

**Experiences of Home-based Caregivers of Advanced Cancer Patients from a Regional
Faith-based Palliative Care Center in Kenya**

Faith Lelei

**A Thesis Presented to the Institute of Postgraduate Studies of Kabarak University in
Partial Fulfillment of the Requirements of the Award Masters of Medicine in Family
Medicine**

KABARAK UNIVERSITY

August 2019

DECLARATION

This thesis is my own work and to the best of my knowledge, it has not been presented for the award of a degree in any university or college.

Signed:

Date

Faith Lelei

GMMF/M/1197/09/15

RECOMMENDATION

To the Institute of Postgraduate Studies:

The research thesis entitled '**Experiences of Home-based Caregivers of Advanced Cancer Patients from a Regional Faith-based palliative Care Center in Kenya**' and written by **Faith Lelei** is presented to the Institute of Postgraduate Studies of Kabarak University. We have reviewed the research thesis and recommend it be accepted in partial fulfillment of the requirement for the award of the Masters of Medicine, Family Medicine.

Signed

Date

Prof. Wesley Too

Date

Dr. Mary Adam



Date

Dr. Peter Halestrap



Date

COPYRIGHT

@2017

Faith Lelei

All rights reserved. No part of this Thesis may be reproduced or transmitted in any form by means of either mechanical, including photocopying, recording or any other information storage or retrieval system without permission in writing from the author or Kabarak University.

ACKNOWLEDGMENT

First and foremost, I would like to thank the Lord for giving me the strength and grace in sufficient measure to do this thesis. Jeff, I could not have managed any of this without your steadfast support, which was present right from the very beginning. Josh and Dan, you boys are awesome! My parents and siblings: thank you for being a true family.

I would like to appreciate my supervisors, Dr. Mary Adam, Dr. Peter Halestrap and Prof. Wesley Too. I have grown as a researcher because of your efforts, encouragements and corrections and kind words.

Also, I would like to thank the micro-research team, Mitchelle Nthumba, Carol Mwangi, David Mung'ara and our coach Dr. Peris Kariuki who we began this research journey with.

The palliative team at AIC Kjabe hospital: Joel, Margaret, Eunice, Mary, and Dr. Bob Carter, you have been extremely kind to me, and very helpful. God bless each you abundantly.

DEDICATION

I would like to dedicate this work to the many family cancer caregivers who selflessly step up to care for their sick loved ones against several odds.

ABSTRACT

Cancer is the third leading cause of mortality in Kenya. Eighty percent of cancer cases present at advanced stages, when little curative care can be done and palliative care is their best option of care. Majority of the end of life care in Kenya is done in the home setting, yet little is known about the caregiver's lived experiences. This qualitative study was done with the following objectives: to explore caregivers' burdens, to identify the perceived effects of caregiving on primary caregivers and to identify perceived sources of support for caregivers. A purposive sampling method was used to recruit participants from the palliative clinic. Data was collected using 12 in-depth interviews and direct observation in the patients' home settings. A thematic analytic method was used to analyze the data. Caregiver burden in this study was mostly due to competing tasks, lack of knowledge in managing the symptoms, difficult hospital experiences and financial strains, and vulnerability for female caregivers. Consequently, caregiving had a physical, emotional, psychological and financial impact on the caregivers. Their support systems, which still do not meet caregivers needs; include family members, the neighbors and community, religious institutions, and healthcare workers. Recommendations include the establishment of coordinated efforts with the palliative care team and healthcare workers in dispensaries to support families in end of life care and to introduce the use of phones to aid in the follow up and support of caregivers. Family conferences should include sessions on how to care for and support the primary caregiver. During clinic reviews, caregivers too should be screened and supported accordingly. Further studies are needed to look into the use of telephones for follow up of caregivers, the introduction of caregiver-targeted screening tools on their quality of life and their impact on improving caregivers' well-being and the prevalence of gender-based violence among caregivers.

Key words: Home-based caregiver, Advanced cancer, End of life care

TABLE OF CONTENTS

DECLARATION	ii
RECOMMENDATION	iii
COPYRIGHT	iv
ACKNOWLEDGMENT	iv
DEDICATION	ivii
ABSTRACT	vi
ABBREVIATIONS	Error! Bookmark not defined.i
OPERATIONAL DEFINITION OF TERMS	xi
CHAPTER ONE	1
1.1 Introduction.....	1
1.2 Background to the Study.....	1
1.2.1. Cancer epidemiology	1
1.2.2. Palliative and end-of-life care	2
1.2.3 Palliative Care in Kenya	2
1.2.4 Caregiver burden.....	3
1.3 Statement of the Problem.....	4
1.4 Purpose of the study.....	4
1.5 Objectives of the study.....	4
1.6 Research questions.....	5
1.7 Justification for the Study	5
1.8 Scope of the study.....	6
1.9 Limitations of the study	6
1.10 Assumptions.....	7
CHAPTER TWO	Error! Bookmark not defined.
LITERATURE REVIEW	7
2.1 Introduction.....	8
2.2 General overview of Literature related to experiences of home-based caregivers	8
2.3 Challenges experienced by caregivers	8
2.3.1. Caregiver’s Physical needs	9
2.3.2 Caregivers’ Emotional needs	10
2.3.3 Psychological needs	10
2.3.4 Caregivers’ Financial needs.....	11
2.3.5 Spiritual needs.....	12
2.4 Effects of Caregiving on Caregivers.....	12
2.4.1 Physical effects	13
2.4.2 Ill Emotional and Psychological Health	13
2.4.3 Social strains	14
2.5 Resources and sources of support for caregivers.....	15
2.5.1 Caregivers' knowledge about existing resource.....	15
2.5.2 Provision of healthcare athome	16
2.5.3 community-based palliative care.....	16
2.5.4 Family support networks.....	17
2.5.6 Support from spiritual leaders.....	18
2.6 Conceptual Framework.....	19

CHAPTER THREE21

RESEARCH DESIGN AND METHODOLOGY21

3.1 Introduction.....21
3.2 Research Design.....21
3.3 Location Of The Study.....21
3.4 Population Of The Study22
 3.4.1 Inclusion Criteria22
 3.4.2 Exclusion Criteria22
3.5 Sampling Procedure And Sample Size22
 3.5.1 Sampling Procedure22
 3.5.2 Sample Size And Data Saturation.....23
3.6 Instrumentation24
3.7 Data Collection Procedures.....24
3.8 Data Analysis26
3.9 Enhancing Rigor27
3.10 Ethical Considerations28

Chapter 4: DATA ANALYSIS, PRESENTATION AND DISCUSSION Error! Bookmark not defined.

4.1 Introduction..... Error! Bookmark not defined.
4.2 General and Demographic Information.....30
 4.2.1 General Information.....30
 4.2.2 Demographic Data.....31
4.3 Qualitative Findings..... **Error! Bookmark not defined.**
 4.3.1 Practical Challenges Related To Competing Tasks32
 Role Overload **Error! Bookmark not defined.**
 Great Personal Sacrifice By Caregivers..... **Error! Bookmark not defined.**
 Care-Setup Preferences **Error! Bookmark not defined.**
 4.3.2 Experiences In Symptom Management **Error! Bookmark not defined.**
 Limited Knowledge In Managing Symptoms..... **Error! Bookmark not defined.**
 Difficulties In Managing Symptoms..... **Error! Bookmark not defined.**
 Anorexia..... **Error! Bookmark not defined.**
 Other Symptoms & Comorbidities39
 4.3.3 Experiences Related To Health Seeking40
 Delayed Diagnosis **Error! Bookmark not defined.**
 Challenges Related To Physical Access To Hospital .. **Error! Bookmark not defined.**
 Hospital Experiences41
 “Main Hospital” Vs. “Smaller Hospital”42
 4.3.4 Financial Deprivation Related To Cancer Care43
 Loss Of Income & Increased Expenditure.....43
 Challenges Related To The National Hospital Insurance Fund..**Error! Bookmark not defined.**
 Poor Pain Management & Quality Of Life Secondary To Financial Deprivation.....44
 4.3.5 Caregiver Well Being: Influence Of End Of Life Care45
 Physical Effects.....45
 Psychological Effects.....46
 4.3.6 Hope In The Midst Of Hopelessness47
 4.3.7 Vulnerability And Potential For Abuse For Female Carers.....47
 4.3.8 Caregivers’ Support System48
 Family & Clan Network.....48

Social And Community Network.....	Error! Bookmark not defined.
Spiritual Support	Error! Bookmark not defined.
Other Healthcare Providers.....	Error! Bookmark not defined.
4.4 Discussion	53
4:4:1 Caregiver Burden.....	53
Practical challenges related to competing tasks.....	53
Financial burden.....	55
Access to healthcare and symptoms management.....	55
Vulnerability and potential for abuse for female caregivers.....	57
Caregiver burden among males.....	58
4:4:2 Impact on caregivers.....	58
Physical Effects.....	59
Emotional and psychological.....	60
Spiritual Effects.....	60
Financial impact.....	61
4:4:3 Caregiver's support systems.....	62
Family.....	62
Social and community networks.....	63
Role of religion.....	63
Other healthcare workers.....	63
 CHAPTER FIVE	 65
SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS	65
5.1 Introduction.....	65
5.2 Summary	65
5.3 Conclusions.....	66
5.4 Recommendations.....	66
5.4.1 Policy Recommendations.....	66
5.4.2 Recommendations for further research.....	67
References.....	1
Appendix 1: Semi-Structured Interview Guide	0
Appendix 2: Informed Consent Form.....	1

ABBREVIATIONS

AIC	Africa Inland Church
AIDS	Acquired Immune Deficiency Syndrome
HIV	Human Immunodeficiency Virus
IV	Intravenous
KEHPCA	Kenya Hospice and Palliative Care Association
W.H.O	World Health Organization
HIV	Human Immunodeficiency Virus
KEMRI	Kenya Medical Research Institute
NHIF	National Hospital Insurance Fund

OPERATIONAL DEFINITION OF TERMS

Primary Caregiver: This is an informal, unpaid, family member who is responsible for the care of the patient.

Caregiver burden: This is the stress or strain that caregivers feel as a result of taking care of the patients.

CHAPTER ONE

1.1 Introduction

This chapter includes the background, statement of the problem, the purpose of the study, the objectives, research question, justification of the study, the scope, limitations of the study, and the pre-understanding.

1.2 Background to the Study

1.2.1. Cancer epidemiology

The global and local burden of cancer is increasing. It is a leading cause of death worldwide. According to the World Health Organization (WHO), cancer accounted for 8.8 million deaths in 2015 (WHO, 2018). WHO (2018) reckon that 70% of the cancer burden in the world is in sub-Saharan Africa. It is the third cause of mortality in Kenya with an annual incidence of 28 000 per annum, and 22, 000 dying in Kenya each year due to cancer according to the Kenya National Cancer Control Strategy (2011). Over 60% of those affected are below the age of 70 years. It is important to note that population-based data does not exist in the country. Therefore, it is possible that these figures underestimate the actual incidence and mortality in Kenya.

The Kenya Medical Research Institute (KEMRI), (2011) report that 80% of the cancer patients present in terminal stages. At this stage, curative care is unlikely, and palliative care is their best option. WHO (2007) underscore that palliative care is a humanitarian urgency for individuals with life-limiting illnesses to reduce unnecessary suffering for both patients and caregivers.

1.2.2. Palliative and end-of-life care

Palliative care, as defined by WHO (2002), is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

End of life care is part of the continuum of palliative care, especially in the last year of the patient's life. However, this timeline is generally difficult to predict accurately. The Kenya National Palliative Care Guidelines (2011) defines the end of life care as "special time before death when the patient and family require holistic support." It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It often includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support. Notably, one cannot discuss end of life care and omit the caregivers. The family members are always included.

1.2.3 Palliative Care in Kenya

Palliative care in Kenya has been growing over the past few years. The Kenya Hospice and Palliative Care Association (KEHPCA) 2015-report notes that they have managed to scale up palliative care services around the country. Currently, they have over 60 sites offering palliative care either within a hospital context or as a stand-alone facility. Majority of these offer out-patient services. Only three units offer inpatient hospice services in our setting with a cumulative total of fewer than fifty beds. This ultimately transfers the burden of end-of-life care to family members, who many a time are not well equipped or prepared to handle the challenges that come with taking care of the terminally ill. From a patient perspective, Downing et al. (2014) found that most Kenyans preferred to receive their end of life care at

home, and even die at home, based on a Kenyan population-based street survey.

1.2.4 Caregiver burden

Caregiver burden has been defined as the type of stress or strain that caregivers experience related to the problems and challenges they face as a result of the status of the care recipient. It is the state resulting from necessary caring tasks or restrictions that cause discomfort for the caregiver (Zarit, Reever, & Bach-Peterson, 1980).

There are several studies in resource-rich settings that have described the caregiver burden and the effects of caregiving on their caregivers. The sources of caregiver burden in those settings have been broadly categorized into physical, emotional, spiritual, psychosocial and financial. The caregiver burden has been shown to have ill effects on the health of the caregivers: physically, emotionally, mentally and psychologically. Evidence-based caregiver interventions are well documented, as well as resources available to caregivers (Harding & Higginson, 2003).

On the contrary, the caregiver unmet needs, the effects they experience as a result of caregiving, and potential resources and sources of support largely remain unknown in the East African setting. However, research into palliative and cancer care in Africa is now growing. The few studies on caregiver burden and effects of caregiving on caregivers in Africa have been done in Southern Africa and Western Africa, and previously have focused on HIV/AIDS. A PubMed search using the terms “Africa”, “Advanced cancer” and “caregivers” yielded 9 articles, 2 of which were published in 2018. None of the studies were from East Africa. This serves to show the dearth of literature in this setting on the subject of advanced cancer caregivers in East Africa.

1.3 Statement of the Problem

There is a growing burden of cancer in the Kenya. Majority of the patients present in their terminal stages when palliative care is their best option. With the limited inpatient hospices, the burden of end of life care in Kenya falls mostly on the family members. We have limited data in our settings on family members lived experiences: their challenges, their caregiving effects and their sources of support. The caregiver's well-being is important for them to be able to provide quality care for their dying relatives. Overwhelmed caregivers lead a poor quality of life, and it does have a bearing on the quality of care to the patients and with possible lower quality of life for the patient as well (Litzelman, Kent, Mulika & Rowland, 2016). The main beneficiaries of this study will be the cancer patients themselves, the informal/home-based caregivers, and all stakeholders involved in cancer care.

1.4 Purpose of the study

The purpose of this study is to explore the caregivers' lived experiences while taking care of their family member, the effects of caregiving of the caregivers, and their perceived sources of support.

1.5 Objectives of the study

The specific objectives of the study are as follows:

1. To explore challenges perceived by primary caregivers
2. To identify the perceived effects of caregiving on the caregivers
3. To describe perceived sources of support for primary caregivers

1.6 Research questions

1. What challenges do caregivers of advanced cancer patients from AIC Kijabe Hospital go through?
2. What are the effects of caregiving on caregivers of advanced cancer patients from AIC Kijabe Hospital?
3. What do the caregivers of advanced cancer patients from AIC Kijabe Hospital consider as their sources of support?

1.7 Justification for the Study

Research from the resource-rich settings has shown the extent of caregiver burden and the effects of caregiving on the caregiver. In Africa, research in palliative care has often focused on HIV/AIDS patients. Furthermore, the focus has been more on the patients, and less on the caregivers. End of life care in Kenya is mostly offered in the patient's home settings, as there are extremely few inpatient hospice beds in the country. Despite this, little is known about the cancer caregivers' lived experiences: the caregiving burden, the effect of caregiving on them and their sources of support.

This study will be of direct benefit to the patients and caregivers who will participate in this study. They will benefit from a home visit, and an extended and undivided palliative care consult in their own homes, without the hustle of travel to the hospital. Upon completion of the study, other cancer caregivers in the palliative clinic will benefit from the information gained, particularly regarding how to improve their quality of life and the care they provide. The second group who will benefit from the studies will be healthcare workers and other participants of cancer care in AIC Kijabe Hospital. This study will inform them of the lived

experiences of cancer caregivers in our setting. This information will help shape and inform the care they give to not only the patients but also the caregivers.

The findings of this study can also be extrapolated to similar settings in this country, and where it's not possible; it will serve as a guide for similar studies to be replicated in other settings. It will also provide useful information to KEHPCA and other palliative bodies in this region on the lived experiences of cancer caregivers and aid the development of guidelines on the care of cancer caregivers.

1.8 Scope of the study

The participants of this study were drawn from AIC Kijabe Hospital, which is in Kiambu County. Kijabe Hospital, including the palliative department, receives patients from all over the country, and even out of the country.

1.9 Limitations of the study

Our study excluded caregivers of paediatrics with cancers. This was due to the assumption based on literature that the experiences of paediatrics end of life care are different from those of adults (Benini, Spizzichino, Trapanotoo & Ferrante, 2008). Hence the researcher assumed that the approach to end of life care for the paediatrics may be different from those of the adults. However, we cannot definitively reach such a conclusion until a similar study is done on the caregivers of paediatrics in our setting.

Kijabe is only one of more than 60 sites and may have a patient selection bias that limits generalization of the results to palliative care in Kenya. In addition, time and resources to

expand this study to caregivers in other hospitals and settings was also a limitation, which may also affect the ability of this study to be generalizable to a wider populace.

Palliative care is broad and includes the end of life care for a wide variety of illnesses. However, this study will specifically look at caregivers of advanced cancer patients. It is not clear at the outset if the results of this study will be generalizable to caregivers of patients with other life-threatening illnesses.

1.10 Assumptions

The researcher assumed that the participants would welcome the researchers into their homes and provide honest responses to the interview questions. The second assumption was that the inclusion criteria of the sample would be appropriate and assured that the participants all have the experience of caring for patients with advanced cancers. The final assumption that the researcher made was that the participants would have a sincere interest in participating in the research, and not merely in the home visit by palliative care providers.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

This chapter shall include a general overview of literature related to the main concepts as well as a review of literature based on each of the four objectives. The chapter ends with a conceptual framework.

2.2 General overview of Literature related to experiences of home-based caregivers

This study seeks to find out the perceptions and the experiences of home-based caregivers offering end of life care for advanced cancer patients. Caregivers, for purposes of this study, shall be defined as persons who provide uncompensated care to their family members. Their tasks usually include assisting with activities of daily living, administering medication, managing symptoms such as pain and watching out for adverse events (Ryn et al, 2011). Other caregiving tasks include home management, meal preparation, and transportation, helping the patient with ambulation, dealing with stool or urine incontinence, managing finances, and other tasks.

2.3 Challenges experienced by caregivers

The first objective of this study is to identify the challenges perceived by primary caregivers. In general, Kim and Schultz (2008) found that cancer caregivers have been found to report higher burden than caregivers for individuals with dementia, diabetes or frail elders.

An American survey by Kim and his colleagues identified the following main areas of unmet caregiver needs and concerns: psychosocial, financial, medical and activities of daily living (Kim, Kashy, Spillers & Evans, 2010). A study done in India described and summarized five things that caregivers of advanced cancer patients in their setting needed: Medical needs,

psychological needs, financial needs, information needs, and social needs were the unmet needs (Joad, Mayamoi & Chaturvedi, 2011). In Nigeria, Akpan-Idiok & Anarado (2014) found that caregivers of cancer patients experienced different burden levels, with about half of the study participants terming their burden level as being severe. The same study showed that the forms of burden experienced were physical, psychological financial, and social. Studies reviewed report five main areas of caregiver unmet needs: physical, emotional, psychosocial, financial and spiritual.

2.3.1. Caregiver's Physical needs

Streid, Harding, Agupio, Dinat, Downing J, Gwyther L,& Selman (2014) interviewed primary caregivers of patients with incurable progressive illnesses, (the majority with HIV, few with cancer) in Uganda and South Africa. They found that one of the significant stressors for caregivers was just day-to-day patient care. Informal caregivers of patients dying at home in South Africa reported challenges with practical functional care. (O'Neil, Prigerson, Mmoledi, Sobekwa, Ratshikana-Moloko, Tsitsi..... & Blanchard, 2018).

Caregiving is a 24-hour job, as some patients require care even at night. Feeding, lifting, bathing, turning the patient day after day amongst other is exhausting. Some caregivers report back pains, which are mostly mechanical in nature and due to the strenuous work they do. This job can be done for several months depending on the stage of disease and the patients' prognosis.

Maltby and his colleagues in their systematic review found that at least 72% of caregivers had moderate to severe sleep disturbances (Maltby, Sanderson, Lobb & Phillips, 2017). The sleep disturbance could arise from sleep interruptions due to the need for taking care of the

patient at night. It could also be attributed to the psychological impact of taking care of a very sick loved one or as a sign of depression.

The fatigue and physical strain could also be brought about by the fact that the caregivers are often not just taking care of one person alone. In the study by van Ryn, *et al* (2015), 21% of the caregivers surveyed took care of at least one other individual and 49 % were still employed.

2.3.2 Caregivers' Emotional needs

A qualitative study was conducted in South Africa to find out the experiences of family caregivers of cancer patients using the Public Health System in South Africa. One of their three themes was the emotional response towards the cancer diagnosis and caregiving. The caregivers in that study reported that they were overwhelmed, emotionally broken, and felt that they were alone in the caregiving journey. They also said that they felt that the rest of the family was uncaring (Cur, Moshima, Ngubeni & Zondi, 2017).

Streid *et al*, (2014) identified a lack of emotional support for the caregivers as one of the primary stressors as well. The caregivers had to deal not only with their own emotional distress but also that of their sick patients. Even in terms of providing care, the caregivers in the study by Ryn, *et al* (2015) reported that they were very confident about the physical care they were providing for their patients and felt much less confident about the care of their patients' emotional needs.

2.3.3 Psychological needs

Psychological concerns, both of the caregiver and the patient, are important when considering the well-being of the caregiver. The caregivers often take on the psychosocial aspects of caregiving, sometimes without acknowledgment from the patient or other family members. In

Singapore, it was found that informal caregivers in their setting experienced high caregiver burden with adverse effects on their mental health, and their quality of life (Chua, *et al.*, 2016). Akpan- Idiol, *et al* (2014) demonstrated that the greatest burden in their setting for the caregivers was in the psychosocial domain.

The psychological unmet needs also vary across the patients' stage of illness. Their psychological needs at the time of diagnosis of disease, a treatment phase and during the end of life may be different. It is of essence that healthcare workers be cognizant of this fact so that they can actively screen and examine caregivers for any psychological needs or social stressors that need to be addressed.

2.3.4 Caregivers' Financial needs

Even in settings where healthcare is socialized and provided for by the government, there is still a significant financial strain. In Italy, research by Rossi, *et al*, (2007) revealed that 26% used most or all of their savings in caring for their loved ones. In Singapore, Chua, *et al* (2016) noted that financial strains increased the number of roles that a caregiver had to undertake thereby increasing the caregiver burden. Financial burdens were still identified as a stressor in the study by Streid *et al* (2014) in both Uganda and South Africa. Adol's study (2011) in Kenyatta showed a statistically significant relationship between finances and depression. The more financially strained a caregiver was, the higher the likelihood the caregiver would experience depressive symptoms.

The financial strain arises from two main reasons. The first is the loss of income first from the patient, and then by a caregiver, as some have to abandon their careers or work so that they can focus on caring for the patient. For some, the caregiving role reduces their opportunities for career advancement. The second reason is the increase in medical expenses.

This is rife in Kenya, especially in a population where 82% of women and 78% of men do not have access to any form of health insurance (Kenya Demographic and Health Survey, 2014). It is not uncommon to hear of “*Harambees*”¹ in Kenya where family members and communities gather together to fundraise for a sick patient. Social media has also been used as a tool for fundraising for patients with all manner of diseases requiring further care.

2.3.5 Spiritual needs

Whole person care demands that the spiritual component should not be overlooked. Selman, *et al.* (2018) conducted a study in nine countries, Kenya included, exploring the spiritual care needs, experiences, preferences and research priorities of patients with life-limiting diseases and their caregivers. They found that spiritual care, according to both patients and caregivers, is neglected across all the nine countries that participated in the study. The perceived reasons for the neglect of spiritual care were that caregivers were either not well equipped to discuss it, or that they did not prioritize it. The caregivers expressed need to have their spiritual needs attended to by either healthcare workers or religious leaders.

2.4 Effects of Caregiving on Caregivers

The second objective of this study is to identify the perceived effects of caregiving on primary caregivers. The caregivers are an integral part of the care team, and they play a critical role in providing care and support for their relatives at home. It is important to understand how caregiving affects them, so as to know how to take care of the caregiver.

Kurtz and his colleagues found that the personal perceptions of the caregiving experience-impact on schedule, social functioning, and abandonment-played a central role as

¹ Harambee is Kiswahili word that means “to pull together”. It is a Kenyan tradition where communities come together to raise funds for a charitable cause.

determinants of caregiver outcomes especially regarding depression and physical health (Kurtz M., Kurtz J., Given W., & Given B., 2014). Those who felt that their personal schedule was greatly interfered with abandoned by family members and those who experienced limitations in their social activities were more likely to get depressed and experience ill physical health.

2.4.1 Physical effects

Sternberg, Ruland, and Miaskowski (2010) in their systematic review found more than 200 problems and burdens related to caregiving responsibilities in literature. They were broadly categorized as physical, social, and emotional and the burden related to caregiving. The most common physical problems included fatigue, weight loss, pain, and loss of physical strength, loss of appetite and sleep disturbances.

The caregiving burden literally takes a toll on the physical health of the caregivers. Higher morbidity has been documented among caregivers of patients in western settings. In fact, Schulz and Beach (1999) report that mental and emotional strain in elderly caregivers is an independent risk factor for mortality. One of the reasons given for this is that the caregivers do not have sufficient time for their own self-care.

2.4.2 Ill Emotional and Psychological Health

Ill emotional health has also been reported to result from caregiving. The most common experiences are depression and anxiety according to Sternberg, *et al* (2010). Studies comparing the rates of depression and anxiety between caregivers and patients found that caregivers were more stressed and anxious (Sklenarova, *et al.*, 2015). Spouse caregivers are a

high-risk group for depression (Braun, Mikulincer, Rydal, Walsh & Rodin, 2007). In one National referral hospital in Kenya, Adol (2014) found the prevalence of depression to be 62.7% among caregivers of palliative patients, four times higher than in the general population. In her study, spouses and those who had been caregiving for longer periods of time had the greatest risk for depression.

Beyond depression and anxiety, caregivers also experience other difficult emotions related to caregiving such as uncertainty, hopelessness, and the fear of death. They are uncertain about the care they are providing, uncertain about the future, uncertain about what to do with finances or the lack of it, uncertain about what the patient really needs, uncertain about many things. Some of them struggle with anticipated grief because of the hopelessness they feel about their patients' condition. They are concerned about what will happen after the patient they are taking care of dies. The fear of death and how or where it occurs may be stressful for the caregiver. It has sometimes been described as a "roller coaster of emotions."

However, not all emotional experiences of caregiving are negative. One study reports that some caregivers actually appreciated the increased time spent together while caring for their patients (Sternberg, *et al.*, 2010). Others felt good about the role they played, while others said they found a purpose and meaning. This observation is also present in the study by Akpan-Idiok, *et al* (2014). For other caregivers, caregiving gave them a great sense of satisfaction, and despite the strains experienced, they did not regret caring for their patients.

2.4.3 Social strains

There are also social strains that occur as a result of caregiving. The caregivers in the study by Maree and her colleagues reported that it was a significant sacrifice to step in to care for

their loved ones. The caregivers say they had to put their lives on hold to be able to care for the patient. They made sacrifices involving their children, work, possible relationships and their normal activities (Maree, Moshima, Ngubeni & Zondi, 2017).

In a different study, the majority of the caregivers did not have time to attend social gatherings or meet with other family members to socialize (Joad, *et al*, 2011). The inability to attend to other social obligations certainly has the potential to cause distress. Obligations such as parenting, spousal support, their children's well-being, and studies and others when not met in the long run can lead to dysfunctional families if not well handled.

The reason it is important to evaluate the effects of caregiving on the caregiver is that it does have an impact on the patient. Litzelman, Kent, Mulika, and Rowland (2016) established that patients whose caregivers had depression or depressive symptoms felt that they experienced poor quality of care. The National Palliative guidelines (2015) in their document assert that healthcare workers need to optimize the general health of caregivers so that they can offer a higher quality of care for their loved ones.

2.5 Resources and sources of support for caregivers

2.5.1 Caregivers' knowledge about existing resources

The third objective is to identify perceived sources of support for primary caregivers. Burns, Dixon, Smith, and Craft (2004) in Australia showed that many of the caregivers were unaware of the support services available to them, underutilized the services. This was attributed to systemic and regional weaknesses in communication between the support systems and families. It would be unfortunate to have services and resources to improve the experiences of the caregivers, and they don't access it due to lack of knowledge on their

existence. There needs to be a relevant and effective means of informing caregivers the resources available to them. At the point of enrolment into palliative care, the patients and their family members need to be sensitized on all the resources and potential resources available to them.

2.5.2 Provision of health care at home

The study by Joad, *et al* (2011) found that the caregivers felt that they would have benefited from the greater physical presence of the healthcare providers in the home setting. This was because they felt inadequate to provide the care their patients needed, and they felt their patients would have received better care from the professionals. Some of the direct medical care such as changing dressing and pressure sores, attending to symptoms like pain and nausea would be easier for a healthcare provider. Some were anxious about what to do if their patient worsened at home or who to turn to in case of a medical emergency. It is appreciable why the caregivers would desire the more physical presence of healthcare providers, particularly if they have not received enough training on caring for the patients. This is where home visits by palliative teams are particularly useful. The main challenge with them is that they may be few and far apart, and fail to satisfactorily meet the needs of the caregivers and the patients.

2.5.3 Community-based palliative care

There have been efforts to involve the community through community health volunteers in offering end of life care at the community level. In Uganda, Jack, *et al* (2011) reported about the impact of a community volunteer program to HIV/AIDS palliative patients. These were volunteers trained to provide support to patients in their home settings. It was noted to have a positive impact on the patients, families and the hospice team. The Kenya National Cancer

Control Strategy (2011) in its document underscores the need to strengthen home-based palliative services. This too is echoed by the National palliative care guidelines (2015).

The National palliative care guidelines (2015), advocate for palliative care to be offered by a multidisciplinary team to cater to all domains affecting the patients, caregivers, and their families. They, however, do not mention the players in the multidisciplinary team. The document reads;

Carers shall be provided with adequate resources for patient care. Regular team meetings and social gatherings shall be promoted to help reduce stress and burnout. Supervision, training and support shall be provided to health workers, family and community members. (National Palliative Care Guidelines, 2015, p 22).

The extent to which this has been achieved at a county or national level is not known.

2.5.4 Family support networks

While some caregivers experienced stress from their family members and their communities, Streid, *et al* (2014) also noted something contrary. He found that some caregivers drew a lot of support from their families, communities. This support was in form of help doing day-to-day activities and in material gifts. Those that enjoyed a healthy patient-caregiver relationship also enjoyed rewarding interactions and were less likely to be psychologically distressed. In India, the source of strength and support besides religion is family members (Joad, *et al*, 2011).

2.5.6 Support from spiritual leaders

Majority of Kenyans are religious, with 82% being Christians and 11% Muslims (Kenya National Bureau of statistics, 2013). Many people, in difficult times, turn to religion. Some use religion to explain their illness. Others blame God or whoever Superior Being they worship whilst others draw strength from their religion during hard times. It is not uncommon in our Kenyan settings to find patients and their families seeking prayer when someone is unwell. Some religious leaders even conduct prayers at the patients' homes, either by invitation of the family or the leaders' own conviction to visit their sick congregants.

In the study by Maree, *et al* (2017), many caregivers said that they turned to religion and religious practices as a coping mechanism. Selman, *et al* (2018) reported that patients and their caregivers' valued spiritual care from both health care providers and religious leaders. Their preferences on who should provide spiritual care were dependent on the individual patient or caregivers' preference, the severity of the distress or the skills of the healthcare provider. Nonetheless, the caregivers expressed desire in having healthcare workers who were competent in the provision of spiritual care, which they felt was a lacking component.

It is worth appreciating that what may work for one caregiver and their family may not be helpful for another. The support needs to be individualized to know what they need and bridge the gap based on their unmet needs.

In summary, the above literature review shows the extent of research in resource-rich settings on caregivers' experiences and the paucity of the same in our setting. Physical, spiritual, psychological, emotional and financial needs contribute to the caregivers' burden, which

ultimately affects the caregiver's health. The few studies that have been done in Southern and Western Africa reveal some similarities with the Western countries on the caregiver burden and caregiving effects. The potential resources and caregiver interventions, which are well documented in resource-rich settings, have not been studied in our settings among cancer caregivers.

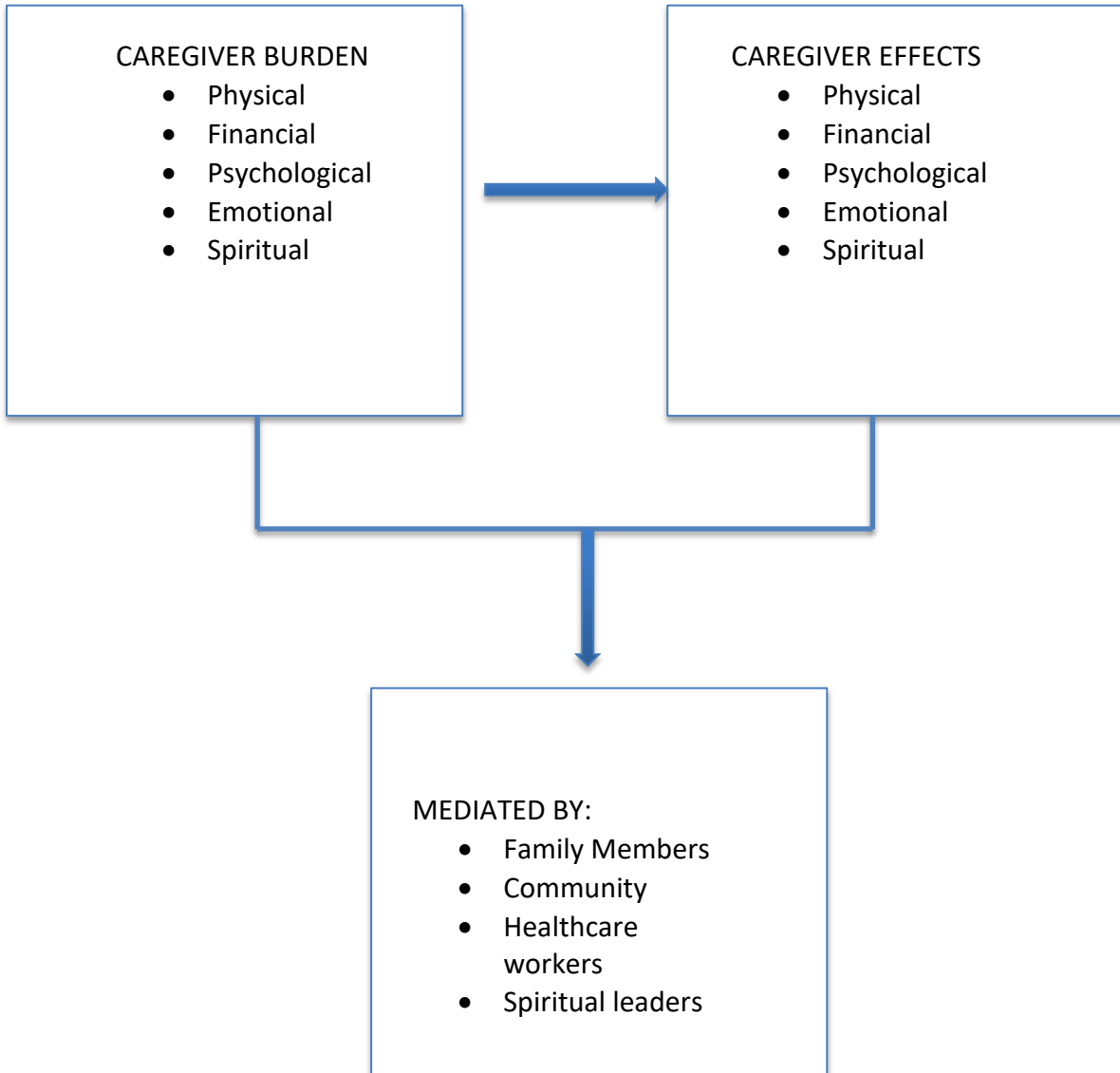
2.6 Conceptual Framework

This conceptual framework shows how the different needs contribute to the caregiver burden and the effects on the caregivers interact. It also shows the different stakeholders that may help reduce both the caregiver burden and the effects of caregiving.

These are the explanations of the terms used in this conceptual framework.

- **Caregiver Burden:** These are the things that can potentially contribute or increase the caregiver burden
- **Caregiver Effects:** These are the potential effects of caregiving on the caregiver
- The caregiving burden and the effects on the caregiver can potentially be mediated or reduced by the group of people listed.

CONCEPTUAL FRAMEWORK



CHAPTER THREE

RESEARCH DESIGN AND METHODOLOGY

3.1 Introduction

This chapter presents the research design, the study region, the study population, the selection criteria, the sampling method, and sampling size, the data collection procedure, ethical consideration, and the data analysis procedures.

3.2 Research Design

The study design will use a phenomenological qualitative approach to find out the caregivers' feelings and attitudes towards caregiving and explore the challenges they face while offering end of life care. This is because the study seeks to find out the lived experiences of the caregivers.

3.3 Location of the Study

The participants of the study were recruited from palliative care database of end-stage patients on home visitation from AIC Kijabe Hospital. The palliative care program is a part of Kijabe Hospital, a 363-bed capacity, non-profit, faith-based hospital. It's about an hour's drive from Nairobi towards Nakuru in Kiambu County, Central Kenya. The counties that border Kiambu County are Nairobi, Murang'a Machakos, Kajiado, Nyandarura, and Nakuru. The interviews took place in the patients' homes.

3.4 Population of the Study

Kijabe Hospital runs an outpatient palliative unit among other services. It took care of approximately 1100 palliative patients in 2016 and 900 in 2017. Eighty percent of these patients had cancer, and almost all of them received their end of life care at home.

3.4.1 Inclusion Criteria

Self-identified caregivers of adult patients with advanced cancers (stage 3 or 4) who are legal adults (over age 18) and understand English or Kiswahili were recruited. The caregivers cared for patients who have a performance status of 3 or 4 according to the WHO performance status staging (i.e. patients who spend more than 50 % of their waking hours in bed, or completely bedridden, and capable of limited or no self-care.) The caregivers ought to have taken care of the patients for a minimum of three months.

3.4.2 Exclusion Criteria

Caregivers who have a background in healthcare provision at a nurse, clinical officer or physician level were also excluded. Due to the logistics of home visits, patients and caregivers who lived more than a 100-kilometer radius from the hospital were excluded. In addition, and caregivers who could not understand either English or Kiswahili were also excluded.

3.5 Sampling procedure and Sample size

3.5.1 Sampling procedure

A purposive sample was used to recruit participants as it was thought to represent the fullest range of caregiver experiences and in order to assure that, caregivers of different genders, age groups, relations with caregivers, educational backgrounds, religions, duration of caregiving

and other relevant variables were selected. The participants were recruited from the Kijabe Palliative clinic. The palliative team schedules home visits to palliative patients every Wednesday as part of their outreach activities. They have a database of patients that are eligible (terminal, bedridden patients) for a home visit. From that database, the palliative team and the researcher held a brief meeting every 2 weeks and discussed the patients eligible for both a home visit and study criteria.

Once identified and agreed upon, the palliative team contacted the patient or caregiver to establish their availability for a home visit. This initial contact was made via a telephone call. If the patient and caregiver were available for the home visit, the researcher then sought preliminary consent via telephone to do the study in addition to the intended home visit. The researcher informed the caregiver and family that participated in the study was entirely voluntary and should they not wish to participate, the home visit by the palliative team would carry on as planned. Once preliminary consent was obtained, the home visit was scheduled. The researcher and one nurse from the palliative team would go for the visit. During the home visit, the researcher obtained written consent. No caregiver or patient refused to take part in the study.

3.5.2 Sample Size and Data Saturation

Twelve interviews were conducted. The initial number chosen was informed by a literature review on suggested numbers that aid in data saturation. Guest, Bunce, and Johnson (2006) suggest that a sample of six interviews may be sufficient to enable development of meaningful themes and useful interpretations and that data saturation occurred within the first 12 interviews. In this study, redundancy of themes and data saturation was attained by the tenth interview but continued to finish the twelve interviews.

3.6 Instrumentation

The interview guide was developed based on a literature review of previous studies on cancer caregivers, their unmet needs and the effects of caregiving on the caregiver. The data collection tool (appendix 1) that was used was open-ended, and contained some specific questions such as the following: “Please tell me how your typical day looks from morning to nighttime”; “ What gives you joy about taking care of your patient?”; “What makes it difficult for you to take care of your patient? “; “Tell me about any training you have received on taking care of the patient.”; “How has taken care of the patient affected your life?”; “If there was something that would make it easier to take care of your patient, what would it be?” The entire interview guide is available in Appendix 2.

3.7 Data Collection procedures

The in-depth interviews were done in the patients’ home for the patient’s and the caregiver’s convenience. It allowed the researchers to see the patient and the caregiver in context. The participants who met the study criteria were contacted via telephone to establish their availability and obtain a preliminary consent prior to visiting them. We made it clear on the telephone while obtaining preliminary consent of the need and intention to meet the primary caregiver.. In all instances, the patients were in their bedrooms, and the interviews took place outdoors, away from the patient. The interviews, all done in Kiswahili, were digitally recorded using an audio recorder, transcribed and translated into English. The interviews took on average 45 minutes to one hour.

The data analysis and coding were done in English. The researcher, who is fluent in both English and Kiswahili reviewed the initial transcripts in both languages to ensure semantic

meanings were maintained. Member checking and validation were done on four caregivers by the researcher. The formal transcripts in English were however not returned to the caregivers. The analysis of the transcripts was based on the semantic meanings translated into English.

In addition, the researcher took field notes documenting observations at the patients' and caregivers' home. Two types of field notes were taken: descriptive and reflective. The descriptive notes aimed to take note of the physical setting, the people involved and the communication between them, the non-verbal communications and any events or actions that particularly stood out. These field notes also aimed to include the researchers' reactions and experience.

To facilitate the researcher's reflexivity, reflective notes were also taken. They included the researcher's reflection and personal accounts of the experience, the frame of mind and feelings, and even speculations about what the researcher was learning and interpretations of the meanings of events and emerging themes.

Caregivers and patients were explicitly explained the purpose of the photos and were told that they would only be used for the research purposes and during the presentation of the data. If they consented, photos were taken as part field visit. The photos offered rich data that supplemented the field notes. Photos included things such as of the terrain leading up to the patient's house, their living environment and anything else that stood out. The photos were stored in password-protected devices and drives that were only accessed by the researcher. Both the field notes and the photos were useful in contextualizing the data obtained from the interviews and contributed to the interpretation of the data. The researcher did not have any relationship with the caregivers or the patients and is not involved in their routine care.

However, a nurse from the palliative team department was present during the data collection, to carry on with the home visit as was usually done.

3.8 Data Analysis

A thematic analytic process described by Braun and Clarke (2006), a six-stage process, was used to analyze the data. Braun and Clarke describe that the analysis can either be an inductive approach where the analysis is primarily data-driven or it can be a theoretic process where the process is more analyst driven. Inductive thematic analysis was used, which gave the researcher the liberty to code the data without trying to fit into a pre-existing code frame or the researchers own analytic preconceptions.

The first step was to familiarize with the data by reading and re-reading the transcripts. The primary researcher conducted the interviews but had someone else transcribe and translate the data set. The initial familiarization and immersion into the data started with cross-checking the accuracy of the transcription from audio and then cross-checking the accuracy of the translation from Kiswahili to English. After this process, the researcher read and re-read the transcripts in both languages.

The second step was to organize the data in a meaningful way and generate codes. As this was data-driven (as opposed to theory-driven), the codes were derived from the entire data set. The researcher did this by highlighting the text and writing notes as different ideas came up. Several codes were extracted during this phase.

The third step was to search for the themes. This was done by examining if the different codes could be collated to form broader themes. The researcher made use of a mind map during this process. Some codes went on to be full themes, but the majority of the codes formed sub-themes. The end of this process saw the preliminary development of themes and

sub-themes.

The fourth step was to review the themes, to specifically ensure that the data support the themes identified. Using the mind map earlier as a framework, the researcher went back to the entire data set to see if there was enough data to support each theme and sub-theme. The end of this fourth stage combined some themes as either there wasn't enough data for each theme, or some themes overlapped.

The fifth step was to name the theme-which was a further refinement of the themes. The aim of this step was to find out the essence of what each theme was about and begin to analyze it. It also served to clarify how the themes and sub-themes relate to each other. The sixth and final step was to write the report.

During the analysis, the researcher tried to keep in mind the anticipated themes as well as the emergent themes as advised by Ziebland and McPherson (2006). The emergent topics are those that were not specifically asked by the researcher but were directly or indirectly raised by the respondents. The anticipated themes were derived from the literature review.

3.9 Enhancing Rigor

Credibility, similar to internal validity in quantitative research, was enhanced by the use of reflexivity of the researcher. In addition to writing a pre-understanding; prior to data collection, the researcher kept a reflexive journal in which entries were made after each home visit. Time spent during the home visits ranged from 2.5 -3.5 hours, which was felt to be enough time for caregivers to say something if they had forgotten. The elaborate process described in the data collection procedure, the decision trail used by the researcher, also speaks to the dependability of the data. Milne and Oberle (2005) also recommend the

following strategies to enhance rigor: flexible yet systematic sampling, ensuring participants had the freedom to speak, ensuring accurate transcription, data-driven coding and on-going attention to the context.

A non-probability purposive sampling method was used to select the participants, in consultation with the palliative team, so as to capture maximal variation. Freedom for the participants to speak was ensured in two ways. The first was to brief the carer while obtaining preliminary consent and reiterating during the home visit that confidentiality would be maintained and that the information they would share would be used to improve the palliative team's service delivery. Secondly, the individual interviews took place away from the patients and relatives, and this allowed them to express themselves without any barriers. After that, accurate, word for word transcription and translation was done and confirmed by the researcher while keeping keen attention to the context. Finally, a data-driven coding and thematic analysis, as described above, was used to analyze the data.

MA, one of the supervisors, read through the transcripts and confirmed the themes and sub themes extracted from the data set. Findings of this study were looked at by supervisors who assessed various stages of thematic analysis and presentation of findings. These processes improved the quality of findings as well as trustworthiness.

3.10 Ethical Considerations

Ethical approval was obtained from the Research and Ethics Committees of both Kijabe Hospital and Kabarak University to proceed with the study. At the National level, a research permit was also sought and obtained from the National Commission for Science, Technology, and Innovation (NACOSTI). It is a national governing Commission approving all research activities in Kenya. Participation was entirely voluntary. Preliminary consent was obtained on

phone 3-10 days prior to the home visit. The researcher obtained written consent from the caregiver at the patients' home before proceeding to conduct the interviews. While the caregiver was engaged in the interview, a palliative nurse/clinician who accompanied the researcher cared for the patient. The participants were informed of their right to withdraw at any point without their decision affecting the care that either they or the patient will receive.

Confidentiality and anonymity were ensured by using codes, and not the participants' names. The list with the real names of the participants and the codes were kept separately from the audio-recordings and the transcripts. The audio-transcripts were deleted from the recording device soon after uploading them into a password-protected device.

CHAPTER 4

DATA ANALYSIS, PRESENTATION AND DISCUSSION

4.1 Introduction

This chapter presents the findings, interpretations and discussions according to the research objectives. The objectives of this study were three fold: to explore the challenges perceived by primary caregivers, to identify the perceived effects of caregiving on the caregiver and to describe their perceived sources of support for primary caregivers.

4.2. General and Demographic Information

4.2.1 General Information

The average time taken observing interactions in the homestead, including doing the interviews, was 2.5-3.5 hours. Three patients died less than 24 hours prior to the scheduled interview. One interview was cancelled upon reaching the patient's homestead. The person whom we had contacted as the primary caregiver relocated back to Nairobi three days prior to our visit. Another caregiver had recently commenced the caregiver role. She was however not eligible for the studies as she was 17 years old. The initial caregiver was concerned about losing her job in Nairobi, hence preferred to resume work and keep getting an income, and employing someone to continue caring for her mother. None of the caregivers refused to give informed consent for the study

4.2.2 Demographic Data

The male caregivers were 4 and the female caregivers were 8. All the study participants and their patients were Christians. None of the caregivers had tertiary level education; they either had primary or secondary school education. The youngest caregiver was 18 years old, and the oldest was 67 years old. The caregiving duration ranged from four months to two years.

Table 1: Demographic Data

	Theme		Sub themes		
	Patient age and Gender	Cancer	Caregiver age and Gender	Relationship	Duration of caregiving
1	79, M	Prostate cancer with spine Mets	53, M	Son	5 months
2.	75, M	Prostate cancer with spine Mets	21, M	Grandson	1 year
3.	89, M	Metastatic pancreatic cancer	41, F	Daughter	4 months
4.	32, F	Metastatic Gastric cancer	26, F	Sister	1 year
5.	63, F	Esophageal Cancer	67, M	Husband	16 months
6.	40, M	Cholangiocarcinoma	37, F	Wife	10 months
7.	84, F	Metastatic Lung Cancer	42, F	3 rd Wife	8 months
8.	75, M	Prostate cancer with spine Mets	18, M	Grandson	18 months
9.	60, F	Cervical Cancer	62, F	Sister	14 months
10.	67, F	Esophageal Cancer	35, F	Daughter in law	2 years
11.	77, F	Cholangiocarcinoma	41, F	Daughter	1 year
12.	66, M	Duodenal Cancer	61, F	Wife	10 months

4.3 Qualitative Findings

1	Practical challenges related to competing tasks	<ul style="list-style-type: none"> -Task shifting and role overload -Great personal sacrifice -Care-set up preferences
2	Experiences in Symptom Management	<ul style="list-style-type: none"> -“ I just use common sense” -Difficulties in dealing with the symptoms <ul style="list-style-type: none"> *Anorexia * Other symptoms and comorbidities
3.	Hope for recovery	
4	Difficult hospital experiences	<ul style="list-style-type: none"> - Delayed Diagnosis -Transport to hospital- a challenge -“Main hospital” vs “Smaller hospital” - Limited resources and human personnel
5	Financial Constraints	<ul style="list-style-type: none"> -Reduced income & extra -Inefficiencies in NHIF -Impact quality of care for the patient & caregiver
6	Impact on caregiver	<ul style="list-style-type: none"> - Psychological -Physical -Caregiver’s children- and ability to care for them
7	Vulnerability & Potential for abuse	<ul style="list-style-type: none"> - Sexual abuse/Gender based violence -Will & Inheritance matters
8	Caregivers’ support	<ul style="list-style-type: none"> -Family members - Neighbors. Friends & community -Religion -Other health care providers

4.3.1 PRACTICAL CHALLENGES RELATED TO COMPETING TASKS

Role Overload

All caregivers had more than one task, more to do than caring for the patient. One major task for the caregivers is farm work, whether subsistence farming or as a source of income.

However, as much as they tried to continue farming, all of them said the degree to which they were farming had substantially reduced. One caregiver said that he had stopped farming altogether. Another caregiver said that their grandmothers' illness forced them to leave their tea and coffee plantations, and they are now just bushes. Others switched their business to something that was less demanding like chicken rearing.

“We decided to let the coffee and tea stay unattended. No one is tending after them; there were some tea leaves which we used to harvest. Well, now I hear it's overgrown and can't even be taken to the factory We left it alone so as to deal with this one first (grandmothers' illness) Because we also have kids in school. We could not have managed all those burdens..... (Silence) And it has been difficult to look for somebody to care for the rural home. I can get for someone, but who will pay them? Laughs” CG 10

The other major task was taking care of other household obligations including child-rearing, for caregivers that had school going children. One caregiver was taking care of the patient's children as well as taking care of her own children. The children are dependent on the caregivers just as much as the patient for their physical, emotional, spiritual and psychosocial needs.

The caregivers' other tasks also compromise the time and care provided to other children. In one visit, we found a seven-year-old child with a dirty burn, which she sustained trying to get porridge out of the fire. One difficulty the caregivers expressed was helping their children to deal with emotions that arose from watching the patient deal with pain, inability to eat, vomiting and other symptoms. Caregiver 8 who had 7 children between the ages of 4 years and 17 years reported:

“Even the children were stressed from the eldest to the smallest. All of them. Even the teachers were asking me what is wrong with the children. I told them (the teachers) to let them be because they are seeing the way their father is in pain. Because they saw him vomiting after eating anything. I don’t know what to do with the children.” CG 6

One caregiver was taking care of two patients, his grandfather with prostate cancer with spine metastasis and his grandmother with a spinal cord injury.

“For me, I serve two masters.... In addition to the farm work, I take care of guka (grandfather) who has cancer (prostate cancer with spine metastasis and paraplegia) and cucu (grandmother) who had a spinal cord injury and even she cannot walk” CG 8

A respondent aged 42 taking care of 2 children under 4 and her husband with metastatic lung disease reported:

“I have to be up by 3 am to milk the cows.... Then I come to help the children prepare for school” CG 7

Another 35-year-old respondent taking care of her mother in law with esophageal cancer and 3 school-going children reported:

“I wake up at 5 30, prepare her (patient’s) porridge, and prepare breakfast for the children, make sure they take it before they go to school” CG 10

The tasks that caregivers did for their patients varied on the dependence on the patient. They mostly included feeding the patient, bathing the patient, laundry, helping with toilet functions, dressing wounds, administering medication, lifting the patients and turning them, taking them outside to sun-bask. Other mental roles include deciding on when the patient required attention and where to take them. One caregiver described that all these tasks made

him feel that he was a prisoner in his own compound because he couldn't go far at any given time. One 53 year old respondent giving care to his father who was paralyzed secondary to metastatic prostate cancer reported:

".... And you see even if it's going out, I cannot go out for long hours, Because I have to know the time for his medication and be present then. CG 1

Great personal sacrifice by caregivers

Caregivers endured these strains at great personal sacrifice and cost. Some felt it was their duty because this was their parent or grandparent. Two of the spouses felt that it was their obligation because of the vows they made to each other when they got married several years ago to care for each other in sickness and in health. Those nursing their siblings said they did it out of the love that they had for them. Two caregivers left their matrimonial homes to care for their loved ones; one with the blessing of her husband and the other with resistance from her husband. Both left their homes with the expectation to return to their homes once their services were no longer needed. Some caregivers even did duties that were culturally and traditionally not perceived to be theirs, sometimes even with cultural breaches.

One respondent aged 41 who left her matrimonial home to care for her mother said:

"I told him that he can always get another wife, but I cannot get another mother. So I am going to take care of my mother whether he likes it or not..." CG 9

Another caregiver (husband) taking care of his wife who had advanced esophageal cancer reported:

"I have no maid, I don't have any money to employ one.... I cook for her; I boil for her drinking water.... I do her laundry" CG5

Another caregiver (grandson) aged 18 taking care of his grandmother who was paraplegic and his grandfather who was also paralyzed secondary to metastatic prostate cancer reported:

“She just has different issues, for example, if she needs to relieve herself, I take her to the toilet, she just goes there and sits. When she is done, I go for her...” CG 8

Care setup preferences

Although stating that they were overwhelmed and are paying a big price for caring for their patients, all caregivers still preferred home-based care. The ideas of a respite program or care away from the patient’s home were not welcome to most of the caregivers.

Only one caregiver expressed a desire to be relieved of his duties for two or three hours per day so as to be able to earn a living, but he still wished to be the primary caregiver. Another caregiver wished that she did not have several financial obligations for her to be able to resign from work so as to be able to care for her father full time.

Caregiver 10 who was taking care of her mother with esophageal cancer and juggling clothes hawking business reported:

“I can’t move her elsewhere, I do not want that...let me take care until the last minute” CG 10

4.3.2 Experiences in Symptom Management

Limited knowledge in managing symptoms

Half of the caregivers reported that they had some training. The training was in form of one sit down with one of the palliative care nurses and some education on what to do, which

lasted on average 45 minutes. Most caregivers said they just use their common senses and try and figure out what to do. However, as time goes on, the caregivers were more familiar with the tasks and confident with symptoms management. A grandson to one of the paralyzed patients reported:

“I have not been taught.... I just look at what is the best thing for him at that moment and do it” CG 2

Caregiver 5 who was taking care of his wife with esophageal cancer reported:

“I have not been trained... And it’s not that I have been told of something like that and refused to go...I just use my common senses” CG 5

When stranded, caregivers consulted with other family members when they needed to make decisions concerning the patients’ care. Caregiver 3 wished that the palliative team were able to do more frequent visits and teach, and help out. One of the caregivers had a cancer booklet from Kenyatta that was in English. Unfortunately, the caregiver does not understand English and wished there was a booklet in Kiswahili or mother tongue.

Difficulties in managing symptoms

Anorexia

The hardest symptom for most caregivers to manage was the patient’s anorexia. This was recurrent in all patients, and their caregivers. The caregivers attributed the patients’ getting worse and weaker to their poor eating. Most of them asked for nutritional advice on what to cook and feed the patient, and for drugs that could enhance their appetite. Caregiver 11 understood why the patient wasn’t eating and wouldn’t struggle with her mother. However, her siblings would still try and force their mother to eat something and would encourage the

caregiver to ensure their mother eats. Caregiver 1 who was taking care of his father with metastatic prostate cancer and stage four decubitus ulcers reported:

“Now you find out that we end up not being in good terms with each other because of not eating” CG 1

Another caregiver aged 26 who was taking care of her sister with stage 4 gastric cancer reported

“The hardest part of taking care of her is that she refuses to eat” CG4

Other symptoms & comorbidities

The other challenges came with other care like wound care, turning the patient's in bed, toileting, drug administration. Dealing with other morbidities, especially among older patients also posed challenges. Caregiver 1 while taking care of his father with stage 4 decubitus ulcers and paralysis reported:

“Yes, I have gotten used to it (caring for the patient) because from the start, something like the wound, I could not come near it, but now I am used to it. Turning him around and dressing him is a problem.... when I am alone, there is no way I can take him out of bed. Putting him in the diapers is a challenge because it is near the bed sore is.” CG1

Another caregiver taking care of her father who was diabetic, hypertensive, with pancreatic cancer and cholestatic pruritus lamented:

“The problem with him is he itches a lot... And I don't know how to help him. Sometimes I just get a maize cob and ask my son to help him itch with it...He is diabetic and doesn't eat well, yet he is still injecting himself his usual insulin dose, causing him to get into frequent low sugars. He has to sleep with sweets bedside.... I don't know whether to continue giving him the insulin if he continues eating like this” CG3.

Some caregivers were very grateful for the counseling provided at the palliative clinic, and others wished for more. Most caregivers expressed desire in getting more training on the care of their loved ones. They hope that the training will cover areas like nutrition for the patient, symptom management, wound care and counseling for the caregivers to help them cope better.

4.3.3 Experiences Related To Health Seeking

Delayed diagnosis

All families' narrated difficult hospital experiences; especially leading up to diagnosis, and for treatment occasionally. All families went to more than three hospitals before finally reaching a diagnosis, others up to 6 different hospitals. This contributed to a delayed diagnosis, as this would happen over time. The reasons for visiting different hospitals varied; sometimes it was referrals from the smaller healthcare facilities, other times it was due to financial constraints. Other times it was due to dissatisfaction with the kind of care that the patient was receiving at the time. One caregiver reported:

“We started going to hospitals we went to Kiambu general, we went to Aga Khan, Kiambu, and we've gone to radiant, we went to Nairobi west, we've gone to many hospitals. In that process, someone suggested to us Kijabe hospital” CG 2

Some had to travel very far to access healthcare. For instance, one patient had to travel about 300 kilometers from their home to another hospital for a procedure. For this patient, Kenyatta National Hospital which is a national referral hospital would have been an option, but they had felt very frustrated with the long queues, costs and significant delays there. The infrastructure and some of the terrains that the patients had to endure, sometimes on a motorbike, were uncomfortable for the patients and their caregivers. We had one patient to visit just 5 kilometers away, but it was a 45-minute journey because of the terrain and terrible road. For another patient, we had to postpone a visit because heavy rains rendered the road to their home inaccessible. Unfortunately, the patient died before we got a chance to schedule for another visit. The caregivers were also concerned if things took a turn for the worse, especially at night, because the infrastructure and the means to get to the hospital at night

posed significant challenges to the families. One caregiver who was taking care of her husband with cholangiocarcinoma reported:

“We were told there is a machine that Kijabe did not have but was there in Tenwek, a hospital I did not know about and hadn’t even heard of it.” CG 6

Hospital experiences

Upon arrival at the hospital, they would face more challenges including limited supplies and long queues. The long queues are particularly a challenge for patients who have limited mobility, and patients who otherwise spend their waking hours in bed. In terms of communication, some felt that they were being taken around in circles without an explanation of what was going on. Others were, however, grateful that efforts were made to communicate to them even in their mother tongue to ensure that they understood their condition. One caregiver who lived 50 kilometers away from the hospital reported that:

“Going to the hospital is a full day thing... we leave at 5 am and don’t get back before 5 pm. CG 10

Another one stated:

“We carry our own wheelchair with us, most of the time you find all the wheelchairs in the hospital have been occupied” CG 1

On the resources available and the perceived quality of care they received from hospitals, one caregiver cited the frustrations they encountered, even with something as basic as pain control.

“She went to another hospital for transfusions blood.... we arrived at 1 but she was admitted at around 5 pm, to be given a bed yes, we are told that the doctor has not arrived and she was in so much pain...they were just looking at her...they don’t allow people to go in with food, and you know she can’t eat the food there” CG 4

“Main hospital” vs. “Smaller hospital”

The challenges encountered in the referral hospitals necessitated some caregivers to identify a “smaller hospital” nearby to help in some of the caregiving. The main challenge identified with this was polypharmacy. For instance, one patient was on two different brand types of omeprazole and another on two different brand types of paracetamol. Therefore, the risk of adverse events with the drugs is present. Caregiver 11 and their family opted to engage a clinician from nearby health to be given intravenous fluids in the house on alternate days.

“We usually take him to the hospital at Ngecha (close to the patient’s home) ...they know him well there.” CG 3

The regular clients of the palliative clinic expressed delight in the efficiency of the services in the clinic, as opposed to the main hospital. One respondent taking care of her husband with metastatic lung cancer reported:

“Down there (main hospital), there was someone who wasn’t treating us right, telling us to wait for one minute and the delays, we stayed in the hospital until 10 pm from 10 going for labs and waiting, but in palliative, it’s fast and efficient, with caring people. We will not go to down there (main hospital) again” CG7.

Majority of the caregivers interviewed shied away from getting herbalists or getting herbal medications for their patients for fear of side effects. Those that admitted to using herbal medications used them before the cancer diagnosis for arthritis, ulcers, and diabetes.

One of the respondents taking care of his wife reported that he could not allow his wife to access the herbal medications.

“...And you know the local ones (herbal medications) sometimes are strong, these herbal people, they do not have the ability to measure the correct dosages like the doctors in the hospitals” CG 5

Another 61-year-old caregiver taking care of her husband with metastatic duodenal cancer reported:

He has not used any herbal medications. He does not even like them. Even before this disease, even earlier, he did not like the local medicine. (CG 12)

4.3.4 Financial Deprivation Related To Cancer Care

Loss of income & Increased expenditure

The patients and their caregivers strained financially partly due to the lack of income from both patient and the caregiver, with additional healthcare costs. Often, the caregivers have to leave employment or farming as much as they would so that they can dedicate more time to the patient.

“...The time I would have spent looking for money is spent here taking care of her... I don't have a house help who could take care of her because I don't have money to hire one” CG 5

Concerning their financial sustainability and future, one grandson reported:

“Cucu (my grandmother) has taken many loans to be able to care for them, and they have defaulted on the payments. I am scared that one day soon this land or some property will be auctioned” CG 8

Challenges related to the National Health Insurance Fund

The NHIF delivery packages have improved, and are able to partly or fully cater for the cost of surgeries, chemotherapy and radiotherapy. They however, do not cover outpatient costs, consultation fees, and transport costs to the hospitals. The caregivers were of the opinion that

NHIF needs to pay for a lot more. Some caregivers cited frustrations and delays in getting NHIF to approve the treatment, and to actually authorize for the procedures. On one occasion, the patient already had the IV cannula in place, and preloaded with IV fluids, just waiting for authorization of the drugs. When the authorization did not happen in time, the patient went home without receiving chemotherapy. Caregiver 5 who was taking care of his wife advanced esophageal cancer which required repeat esophageal stenting reported:

“At the same time, I thought of having NHIF would help me: it has not helped me...I had to sell my property” CG 5)

A 60 year old caregiver who left her marital home to care for her sister with advanced cervical cancer reported:

“She missed a chemotherapy session because the approval hadn’t yet gone through...the next time we paid cash so that she doesn’t miss another dose.... I had to make several trips to the NHIF head office in Nairobi to request them to pay for the radiotherapy and for the second type of radiotherapy that was directed to the uterus”
CG 8

Poor pain management & quality of life secondary to financial deprivation

The impact of the financial strain was felt on two levels. The first was on the caregivers’ families and their day-to-day needs. The second was on the impact of the care that the patient received, including their pain management.

All the patients we visited had morphine syrup in their houses. However, we noted some patients and caregivers rationing the morphine-either giving a lower dose or longer durations so as to “stretch it out “as much as possible. Most of them also had with them lactulose, and only two caregivers mentioned challenges with constipation. The principal concern, however,

was the cost of the morphine and the other drugs. One caregiver whose patient was on morphine and lactulose reported:

“This time around, the drugs were a bit hard to get. It’s hard sometimes because we are not well up financially...it has been 2 years of spending a lot of money” CG10

Another caregiver cited inability to attend events and meetings organized by the palliative department due to financial and logistical challenges.

“We didn’t make it come (for the support group meeting), because we had come for clinic two days before that day. So we couldn’t manage to come that soon” CG 1

Almost all caregivers felt that if there was a way that the financial burdens could be relieved from them, they would be able to deliver better care, feel less overwhelmed and they would be more present to care for their loved ones.

4.3.5 Caregiver Well Being: Influence Of End Of Life Care

The caregivers in this study experienced physical, emotional, and psychological effects of caregiving. There was a determination and resilience from the caregivers, to not allow their current situations to get in the way of caring for their patients. As one caregiver put it, “I can’t let this affect me”.

Physical effects

The physical effects ranged from eating disturbances with accompanying weight loss and sleep disturbances. One caregiver described actually feeling physical pain when she sees her loved one in pain. Caregiver 6 spoke of a time when she physically felt unwell, and required hospital admission before they realized that she was simply overwhelmed, and had counseling prior to discharge. Caregiver 12 opted to postpone her own healthcare needs. She was scheduled for a total hip replacement due to severe right hip osteoarthritis-that even

affected her mobility in the house. She “chose” to postpone her care because “she did not have time” and the “resources” they had were being channeled towards the husband’s health.

One 18-year-old respondent taking care of his grandfather who was paralyzed secondary to metastatic pancreatic cancer reported:

“I normally don’t sleep well, I just sleep here on the couch, so that I can be able to respond to him when he calls” CG 2

Another caregiver supporting her sister through chemotherapy stated:

“During this period, I have lost about 5 kgs...I think it’s because I am not eating. It’s hard to eat when she doesn’t eat.” CG 9

Psychological effects

The mental and psychological effects were due to anxieties of what next, should the patient die. Occasionally, it was due to anticipated grief. One caregiver reported:

“I can say I have been most affected psychologically because I wonder what next. I wonder when I have gone to work and left him if he will still be there. When I find him in the bedroom I tell God thank you ”CG 3

“I was stressed because, in Kenyatta, I was told that he would die, and even he (the patient) seemed to agree....” CG6

It’s also imperative to consider the impact on the children as well. If the caregiver has parenting responsibilities, they need to be equipped on how to care for the children, as they too feel the stress, and can get overwhelmed. This is depicted in the excerpt below.

“Even the teachers were asking me what is wrong with the children.....they regressed in their studies.” CG 6

4.3.6 Hope In The Midst Of Hopelessness

Almost all the caregivers were hopeful about recovery for their patients. To put this in context, the participants of the study were patients who had advanced cancer, with a WHO status of 3 of 4 (patients who spent more than 50% of their waking hours in bed or completely bedridden, and capable of limited or no self-care.) At the time of writing this paper, a month after data collection, and 8 out of 12 patients had died, including the ones whose excerpts I have put below. This hope for recovery is also shared by the church sometimes and perpetuated by it. One 21-year-old respondent said:

“So you see I’d rather stay here helping him until he gets well” CG 2

Another caregiver taking of her sister reported:

“There is a day she (the patient) said she will die, I told her no, she will not die but live...I still pray for L to get well, so that she can bring up her children because I cannot bring up her children the way she would have...It's better for her to stay here with us as long as we are able to see her, even if she remains weak... I want her to recover... the church members come to pray for her, and tell her that she will recover” CG 4

As such, it was difficult to initiate the discussion on whether they are aware of the symptoms at the very end of life when death is approaching and whether they know what to do when that time comes.

4.3.7 Vulnerability And Potential For Abuse For Female Carers

Female caregivers seem also to be vulnerable and this puts them at risk for potential abuse, and even actual abuse on some occasions. This seems to be closely related to the financial

constraints that come with the caregiving. The potential for abuse is present when the patient is alive and even anticipated when the patient dies. The abuse could be in verbal, physical or sexual abuse. Caregiver 6 who was taking care of her husband with cholangiocarcinoma reported:

“This illness has made me very vulnerable to other people.... When he (the patient’s friend) comes to the committee meetings for the Harambee he would be full of abuses because I refused his sexual advances... One time, at night after a committee meeting, he touched me inappropriately....Another one even told me that when my husband dies, he would like to marry me as his second wife.... and my husband knew the men who were making sexual advances” CG 6

Another respondent who was a third wife reported:

“You know when there are three households, there might be problems with distribution of his wealth and land. I wish that he would be able to walk and show me all his property and hear how he would like to divide it among the three of us. I am scared that if he doesn’t divide it before he dies, the sons of the first wife may not give me anything, and even kick me out of the homestead, yet I am the one with the youngest children.” CG 7

4.3.8 Caregivers’ Support System

The caregivers derive support primarily from their family members, both nuclear and extended. The neighbors and community, together with their religious communities also play a part in supporting the caregiver.

Family and Clan Network

The degree to which these caregivers felt they got support from the extended family ranged from “very little support” to “very good support.” There are caregivers who got reasonably

good support (in the judgment of the caregiver). These were the families that still lived in the traditional villages where the siblings are a stone-throw away. Twice in such family setups, there had to be a negotiation on who was the primary caregiver. In these instances, we defined the primary caregiver as the one who does more than 50% of the caregiving tasks, or more than 50% of the time.

One caregiver who worked in a flower farm during the day mentioned:

“She (my sister in law) takes care of him during the day and I take over at around five pm until the following morning” CG 3

The family members supported the caregivers in different ways. The first was to help in different chores that need to be done, like laundry, cooking for the patient, cleaning the house. In as far as healthcare was concerned, relatives helped each other with the transport logistics; taking the patients to the hospital, help in turning the patient, jointly making health decisions for the patient. Occasionally, a family member would come and relieve the caregiver for a few hours so that the caregiver can get something else done. This was partly appreciated, but sometimes the caregivers also felt that something would not be done as well as they would have done it.

Other families helped significantly with the finances. Some family members came together to financially support one family member to serve as the primary caregiver. In these instances, the caregivers felt that the support was inadequate but did not feel it was appropriate to tell the siblings. This was partly because they did not consider it a “payment” to care for their loved one, rather a token of appreciation. One respondent with a wife and 4 children taking care of his father reported:

“I can’t depend on that alone for my family (the family contribution)... if I got 2-3 hours a day to work somewhere so that I can meet my needs, I would be happy.” CG 1

Even when there seemed to be adequate family support, the caregivers felt that the family could chip in a little more, or they could do more. The caregivers would not feel comfortable sharing this with the larger family but talked about it during the interview.

Sometimes, there is limited or no family support making the caregiving task harder financially and psychologically for the patient and the caregiver.

Caregiver 10 who was taking care of her mother in law reported:

“Other times it is hard because currently she is at my place. And we are many; we are four. When she fell ill, she was brought to my place. Everyone left and went to their own homes, and the burdens were left with me.... Sometimes when they come to visit, they come empty-handed...I am the one to figure out all her meals and how she will stay here.....” CG 10

Another 18-year-old respondent pleaded for his family to be united.

“The only thing I would plead for is for this family to be united, my aunty and uncle are far, but the one who is close by should just come and spend time with the family, just stay with them and go away when their visit is done. When grandpa sees that, he will be happy...” CG8

Social and Community Networks

The neighbours, churches, and community also still play an active role in the care of the patients and the caregiver's well-being. However, the caregivers' expectation for their input is not as great as that for fellow family members. The roles they did were mainly two: Participate in ²**Harambees* to help financially in the care for their patients. The second was to help in practical chores like laundry, collecting firewood, keeping the patient company so that the caregiver could go the market, etc. Some caregivers had also hoped for financial aid

² *Harambee* is a Kiswahili word that means “to pull together.” It is a Kenyan tradition where communities come together to raise funds for a charitable cause.

from government officials or their contributions during *Harambees*, but this was not to be. Very few of the caregivers had heard about support groups. Those who did had not managed to come for any of them either because of logistical strains (difficulties in organizing the transport) or failure to understand what the support group was about. One respondent taking care of his grandfather said:

“You see like this gentleman (their neighbor), he comes to give him company so that he may not get bored ”CG 2

Another caregiver taking care of her mother with cholangiocarcinoma and bedridden reported:

“Her very close friend comes to wash her on alternate days” CG 11

Relating to support from government officials and leaders, caregiver 6 who was taking care of her husband with cholangiocarcinoma and reported:

I approached the senator, governor, and MCA, who promised to come for the Harambee (fundraising) but did not turn up nor send their contributions.” CG 6

Spiritual Support

Caregivers turned to religion for many things. They believed that their faith would heal their patients, provide for their daily needs, and give them strength to deal with the day-to-day challenges of caregiving. They also depended on their faith, in a somewhat resigned manner, on the ultimate fate of their loved ones. One caregiver reported that members of her church formed her greatest support network.

“Those who helped me are those with whom we go to church with...My sister in Christ (fellow church member) hosted us while we were in Tenwek...”CG 6

Another respondent expressed the confidence she and her family had in God to heal their loved one.

“And we believe God will heal her...God has helped us...God led us....We have seen God that during this whole process we have not lacked money for travelling...God has helped me so as to help my sister....” CG 9

Other healthcare providers

All caregivers were very grateful for the home visits during which the palliative nurse or clinician reviewed the patient and discussed way forward. They appreciated the extra time spent in the home, as opposed to rushed consultations in the hospital.

Healthcare providers available in the home setting provided guidance and help to the caregivers, in various forms. These were either nurses or clinical officers that were from nearby facilities or neighbours to the patients that would do house calls. They helped the patients with tasks as dressing changes, administering intravenous fluids, and sometimes just the reassurance that the caregivers were doing the right thing. This came at an extra cost, but the convenience, especially to the patient, was welcome.

One of the caregivers greatly appreciated the phone calls made by the palliative department to check on the patient, and on the caregiver. They found that to be useful particularly in encouraging the patient, which in turn encouraged the caregiver.

Caregiver 4 who supported her sister through pregnancy, and delivery with stage 4 gastric cancer mentioned:

*“What I will add is about Kijabe doctors because they have helped her a lot; they even call her on phone.... they really talk to her.... they have really taken care of her”
CG 4*

The palliative care providers offered debriefing sessions to the caregivers. There is also a bereavement support group that is open to all family members who have lost a loved one, and care and counseling are offered during the support group meetings.

4.4 DISCUSSION

The purpose of this study was to explore the cancer caregivers' lived experiences. This study was done with the following objectives: to explore the cancer caregiver burden in our setting, identify the perceived effects of caregiving on the caregivers and identify the perceived sources of support for the primary caregivers.

4.4.1 CAREGIVER BURDEN

Family caregivers play a key role in palliative care in sub-Saharan Africa, a context fraught with inadequate healthcare services coupled with poverty, making home-based care the available option for many chronically and terminally ill persons (Streid, *et al*, 2014). The significance of the caregiver role is indicative of the need to support the caregivers' well-being.

The cancer caregiver burden was defined as the stress or strain that caregivers feel as a result of taking care of patients. The caregivers talked about it directly naming competing tasks, financial strains, symptom management, and for the females: sexual harassment and abuse.

Practical challenges related to competing tasks

All the caregivers interviewed had other responsibilities to handle. The data demonstrated a tension between the pleasure they derived from caregiving, and the strain and pressures from other responsibilities. Their caregiving role started prior to the cancer diagnosis and continued ending only in the patient's death.

As the disease progressed, the level of patient dependence increased, and so did the demands on the caregiver. The other realities of life like farm work, childcare and other social responsibilities remained, and no provision was made to adjust for this. In addition, caregiver labor costs were often unappreciated by their family members and completely unrecognized by the healthcare system at large (Yarboff, *et al.*, 2009). This is similar to our setting where the caregivers contribution to the informal healthcare workforce goes unrecognized and uncompensated by the government and the healthcare system. There was no alternative option to support the caregiver. It is thought that hospice support and respite care to support caregivers are a luxury of the rich in Kenya.

Given B., Given C. and Sherwood (2012) mention up to thirty different tasks that caregivers are involved in, the majority of which our caregivers shared. Tasks included; medication acquisition and dispensing, symptom management, meals and nutritional assistance, supervision of treatments, adherence, emotional support, communication with the healthcare providers, and many others. This data provided evidence of the caregivers' skills for complex coordination of tasks and logistics required to deliver needed care.

Role-related strain experienced by family caregivers was evident in this study. In other studies, role strain correlates to the number of other competing roles, which in turn is determined by the stage of lifespan that a caregiver was in (Bernard & Guarnaccia, 2003; Burrige, Winch, & Clavarino, 2007). Kim and his colleagues had findings that supported the role-strain theory: that the more social roles a caregiver carries out, the more likely the caregiver is to experience stress, strain and negative affect (Kim, *et al.*, 2008). This implies that for caregivers who also had to care for their own children and other farm work would, therefore, be expected to experience greater role-strain, and potentially be more overwhelmed, than caregivers who simply had one caregiving task alone. While there were

no objective assessments done to assess caregivers' burden, it did seem true in this study that caregivers, particularly those that had school going children experienced a greater burden.

Financial burden

The financial burden was a dominant theme. The reasons for the financial strains included increased healthcare costs and loss of income from both patients and caregivers. This was exacerbated for families already living below Kenya's poverty line. In response to the question of what else could help them, the majority wished that there was a way to either relieve them of the health care costs or if they could get access to extra finances. Nayak and his colleagues recommended reducing the economic burden on oncology caregivers as one of the measures that could improve caregiver's quality of life. Nayak, *et al.*, 2017). The availability of financial resources would afford caregivers more time to care for their loved ones, and not have to worry about looking for food, medicine, and other essential necessities.

The role of insurance in reducing this burden deserves special mention. The National Health Insurance Fund is making some strides in its attempt to cater to cancer care, particularly in terms of diagnostics, chemotherapy, and radiotherapy. However, its inefficiencies continue to cost some patients early and timely access to interventions and treatments. Its role in accessing palliative care services is also yet to be fully explored. * Increase this paragraph

Access to healthcare and symptom management

Financial difficulties exacerbated the challenges with access to healthcare. Physical access, being able to reach a hospital, was a daunting task for most families due to the infrastructure. They had to travel long distances or visit several facilities in order to be able to get healthcare. This is true in many African countries where specialized care is only available in

the big cities including Kenya. A study done in Kenya found that 40% of patients travel more than one hour to reach the nearest government health facility (Noor, Amin, Gething, Atkinson, Hay & Snow, 2006). According to WHO (2014), Kenya has limited personnel and only 12 facilities capable to provide cancer treatment, two in Eldoret, one in the Coast and the rest in Nairobi. The consequence as found in this study were two; either incur travel costs, sometimes with very poor road infrastructure, to get to the main hospitals or choose to work with a “smaller” facility within reach which may not be well equipped to care for the palliative patients or do not understand how to meet palliative needs for their patients.

Dealing with symptoms was one of the things that caused significant strain to the caregivers. Majority of the respondents, when asked what made their work difficult, referred to one symptom or something that their patient was going through. Caregivers reported difficulties in watching their loved ones go through difficult or distressing symptoms. Very few expressed that they had training in caregiving and reported to just use “common sense”. Dione-Odom, *et al* (2015) also reported a similar finding of strain associated with managing symptoms and medication. Van Ryn, *et al* (2011) in his study found that half of the caregivers reported not getting training that they perceived was necessary, similar to our study’s findings. Milligan and Connolly (2014) further state that the carers need specific knowledge and skill at different points over the duration of care, as the needs may keep changing as the disease progresses. This implies the need to keep upgrading caregiver’s information depending on their current situation.

There may be a benefit to the training of caregivers at different points in the disease to phase to enable them to manage the distressing symptoms and assess if such an intervention would help reduce their emotional burden. Ultimately, the caregivers need to have an assurance that

they are doing the right thing and that they have access to someone that can guide them if they need clarification.

Communication too plays a role in the caregivers' informational needs. Caregivers' for whom English is not their primary language may face further challenges in their provision of care because of language and literacy barriers that make medical information harder to access and process. In this study, one caregiver was particularly grateful for healthcare workers that communicated in the patient's native languages. Healthcare providers should strive to communicate with the patients and caregivers in their preferred language, to facilitate greater understanding.

Vulnerability, abuse, and potential for abuse for female caregivers

One of the emerging themes from this study was the abuse or potential for abuse for women (spouse) caregivers. This finding has also been documented in Botswana among younger women caregivers. While the older women reported feeling overwhelmed and neglectful of their own health, younger women reported being physically abused, sexually exploited and depressed (Lindsey, Hirschfeld & Tlou, 2003). In South Africa, while examining gendered home-based care among HIV/AIDS patients, Olagoke (2006) noted one of the challenges as the risk of sexual abuse. Volunteer caregivers would not even visit with the family or patient for fear of abuse, even when sent in pairs. This certainly impacted on the quality of end of life care that the patient could receive.

In this study, the source of the abuse came from the extended family, or from the friends and neighbors of the patient. The carers kept quiet about it, as with many other victims of abuse,

and would strive to still offer the best care under the circumstances. Upon conferring with two separate lawyers on the women who reported abuse or attempted abuse, my hands as the researcher were legally tied. The law in the land states that for persons over the age of eighteen who were abused, the victims have to be willing to report the case themselves, and due process followed. For persons under the age of eighteen, I would then have the duty of care, and duty to report the matter.

Caregiver Burden among Males

In this study, two-thirds of the caregivers were female. Traditionally, caregiving is the women's role, and this observation has been noted in other studies, even with other illnesses. Kalavina (2014) and Kipp (2007) in their studies found that women bear a greater caregiving burden because even when men participate in caregiving, they are more likely to be assisted by female caregivers. This was true in this study. Three out of the four men had help in doing other house chores, especially cooking and cleaning the house from other family members. Yusuf, *et al* (2011) suggest that men may experience a greater strain in caregiving, as they may not be conversant with the tasks and responsibilities of caregiving. This was observed in the other male caregiver who did not have a female member of the family to help out.

4.4.2 IMPACT ON CAREGIVERS

Although most caregivers experienced a deep sense of satisfaction and joy with caregiving, it was also associated with a negative impact on their physical, psychological and financial well-being. Romito and his colleagues (2013) note that for caregivers, similar to cancer patients, the negative impacts are experienced to a greater or lesser extent, depending on the socio-demographic characteristics of the caregivers. Those with fewer resources potentially

experienced greater caregiving effects (Romito, Goldzweig, Cormio, Hagerdoon & Anderson, 2013).

Various factors play into the extent to which the caregiver experiences the caregiver burden, and in addressing the caregiver burden and impact on caregiving, these factors should be put into consideration. Otis-Green and Juarez (2012) argue that culture, relationship changes and the degree of social support impact the degree to which caregivers feel the impact of caregiving. In cultures where intergeneration caregiving is expected such as ours, an inherent part of the wife, of children to the patient may be the perception of filial responsibility, and hence “not allowed to express a negative impact.”

Physical Effects

The main physical effects noted in this study were generalized fatigue, sleep disturbances, feeding disturbances and caregivers neglecting their own physical health. The physical effects occur primarily because caregiving is equivalent to a full-time job (Girgis, Johnson, Aoun & Currow, 2006).

Sleep disturbances were mostly due to caring for the patients at night as well, and a few mentioned worry and anxiety as keeping them up at night. For others, it was due to the fact that they had to wake up as early as 3 am to start their days' activities. In comparison to China, sleep disturbances among caregivers were due to their own ill health, financial burdens, and patients undergoing treatments. Predictably, those who reported sleep disturbances experienced higher physical and mental fatigue severity (Zhang, Yao, Yang & Zhou, 2014).

Caregivers also reported poor feeding, anorexia and weight loss experienced during the

caregiving period. It was more common among caregivers who had patients who themselves weren't eating. The patient's lack of eating caused significant distress to the caregivers and experienced a loss of appetite. For other caregivers, it was that they were very busy doing other chores that they did not have time to eat. Glajchen (2012) found that caregivers frequently lack time for their own self-care, including right nutrition; time to exercise, honoring their own doctor's appointments and other health promotion activities.

Emotional and psychological effects

The emotional concerns that came up were those of sadness as a result of being isolated by their families and having to bear the burdens with little or no support from them. Separation from their families, especially for the women who had to physically relocate from their marital homes in order that they may care for their loved ones also contributed to the emotional burdens. Sklenarova, *et al* (2015) noticed the emotional impact being greatest in caregivers who felt they lacked in financial, social and psychological support experienced greater emotional impact of caregiving.

The most common psychological effects in other studies are depression and anxiety. For instance, in a Moroccan study, the main psychological effects were depression and anxiety were present in 22% and 79% of the caregivers, respectively. (Lkhoyaali et al, 2015) In this study, there was no formal assessment of the degree of psychological disturbance and mental illness. However, screening caregivers for these conditions are something that palliative care providers should consider doing during patient visits.

Spiritual effects

Spiritually, caregivers expressed hope in God for their patients' recovery. This was despite advanced disease in all patients. The hope for recovery was unexpected, especially considering these were patients who had been through the palliative clinic and had some degree of counseling. From a study in Morocco by Lkhoyaali, *et al* (2015), 75% of caregivers desired a maximalist treatment for their loved ones, and only 10% preferred limited care in their terminally ill patients. Partly underlying this was a belief in God and a hope for their loved ones' healing. Vespa, *et al* (2018) found that spirituality could actually be a source of strength and a potential avenue for therapeutic intervention. This was based on his study findings that caregivers who experienced low spiritual well-being had a poorer quality of life. Spirituality was used to help patients and caregivers cope with anxiety, depression and even the fear of death.

Financial Impact

Regardless of whether one is in the developed or developing countries, or socio-economic status, a cancer diagnosis has a significant impact on the patient and affected family (Azzani, Roslani & Su, 2015). The impact of the financial strain in our setting that was particularly startling was 'morphine rationing'. All patients had morphine in their houses, but either took inadequate doses or at longer time intervals so that the drug 'doesn't run out'. Another financial limitation was the quality and services that they could access, including support group meetings. This was similar to a Tanzanian study where caregivers expressed challenges in accessing the medication either as a result of cost, transportation or availability. Caregivers in that setting often sold their possessions or take on additional responsibilities in order to make enough money to pay for the medication (Walker, 2011).

The disease has the potential to induce or worsen poverty (Yusuf, *et al.*, 2011). Studies from the west have shown caregivers sometimes even declare bankruptcy as a result of caregiving-related costs. In this study, we saw one caregiver who had defaulted on loan repayments and lived in fear of their property being auctioned, and other caregivers selling land and livestock to raise funds necessary for treatment and care. This then leads to a vicious cycle.

4.4.3 CAREGIVER'S SUPPORT SYSTEMS

The principal source of support was from the family members. The neighbors, the community and the church also played different roles that were considered valuable by the caregivers.

Family

One may infer that it is normal practice for extended family and community to be involved in caring for ill relatives and to support bereaved families. These findings resonate with published accounts of caregivers who reported their expectations of moral support from family and community members and the value of such support in easing their burden of care (Amoateng, *et al.*, 2015).

Recent studies in the context of palliative care in Africa argue that modernization, evidenced by rural-urban migration and changes in traditional family structures, has culminated in attrition of extended kinship and community support systems for ill persons (Gysels, Pell, Straus, & Pool, 2011; Powell & Hunt, 2013). This was noted in most of our participants. One caregiver was tasked with the primary role, while other family members were more detached and away in urban areas. The caregivers, in their assessment, felt that there was a lack of family cohesion, and sometimes felt socially isolated from the rest of the rest of the family as a consequence of the caregiving.

Regardless of the situation, caregivers chose to care for their loved ones. Reluctance to do so would have been perceived as socially and culturally objectionable (Mnyaka & Motlhabi 2005). While the fear of being in breach of social and cultural norms might render it difficult for caregivers to openly express their struggles to the rest of their family members, they may feel comfortable enough to express it to the researcher. This was the case, in half of the interviews. These findings are consistent with, Burridge, *et al* (2007) who suggested that failure to disclose reluctance might be indicative of two things: the participants desire to give desirable responses and caregiver reluctance being deemed a taboo topic.

Social and Community networks

The social and community networks are still present and play various roles in the support for the caregiver. Other supporters tended to be involved in practical activities, such as doing laundry, collecting firewood, bathing the patient, and watching over the patient so that the caregiver can go to the market. This kind of support was considered valuable by the caregivers. It also seemed expected from the caregivers, maybe because of the communal nature of the African society. In America, Cagle and Kovacs (2011) also reported on caregivers receiving support from multiple areas including family, friends, and neighbors.

Role of religion

Majority of caregivers depended on religion and their faith to help them. Its findings are similar to those of Maree, *et al* (2007) in South Africa who found that almost all caregivers turned to religion for coping. Given the perceived need for caregivers for spiritual support and the perceived absence from health care workers, there may be a role for the church or

other religious organization to fill this need. In addition, these findings may identify an educational need for healthcare workers in the area of spirituality and end of life care.

Other healthcare workers

Caregivers appreciated help from healthcare workers, both in and out of the hospital. Enhanced access to professional advice is a viable way to increase caregiver's confidence in their ability to carry out practical aspects of home-based care. Nurses and other health care workers can provide information and skills training on various aspects need to offer quality home-based care (Bee, Barnes & Luker, 2009).

Caregivers in this study appreciated phone calls from the palliative department or receiving advice or instruction via telephone guide them on what to do. Telehealth has been used in the West to support and guide caregivers and provide online support group meetings (Chi & Demiris, 2015). In a study in Kenya, Uganda, and Malawi, healthcare workers were able to access patients in homes even without running water or electricity to support caregivers through a simple but sophisticated form of telehealth. Even where caregivers did not have airtime, they were encouraged to 'flash' the healthcare providers who would then call back and respond to the patients' and caregivers needs (Grant, Brown, Leng, Bettega & Murray, 2011).

CHAPTER FIVE

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

5.1 Introduction

This final chapter shall include a summary of the findings, and the conclusions arrived at based on the results. It also includes policy recommendations and interventions that can be done and recommendations for future research.

5.2 Summary

This qualitative study sought to explore the cancer caregiver burden and its main contributors, the impact on the caregivers, and their sources of support.

The caregiver burden in this study is attributable to four main things, practical challenges related to competing tasks, symptom management, difficult hospital experiences and financial constraints. For female caregivers, there is added to the vulnerability that predisposes them to abuse or potential for abuse, whether physical, emotional or sexual. The result of this is a negative impact on the caregivers physically, emotionally, psychologically and financially. Spiritually, the effect on them was an increased hope, even for the recovery of their patients.

Caregivers derived their support from family members, neighbors, friends, religious institutions they are affiliated to and other healthcare providers- mostly family members or from nearby health centers. However, caregivers felt that the family members could contribute and support them a lot more.

5.3 Conclusions

The caregiver burden for advanced cancer patients in this setting is due to financial strains, competing tasks, and lack of access to quality and timely healthcare and information on how to manage symptoms. In females, the extra burden is the vulnerability and potential for sexual, physical or emotional abuse. All these, despite caregivers having a sense of joy and accomplishment in their roles, affect the caregivers in a physical, emotional, psychological, spiritual and financial way.

Families, neighbors, religious institutions and other healthcare providers constitute their support system. However, their contribution is far less compared to what the caregivers actually need. The caregivers suggested interventions included counseling, debriefing, skills training, nutrition advice, and telephone calls. All further interventions should not add further strain in terms of finances.

5.4 Recommendations

5.4.1 Policy Recommendations

- i. There is a need to have a primary palliative nurse who can coordinate care between a tertiary facility and the dispensaries/health centers within the patient's reach.
- ii. Continue and expand using phone calls to communicate with patients and caregivers in an attempt to meet their needs
- iii. Palliative care units need to be more proactive about support groups for caregivers, where they can share their challenges and be of encouragement to each other.
- iv. A caregiver- tailored screening tool could be introduced to assess for caregiving burden, the impact on the caregiver and their ability to care for their patients. This would help healthcare workers assess the caregivers' willingness and ability to offer quality end of life care and any further interventions that may be of benefit to the caregiver.

- v. Training the community health workers, church-based workers, and volunteers and equipping them with simple palliative care manuals that have simple protocols will be a useful way to maximize skills available at the community level, in communication with palliative care nurses, clinicians and doctors.
- vi. The family debriefing meetings should be done with the primary caregiver and other support persons where necessary so that they can all be on board on what the patient and primary caregiver needs. The debriefing meetings should include a session/talk on how the other family members should support the primary caregiver.
- vii. At the policy level, NHIF approvals for diagnostic and treatments for cancer patients should be easier than the current process. Provisions should be made to make morphine and other essential palliative care drugs more accessible and highly subsidized. The screening programs for cancers should also be subsidized to allow for earlier rather than later cancer diagnosis.

5.4.2 Recommendations for further research

- i. A study in this context on the use and impact of phone calls to reduce caregiver burden and caregiver unmet needs that could potentially be done as a quality improvement project
- ii. A study on the effectiveness of family meetings/conferences with the entire family in reducing primary caregiver burden
- iii. A study on the impact of a caregiver-tailored screening tool on caregiver's quality of life
- iv. Further study into gender-based violence in home-based caregivers

REFERENCES

- Adol, E. A. (2014). Prevalence of depression among caregivers of patients receiving palliative care in Kenyatta national hospital .
- Akpan-Idiok, P.A. &, Anarado, A. N. (2014). Perceptions of Burden of Caregiving by Informal Caregivers of Cancer patients attending University of Calabar Teaching Hospital, Calabar, Nigeria . *Pan African Medical Journal*, 18 (159).
- Azzani, M., Roslani, A. C., & Su, T. T. (2015). The perceived cancer-related financial hardship among patients and their families: A systematic review. *Supportive Care in Cancer*, 23, 889–898.
- Braun M., Mikulincer M., Rydall A., Walsh A. & Rodin G. (2007). Hidden Morbidity in Cancer: Spouse caregivers. *Journal of Clinical Oncology*. 25 (30) 4829-4834
- Braun V. & Clarke V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*. 3 (2) 77-101
- Burns C.M. (2004). Patients with advanced cancer and family caregivers' knowledge of health and community services: a longitudinal study . *Health and Social Care in the Community* , 12 (6), 488-503.
- Cagle J.G., &, Kovacs P.J. (2011). Informal caregivers of cancer patients: perceptions about preparedness and support during hospice care. *The journal of Gerontological social work*. 54 (1). 92-115
- Chi N. &,Demiris G. (2015). A systematic review of telehealth tools and interventions to support family caregivers. *Journal of telemedicine and telecare*, 21 (1) 37-44
- Chua C.K.T., Wu J.T., Wong Y.Y., Qu L., Tan Y.Y., Neo P.S.H., & Pang G.Y. (2016). Caregiving and its resulting effects- the care study to evaluate the effects of caregiving on caregivers of patients with advanced cancers. *Cancers*. (8) 105

- Connolly J. & Milligan S. (2014). Knowledge and skills needed by informal carers to look after terminally ill patients at home. *End of life journal*. 4 (2)
- Dionne-Odom J.N., Azuero A., Lyonns K.D., Hull J.G., Tosteson T., Li Z., &, Bakitas M.A. (2015). Benefits of Early versus delayed palliative care to informal caregivers of patients with advanced cancer: Outcomes from the ENABLE III Randomized controlled trial. *Journal of Clinical Oncology*. 33 (13) 1446-1552
- Downing J., Gomes B., Munene G., Daveson B.A., Powell R.A., Mwangi-Powell F. N., . & Harding R. (2014). Public preferences and priorities for end-of-life care in Kenya: a population-based street survey . *BMC Palliative Care*, 13 (4).
- Girgis A., Johnson C., Aoun S. & Currow D. (2006). Challenges experienced by informal caregivers in cancer. *Psycho-oncology* 34 (1)
- Given B.A., Given A.W. & Sherwood P. (2012). The challenge of quality cancer care for family caregivers. *Seminars in Oncology Nursing*. 28 (4) 205-212
- Glajchen M. (2012). Physical well-being of oncology caregivers: an important quality of life domain. *Seminars in oncology nursing*. 28 (4) 226-235.
- Grant L., Brown J., Leng M., Bettega N. & Murray S.A. (2011). Palliative care making a difference in rural Uganda, Kenya and Malawi: three rapid evaluation field studies. *BMC Palliative Care*. 10 (8)
- Guest G., Bunce A. & Johnson L. (2006). How many interviews are enough? *Field Methods* 18 (1) 59-82
- Harding R., Ephiaphaniou E., Hamilton D., Bridger S., Robinson V., George R., . & Higginson I.J. (2012). What are the perceived needs and challenges in home cancer

- palliative care? Qualitative data to construct a feasible psycho-educational intervention. *Supportive Care in Cancer*. 20 (9) 1975-1982
- Harding R. & Higginson I.J. (2004). Palliative Care in Sub-Saharan Africa: An Appraisal. *Kings College, London*
- Harding R. & Higginson I.J (2005). Palliative care in Sub-Saharan Africa. *The Lancet*, 365 (9475) 1971-1977
- Harding R., Leam C., Pearce A., Taylor E. & Higginson I.J. (2002). A multiprofessional short-term group intervention for informal caregivers of patients using a home palliative care service. *Journal of Palliative Care*. 18 (4) 275-281
- Jack B.A, Kirton J., Birakutaraki J. & Merriman A. (2011). A bridge to the hospice!: the impact of a Community Volunteer Programme in Uganda. . *Palliative Medicine*, 25 (7), 706-715.
- Joad A.S.K., Mayamoi T.C. & Chaturvedi M. (2011). What does the informal caregiver of a terminally ill cancer patient need? A study from a cancer center. *Indian Journal of Palliative Care*. 17 (3) 191-196
- Kenya Hospices and Palliative Care Association. (2015) Annual Report 2015. Retrieved from kehpc.org/wp-content/uploads/FINAL_ANNUAL_REPORT_2015-.pdf
- Kim Y. K., Kashy D.A., Spillers R.L. & Evans T.V. (2010). Needs assessment of family caregivers of cancer survivors: three cohorts comparison . *Psycho-oncology*, 19, 573-582.
- Kim Y. & Schulz R. (2008). Family caregivers' strains: comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *Journal of Aging Health*, 20 (5), 483-503.

- Kurtz M.E., Kurtz J. C., Given C.W. & Given B.A. (2004). Depression and physical health among family caregivers of geriatric patients with cancer – a longitudinal view. *Medical Science Monitor*, 10 (8), 447-456.
- Lindsey E., Hirschfeld M. & Tlou S. (2003). Home-based care in Botswana: experiences of older women and young girls. *Healthcare women Int* 24 (6) 486-501
- Litzelman K., Kent E.E., Mollica M. & Rowland J.H. (2016). How does caregiver well being relate to perceived quality of care in patients with cancer? Exploring associations and pathways. *Journal of Clinical Oncology* 34 (29) 3554-3561
- Lkhoyaali S., El Haj M.A., El Omrani F., Layachi M., Ismail N., Mrabti H. & Errihani H. (2015). The burden among family caregivers of elderly cancer patients: prospective study in a Moroccan population. *BMC Research Notes* 8: 347
- Maltby K. F., Sanderson C.R., Lobb E. A. & Phillips J.L (2017). Sleep disturbances in caregivers of patients with advanced cancer: A systematic review. *Palliative & Supportive Care*, 15 (1), 125-140.
- Maree C.J.E., Moshima D., Ngubeni M. & Zondi L. (2017). On being a caregiver: The experiences of South African family caregivers caring for cancer patients. *European Journal of Cancer Care*. 27 (2) doi: 10.1111/ecc.12801.
- Milne J. & Oberle K. (2005). Enhancing rigor in a qualitative description: a case study. *Journal of Wound Ostomy & Continence Nursing*. 32 (6) 413-420
- Ministry of Health. (2013). National Palliative Care Guidelines. Nairobi, Kenya. Government of Kenya
- Ministry of Public Health and Sanitation & Ministry of Medical Services. (2011). National Cancer Control Strategy. *Nairobi, Kenya*. Government of Kenya
- Mnyaka M. & Molthabi M. (2015). The African concept of Ubuntu/Botho and its socio-moral significance. *Black Theology* 3 (2) 215-237

- Nayak M.G., George A., Vidyasagar M.A., Mathey A., Nayak S., Nayak B.S., .&Kamath A. (2017).Quality of life among cancer patients.*Indian Journal of Palliative Care.*23 (4) 445-450.
- Noor A.M., Amin A.A., Gething P.W., Atkinson P.M., Hay A.I. & Snow R.W. (2006). Modelling distances travelled to government health services in Kenya. *Tropical Medicine and International Health.* 11 (2) 188-196.
- Olagoke A. (2006). Gendered home-based care in South Africa: more trouble for the troubled. *Journal of AIDS research.* 5 (3) 237-247
- O'Neil D.S., Prigerson H.G., Mmoledi C.K., Sobekwa M.,Ratshikana-Moloko M., Tsitsi J.M.,.....& Blanchard C.L. (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 Symptom Management.* <https://doi.org/10.1016/j.jpainsymman.2018.03.017>
- Otis-Green A. & Juarez G. (2012). Enhancing the emotional well being of family caregivers. *Seminars in Oncology Nursing.* 28 (4) 246-255
- Romito F., Goldzweig G., Cormio C., Hagedoorn M. & Anderson B. (2013). Informal caregiving for cancer patients. *Cancer* 119 (11) 260-269
- Rossi P.G., Beccaro M., Miccinesi G., Borgia P., Constatini M., Chini F., ... Montella M. (2007). Dying of cancer in Italy: impact on family and caregiver. The Italian Survey of Dying of Cancer . *Journal of Epidemiology Community Health,* 61, 547-554.
- Ryn M., Sanders S., Kahn K., Houtven C., Griffin J.M., Martin M., ...& Rowland J. (2011). Objective burden, resources and other stressors among informal cancer caregivers: a hidden quality issue. *Psychooncology.* 20 (1) 44-52

- Saunders B., Sim J., Kingstone T., Baker S., Waterfield J., Bartlam B., . & Jinks C. (2017) Saturation in qualitative research: exploring its conceptualization and operationalization. *Quality and Quantity* <https://doi.org/10.1007/s11135-017-0574-8>
- Schulz R. & Beach S.R (1999). Caregiving as a Risk Factor for Morality. *JAMA*, 282 (23), 2215-2219.
- Selman L., Brighton L.J., Sinclair S., Karvinen I., Egan R., Speck P,.....&Hope J. (2018) Patients' and caregivers' needs, experiences, preferences and research priorities in spiritual care: A focus group study across nine countries. *Palliative medicine* 32 (1) 216-230.
- Selman L., Higgison, I. J., Aguopo, G., Downing, J., Gwyther , L., Mashao, T., et al. (2011). Quality of Life among patients receiving palliative care in Uganda and South Africa: A multicentered study. *Health and quality outcomes*, 9 (21), 01-14.
- Streid J., Harding R., Agupio G., Dinat N., Downing J., Gwyther L.,& Selman L. (2014). Stressors and Resources of Caregivers of Patients With Incurable Progressive Illness in SubSaharan Africa . *Qualitative Health Research* .
- Stenberg U., Ruland C.M. & Miaskowki C. (2010). Review of the literature on the effects of caring for a patient with cancer. *Psycho-Oncology*, 19, 1013-1025.
- Vespa, A., Spatuzzi, R., Merico, F., Ottaviani, M., Fabbietti, P., Meloni, C., Raucci, L., Ricciuti, M., Bilancia, D., Pelliccioni, G., & Giulietti, M.V. (2018). Spiritual well-being associated with personality traits and quality of life in family caregivers of cancer patients. *Supportive Care in Cancer*, 1-8.
- Walker A. (2011). Perceptions of family cancer caregivers in Tanzania: A qualitative study.

- World Health Organization. (2009). Retrieved from
https://www.nbt.nhs.uk/sites/default/files/filedepot/.../WHO_Performance_Status.doc
- World Health Organization (2009). WHO definition of Palliative care. Retrieved from
<http://www.who.int/cancer/palliative/definition/en/>
- World Health Organization. (2007). Cancer control knowledge into action. Geneva, Switzerland
- WHO (2014). Cancer country profiles, 2014: Kenya http://www.who.int/cancer/country-profiles/ken_en.pdf?ua=1
- World Health Organization. (2018) Cancer fact sheet. Retrieved from
<http://www.who.int/mediacentre/factsheets/fs297/en/>
- Yarboff K. R. & Kim Y. (2009). Time costs associated with informal caregiving for cancer survivors. *Cancer* 115:4362-4373.
- Yusuf A.J., Adamu A. & Nuhu F.T. (2011). Cancer burden among poor caregivers of patients with cancer in an urban African setting. *Psycho-oncology* 20 (902-905)
- Zarit S.H., Reever, K.E. & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *The Gerontologist* 20(6), 649–655.
- Zhang Q., Yao D., Yang J. & Zhou Y. (2014). Factors influencing sleep disturbances among spouse caregivers of cancer patients in Northeast China. *PLOS ONE* 9 (10)
<https://doi.org/10.1371/journal.pone.0108614>
- Ziebland S. & McPhearson A. (2006) Making sense of qualitative data analysis: an introduction with illustrations from DIPEX (personal experiences of health and illness). *Medical Education* (40) 405-414

APPENDIX 1: SEMI-STRUCTURED INTERVIEW GUIDE

Experiences of home-based caregivers of advanced cancer patients from a regional

Age..... Gender of caregiver..... Gender of patient.....

Relationship to patient.....

How long have you taken care of the patient?.....

Education level Religion.....

Work /occupation prior to taking care of patient.....

Current work/Occupation (if still working).....

1. Please tell me how your typical or usual day looks like from morning to night.
2. What gives you joy/ makes you happy about taking care of your patient?
3. What makes it difficult for you to take care of your patient?
4. Have you received any training on how to take care of the patient?
5. Which pain medication do you use for your patient? How do you get it?
6. Please tell me about the availability of other family members to help and support you.
7. Please tell me about your experiences in the hospital when you need to take the patient there.
8. Are there times you consider traditional healing methods?
9. How has taking care of the patient affected your life? Physically, Spiritually, Psychosocially, financially?
10. Kijabe tries to put patients and caregivers into support groups. What have been your experiences with them?
11. If there were something that would make it easier for you to take care of your patient, what would it be?
12. Is there anything else you would like to add/talk about in regard to taking care of your patient

Mwongozo wa Mahojiano

Mapito ya wauguzi wa nyumbani wakiwachunga wagonjwa wao kutoka hospitali ya AIC Kijabe wenye saratani ilioenea wanaofanyiwa tibashifa nyumbani.

Nambari...

Umri wa Muuguzi..... Jinsia ya Muuguzi Jinsia ya mgonjwa.....

Uhusiano na mgonjwa.....

Muda umemuuguza mgonjwa

Kiwango cha Elimu Dini yako.....

Kazi uliyofanya kabla ya kuuguza mgonjwa

Kazi unayofanya sasa (ikiwa bado unafanya kazi)

1. Naomba unieleze vile siku yako ya kawaida huwa kutoka asubuhi mpaka usiku.
2. Nini inakupa raha unaposhughulikia na kumuuguza mgonjwa wako?
3. Naomba uniambie nini inafanya kumuuguza mgonjwa wako kuwa ngumu?
4. Umepata mafunzo yoyote yakukuwezesha kumuuguza mgonjwa wako?
5. Naomba unieleze dawa anazotumia wakati mgonjwa ako na uchungu. Mnazipata wapi? Ni rahisi kuzipata?
6. Tafadhali nieleze kuhusu uwepo wa jamii na familia kukusaidia kumuuguza mgonjwa wenu.
7. Naomba unieleze yale unayopitia hospitalini unapohitaji kumpeleka mgonjwa wako huko.
8. Kuna wakati wauguzi wengine wanatumia dawa za kienyeji wanapoona mgonjwa amelemewa. Mmejaribu kutumia madawa ya kienyeji?
9. Naomba unieleze jinsi kuuguza mgonjwa wako imekuadhiri . Kifedha? Kimwili? Kiroho? Kisaikologia?

10. Hospitali ya Kijabe hujaribu kuweka wagonjwa na wauguze katika vikundi vya kusaidiana, yaani support groups. Umejihisi vipi kuhusu muda wako katika hivyo vikundi?

11. Ikiwa kuna kitu ama jambo ambalo lingekusaidia kumuuguza mgonjwa huyu, ingekuwa nini?

12. Kuna jambo lolote ambalo ungetaka kuniambia kuhusu kuuguza/kuchunga mgonjwa wako?

APPENDIX 2: INFORMED CONSENT FORM

Experiences of home-based caregivers of advanced cancer patients from a regional faith-based palliative care center in Kenya.

This consent form is for patients with advanced cancer and their primary home-based caregivers in Kijabe Hospital who we are inviting to participate in a research titled: Experience of home-based caregivers in offering end of life care for advanced cancer patients.

Principle Investigator: Faith Lelei-Mailu

Organization; Kijabe Hospital and Kabarak University

Sponsor: Micro Research

This informed consent has 2 parts: Information sheet and the Certificate of Consent if you choose to participate in the study.

PART I: INFORMATION SHEET

My name is Faith Lelei-Mailu. I am a Family Medicine Masters student who has an interest in palliative care. I am doing a study on caregivers of advanced cancer patients to find out their experiences in taking care of very sick patients at home. We want to understand the challenges they go through so that we can come seek ways to address them and better support the caregivers.

This study will involve the caregivers' participation in an interview, which will take about one to one and a half hours. We have invited you to take part in this study because we feel

your experience, as a caregiver will contribute a lot to our understanding of the challenges that caregivers go through.

Your participation in this study is entirely voluntary. It is your choice whether to participate or not. If you choose not to participate, all the services you and your patient receive in this hospital will continue and nothing will change. We will be asking you to share sensitive information and you may feel uncomfortable or feel distressed. You do not have to answer any question or take part in the discussion if you do not wish to do so. You do not have to give us any reason for not answering any question or for refusing to take part in the interview.

We would like you to know that although there may be no direct benefit to you, your participation in the study will enable us obtain findings, which, we hope, could help you in future as well as others in a similar situation.

The information you give us will be only be accessed by the team that is doing the research. Any information about you will have a number on it instead of your name. Only the researchers will know what your number is.

Once we complete the study, we will share the results of the study together with you and the patients first. We shall do this during the home visits, support groups and clinic reviews in the hospital. After sharing with the participants of the study, we shall also share the results with other people who take care of very sick patients such as the nurses, doctors, and other health care providers, religious leaders. Following the meetings, we will publish the results so that others can benefit and learn from the research.

If you have questions you can ask them now or later. If you wish, you may contact me- Dr. Faith Lelei-Mailu on 0723455261. This proposal has been reviewed and approved by the Ethics and Research Committee of both Kabarak University and Kijabe Hospital. The function of both committees is to make sure that you and the other research participants are protected from harm. You may contact Carol Mwangi from the Kijabe Research and Ethics committee on 0720896182 or Dr. James Kay 0724887431 from the Kabarak Research and Ethics committee if you have any concerns.

PART II: CERTIFICATE OF CONSENT.

I have been invited to participate in a study to find out the experience of home-based caregivers in offering end of life care at home.

I have read the above information or it has been read to me.

I have been given the opportunity to ask questions about it, and any questions I had have been answered to my satisfaction.

I consent to be a voluntary participant in this study.

Name of Participant.....

National Identification Number.....Date.....

Signature/thumb print of participant (caregiver).....

Name of Patient.....

Signature/thumb print of the patient.....Date.....

Researcher/Research

Assistant.....

Signature/thumb printDate.....

FOMU YA MAKUBALIANO

Mapito ya wauguzi wa nyumbani wakiwachunga wagonjwa wao kutoka hospitali ya AIC Kijabe wenye saratani ilioenea wanaofanyiwa tibashifa nyumbani.

SEHEMU YA KWANZA-MAELEZO

Fomu hii ni ya wagonjwa wanaouguza saratani iliyoenea inayo thibitiwa na tibashifa. Inalenga zaidi watu wanaouguza wagonjwa hawa. Tunawaalika kujiunga na utafiti huu wenye mada “ Mapito ya wauguzi wa nyumbani wakiwachunga wagonjwa wenye saratani ilioenea wanaofanyiwa tibashifa nyumbani.”

Mtafiti mkuu: Daktari Faith Lelei-Mailu

Hopitali/Chuo kikuu utafiti unaofanyiwa: Hospitali ya Kijabe na Chuo Kikuu cha Kabarak.

Mfadhili wa utafiti: Micro-Research

Fomu hii inasehemu mbili- fomu ya maelezo na cheti cha makubaliano ambayo utatia sahihi pindi utakapokubali kujiunga na utafiti huu.

FOMU YA MAELEZO

Mimi ni Daktari Faith Lelei-Mailu. Ninasomea shahada ya juu katika taaluma ya matibabu ya Familia nikizingatia tibashifa. Tibashifa ni huduma inayopewa watu wanaouguza wagonjwa yasiyo na tiba kama saratani. Ninafanya utafiti nikizingatia watu wanaouguza wagonjwa wao wenye saratani ilioenea kufahamu hisia zao na mapito yao wakiuguza wagonjwa hawa nyumbani.

Tungependa kufahamu changamoto mnazopitia ili tutambue namna za kukabiliana nazo na jinsi za kuwapa motisha watu wengine wanaouguza wapendwa wao nyumbani.

Utafiti huu unahitaji muuguzi mlinzi wa mgonjwa kuhojiwa kwa muda wa dakika arobaini na tano ama hata muda wa saa moja. Tumekuuliza ujiunge na utafiti huu kwa sababu yale yote umepitia ukimwuguza mgonjwa wako yatatusaidia kuelewa changamoto nyingi wauguzi wenzako wa nyumbani wanapitia.

Kujiunga na utafiti huu ni kwa hiari yako. Uko na huru kuamua kujiunga au kutojiungana utafiti huu. Ukiamua kutojiunga na utafiti huu wewe na mgonjwa wako mtaendelea kupata huduma na mtatibabu yote kama kawaida.

Mahojiano yangu yatakuwa na maswali ya ndani kuhusu hali ya mgonjwa na famililia yanayoweza zua hisia chungu kidogo. Kama swali au mjadala wowote unazua hisia kali/chungu sana kwako sio lazima ujibu swala hilo au ujiunge na mjadala huo. Unaweza kuomba tusitishie mahojiano yetu wakati wowote. Pia si lazima utupatie sababu zako kutojibu maswali yoyote au kukataa kuhojiwa.

Kuna uwezekano kwamba utafiti huu hautakufaa kwa njia yoyote. Lakini kujiunga na kuchangia utafiti huu utatusaidia sisi wahudumu wa afya kupata maelezo tutakayotumia kuwapa motisha watu wengine wanaouguza wagonjwa wao wa saratani nyumbani.

Maelezo utakayotupatia yatawekwa kisiri na yatajulikana na sisi tunaendeleza utafiti huu pekee yake. Maelezo haya yatahifadhiwa na namba maalum ya utafiti ; hakuna mahali jina lako /la mgonjwa wako litatumika. Namba hii itafahamika nami na watafiti wenzangu.

Tukikamilisha utafiti huu, tutawaelezea matokeo ya utafiti huu-pamoja na wagonjwa wetu wanaopata tibashifa Kijabe. Tutaeneza matokeo haya kupitia vikundi vya motisha ya wagonjwa na wauguzi wao wa nyumbani(support group) na pia wakati wa kliniki za wagonjwa humu hospitalini. Pia, tutaeleza wauguzi, madaktari na wahudumu wote wa afya matokeo haya, sanasana wahohudumia wagonjwa wa tibashifa.

Pia, tutachapisha matokeo yetu kwenye nakala za utafiti ili wahudumu wengine wafaidike kutoka utafiti wetu. Ukiwa na maswali, unaeza uliza wakati juu. Ukiwa na hoja au swali baada ya wakati huu, wasiliana nami Dr. Faith Lelei kwa simu ya rununu 0723455261.

Pendekezo la utafiti huu umekaguliwa na kamiti ya utafiti ya hospitali ya AIC Kijabe na Chuo Kikuu cha Kabarak. Kazi kuu ya kamiti hizo mbili ni kuhakikisha ya kuwa wahusika wa utafiti huu wamelindwa kutokana na madhara yoyote. Ikiwa una maswali yoyote kwa kamati hizi, unaweza wasiliana na Carol Mwangi kutoka Kijabe kwa nambari ya simu 0720896182 au Dr. James Kay kutoka Chuo Kikuu cha Kabarak kwa nambari ya simu 0724887431.

SEHEMU YA PILI: CHETI CHA MAKUBALIANO

Nimealikwa nijunge na utafiti wenye mada “ Mapito ya wauguzi wa nyumbani wakiwachunga wagonjwa wa saratani ilioenea wanaofanyiwa tibashifa nyumbani”.

Nimesoma maelezo haya ama nimesomewa na kuelezewa. Nimepewa nafasi ya kuuliza maswali nimeyokuwa nayo, na yamejibiwa kikamilifu. Najiunga kwa utafiti huu kwa hiari yangu.

Jina la Muuguzi

Sahihi.....

Tarehe.....

Mtafiti.....

Sahihi

Tarehe.....

