers of persons living with advanced cancer in Ghana" by the Korle Bu Teaching Hospital-Scientific and Technical Committee/Institutional Review Board.

I am pleased to inform you that institutional approval has been granted for the conduct of your study in Korle Bu Teaching Hospital.

Please contact the Head of Department to discuss the commencement date of the study.

Please note that, this institutional approval is rendered invalid if the terms of the Institutional Reviewed Board/Scientific and Technical Committee approval are violated.

Sincere regards,

Dr. Ali Samba
Director of Medical Affairs
For: Chief Executive Officer

Cc: The Chief Executive
Korle Bu

UNIVERSITY OF ALBERTA

RESEARCH ETHICS OFFICE

308 Campus Tower
Edmonton, AB, Canada T6G 1K8
Tel: 780.492.0459
uab.ca/reo

Notification of Approval

Date:	April 14, 2020
Study ID:	Pro00096564
Principal Investigator:	Bisi Adewale
Study Supervisor:	Anna Santos Salas
Study Title:	Exploring the Experiences of Family Caregivers of Persons Living with Advanced Cancer in Ghana.
Approval Expiry Date:	Tuesday, April 13, 2021

Approved Consent Form:

Approval Date	Approved Document
4/14/2020	Consent Health Care Professionals Clean 8th April V3.docx

Thank you for submitting the above study to the Research Ethics Board 1. Your application, including the following, has been reviewed and approved on behalf of the committee;

- Recruitment Script - new 11 March V2
- Demographic Data for FCG (3/9/2020)
- Demographic Data for HCP (3/4/2020)
- Focus Group Guide New (3/4/2020)
- Interview Guide (3/4/2020)
- Proposal March 11 V2

Any proposed changes to the study must be submitted to the REB for approval prior to implementation. A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

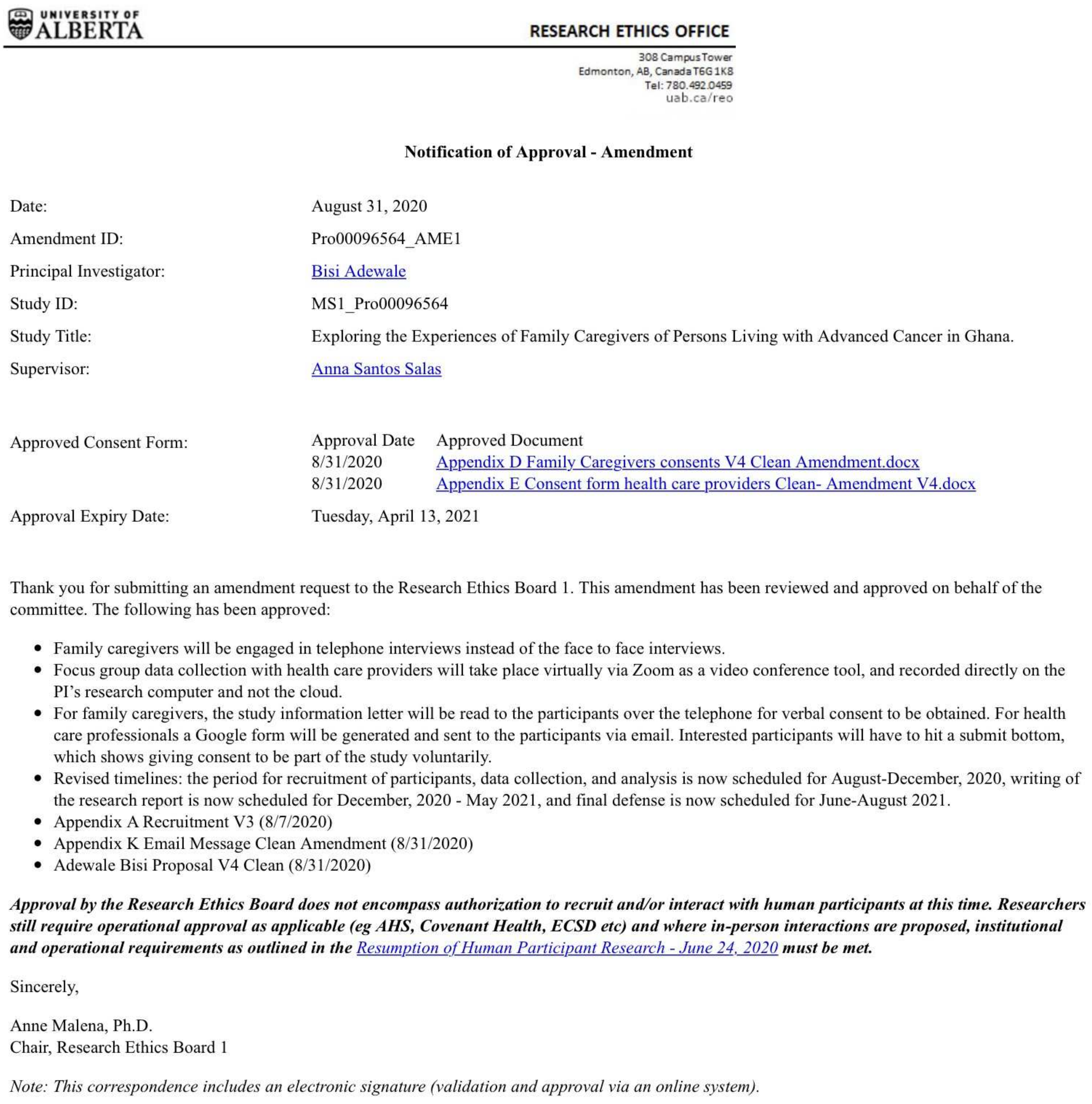
Approval by the Research Ethics Board does not encompass authorization to access the staff, students, facilities or resources of local institutions for the purposes of the research.

Approval by the Research Ethics Board does not encompass authorization to recruit and/or interact with human participants at this time. Researchers still require operational approval (eg AHS) and must meet the requirements imposed by the public health emergency (link to Alberta COVID page).

Sincerely,

Anne Malena, Ph.D.
Chair, Research Ethics Board 1

Note: This correspondence includes an electronic signature (validation and approval via an online system).



UNIVERSITY OF ALBERTA

RESEARCH ETHICS OFFICE

308 Campus Tower
Edmonton, AB, Canada T6G 1K8
Tel: 780.492.0459
uab.ca/reo

Notification of Approval - Amendment

Date:	August 31, 2020
Amendment ID:	Pro00096564_AME1
Principal Investigator:	Bisi Adewale
Study ID:	MS1_Pro00096564
Study Title:	Exploring the Experiences of Family Caregivers of Persons Living with Advanced Cancer in Ghana.
Supervisor:	Anna Santos Salas

	Approval Date	Approved Document
Approved Consent Form:	8/31/2020	Appendix D Family Caregivers consents V4 Clean Amendment.docx
	8/31/2020	Appendix E Consent form health care providers Clean- Amendment V4.docx

Approval Expiry Date: Tuesday, April 13, 2021

Thank you for submitting an amendment request to the Research Ethics Board 1. This amendment has been reviewed and approved on behalf of the committee. The following has been approved:

- Family caregivers will be engaged in telephone interviews instead of the face to face interviews.
- Focus group data collection with health care providers will take place virtually via Zoom as a video conference tool, and recorded directly on the PI's research computer and not the cloud.
- For family caregivers, the study information letter will be read to the participants over the telephone for verbal consent to be obtained. For health care professionals a Google form will be generated and sent to the participants via email. Interested participants will have to hit a submit bottom, which shows giving consent to be part of the study voluntarily.
- Revised timelines: the period for recruitment of participants, data collection, and analysis is now scheduled for August-December, 2020, writing of the research report is now scheduled for December, 2020 - May 2021, and final defense is now scheduled for June-August 2021.
- Appendix A Recruitment V3 (8/7/2020)
- Appendix K Email Message Clean Amendment (8/31/2020)
- Adewale Bisi Proposal V4 Clean (8/31/2020)

Approval by the Research Ethics Board does not encompass authorization to recruit and/or interact with human participants at this time. Researchers still require operational approval as applicable (eg AHS, Covenant Health, ECSD etc) and where in-person interactions are proposed, institutional and operational requirements as outlined in the Resumption of Human Participant Research - June 24, 2020 must be met.

Sincerely,

Anne Malena, Ph.D.
Chair, Research Ethics Board 1

Note: This correspondence includes an electronic signature (validation and approval via an online system).

UNIVERSITY OF ALBERTA
RESEARCH ETHICS OFFICE

2-01 North Power Plant (NPP)
11312 - 89 Ave NW
Edmonton, Alberta, Canada T6G 2N2
Tel: 780.492.0459
www.uab.ca/reo

Notification of Approval (Renewal)

Date:	March 18, 2021
Amendment ID:	Pro00096564_REN1
Principal Investigator:	Bisi Adewale
Study ID:	MS2_Pro00096564
Study Title:	Exploring the Experiences of Family Caregivers of Persons Living with Advanced Cancer in Ghana.
Supervisor:	Anna Santos Salas
Approval Expiry Date:	Thursday, March 17, 2022

Thank you for submitting this renewal application. Your application has been reviewed and approved.

This re-approval is valid for one year. If your study continues past the expiration date as noted above, you will be required to complete another renewal request. Beginning at 30 days prior to the expiration date, you will receive notices that the study is about to expire. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the Research Ethics Board does not encompass authorization to recruit and/or interact with human participants at this time. Researchers still require operational approval as applicable (eg AHS, Covenant Health, ECSD etc) and where in-person interactions are proposed, institutional and operational requirements as outlined in the** Resumption of Human Participant Research - June 24, 2020 **must be met

Sincerely,

Charmaine Kabatoff, REB Consultant, for

Anne Malena, Ph.D
Chair, Research Ethics Board 1

Note: This correspondence includes an electronic signature (validation and approval via an online system).

2022-03-28, 7:29 PM

Notification of Approval (Renewal)

Date:	February 28, 2022
Amendment ID:	Pro00096564_REN2
Principal Investigator:	Bisi Adewale
Study ID:	MS3_Pro00096564
Study Title:	Exploring the Experiences of Family Caregivers of Persons Living with Advanced Cancer in Ghana.
Supervisor:	Anna Santos Salas
Approval Expiry Date:	February 27, 2023

Thank you for submitting this renewal application. Your application has been reviewed and approved.

This re-approval is valid for one year. If your study continues past the expiration date as noted above, you will be required to complete another renewal request. Beginning at 30 days prior to the expiration date, you will receive notices that the study is about to expire. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the REB does not constitute authorization to initiate the conduct of this research. The Principal Investigator is responsible for ensuring required approvals from other involved organizations (e.g., Alberta Health Services, Covenant Health, community organizations, school boards) are obtained, before the research begins.

Sincerely,

Kimberley Kordov, REB Specialist, on behalf of

Theresa Garvin, PhD
Chair, Research Ethics Board 1

Note: This correspondence includes an electronic signature (validation and approval via an online system).

https://arise.ualberta.ca/ARISE/sd/Doc/0/HGRL38CONC8UP7D9AM9A4LIG00/fromString.html Page 1 of 1