PREDICTORS OF HEALTH-RELATED QUALITY OF LIFE AMONG PRIMARY CAREGIVERS OF CANCER PATIENTS IN KAKAMEGA COUNTY, KENYA

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A Research Thesis Submitted in Partial Fulfillment of the Requirement for the award of the Degree of Master of Science in Advanced Nursing Practice (Community Health and Primary Health Care) of Masinde Muliro University of Science and Technology

April, 2024

DECLARATION

This thesis is my original work prepared with no other than the indicated sources and support and has not been presented elsewhere for a degree or any other award.

Signature ……. Date……

Hellen Aoko Odeny

HNR/G/01-53028/2018

CERTIFICATION

The undersigned certify that they have read and hereby recommended for acceptance of Masinde Muliro University of Science and Technology a thesis entitled **"Predictors of Health-Related Quality of Life among Primary Caregivers of Cancer Patients in Kakamega County, Kenya."**

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DEDICATION

I dedicate this thesis to all primary caregivers of cancer patients because the effects of cancer diagnosis go beyond the patient, family and community yet the person who bears the burden of care giving are the primary caregivers.

ACKNOWLEDGEMENTS

First and foremost, I am very much grateful to the Almighty Father for His faithfulness throughout this study. I wish to express my sincere gratitude to my able supervisors: Dr. Tecla Sum and Mr. John Arudo for their endless support, encouragement, guidance and insightful advice throughout my study. I would also like to express my heartfelt appreciation to both my external and internal examiners together with panel of experts during my final defense for their valuable contributions towards this thesis. I wish to appreciate the research assistants who worked tirelessly from the pretest of the data collection tool during pilot to the time we were collecting data, community health volunteers and health records officers who accepted to voluntarily assist in data collection and identification of the caregivers from the records. I will not forget to thank my family for their unlimited support, encouragement and creating an enabling environment to complete this thesis.

Thanks everyone who supported me unconditionally and may God's blessings you all.

ABSTRACT

Primary Stress from the burden of providing care for a patient with cancer frequently results in reduced Health Related Quality of Life (HRQOL) for caregivers. The majority of research done in Western populations has demonstrated a link between higher caring stress and poorer mental and physical health as well as earlier death among family caregivers. The results of those studies could not be directly applicable to the people of Kenya, particularly in Western Kenya where the sociocultural and ethnic backgrounds are distinct. Therefore, the purpose of this study was to identify the variables that were associated with the health-related quality of life of primary caregivers for cancer patients in Kakamega County. The specific objectives of the proposed study were to assess the socio-economic factors, determine patient factors and evaluate and the relationship between psychological factors and HRQoL among primary care givers of cancer patients in Kakamega County. This was an institutional-based transverse analytical study design. Kakamega County Referral Hospital was purposively sampled as it has the hospital with western region cancer centre. The sampling unit were caregivers of cancer patients who were seen in the hospital. The caregivers were systematically sampled from a list drawn from the Cancer Centre register of cancer patients where the caregivers are captured as their treatment supporters and each and every cancer patient is expected to have a caregiver. The sample size was 422 primary care givers after calculation. Data collection tool was contracted from a QOL questionnaire such as WHOQoL-BREF which was created to gauge both objective and subjective aspect of QOL and PHQ9/GAD-7 which are more sensitive and has a wider applicability. The SPSS version 26 is a statistical package for social sciences was used for data entry, cleaning and analysis. Socio-economic factors such as marital status (P=0.043), residence (P=0.005), occupation (P=0.011) and income (P=0.027) were significantly associated with HRQoL. Patient related factors like mode of treatment (P=0.022) and type of test done(P=0.033) were significantly associated with HRQoL. Caregiver knowledge and family support related factors like seriousness of cancer as a disease(P=0.000), other family members offering help with care(P=0.004), other family members with cancer(P=0.038) and chronic illness(P=0.000) were significantly associated with HRQoL. Psychological related factors like depression (P=0.000), anxiety(P=0.017), perceived quality of life(P=0.000) and being satisfied with one's health (P=0.013) were significantly associated with HRQoL. The study concluded that socio-economic factors, psychological factors, patient factors and care giver's knowledge on cancer were associated with health-related quality of life among caregivers of cancer patients. The study recommended that financial charges for cancer management could be subsided as this could relieve the financial burden care givers are facing. Other family members should support primary care givers not only financially, but also psychologically to ease the burden of the primary care giver. Health care providers should create sometime to educate caregivers on various types of cancer their management, side effect of the drugs and how to assist their patients at home thereby easing the burden of cancer, as a seriousness of the disease. Psychosocial support group networks should be established for caregivers through multiple communication channels thereby reducing the mental and psychological burden experienced by caregivers.

TABLE OF CONTENTS

TITLE PAGE ……..i

DECLARATION ii

DEDICATION iii

ACKNOWLEDGEMENTS.....iv

ABSTRACT v

LIST OF TABLES..... vii

LIST OF FIGURES.....ix

LIST OF ABBREVIATIONS AND ACRONYMS.....x

OPERATIONAL DEFINITIONS OF KEY TERMS.....xi

CHAPTER ONE:INTRODUCTION.....1

1.0 Overview 1

1.1 Background to the Study.....1

1.2 Statement of the problem 3

1.3 Justification of the study 4

1.4 Main Objective 6

1.4.1 Specific objectives 6

1.5 Research Questions.....6

1.6 Limitations of the study 6

1.7 Conceptual framework.....7

CHAPTER TWO:LITERATURE REVIEW 10

2.0 Overview 10

2.1 Cancer and its burden on caregivers 10

2.2 Health Related Quality of Life (HRQOL) among primary caregivers 15

2.3 Predictors of Health-Related Quality of Life (HRQOL) among primary caregivers 17

2.3.1 Socio-demographic and economic factors affecting Health Related Quality of Life of primary caregivers of cancer patients.....17

2.3.2 Economic factors affecting Health Related Quality of Life of primary caregivers of cancer patients 19

2.4 Psychological factors affecting Health Related Quality of Life of primary caregivers of cancer patients 22

2.4.1 Primary caregiver's Stress.....22

2.4.2 Primary caregiver's Depression.....23

2.4.3 Primary Caregiver's Anxiety.....24

2.5. Hospital factors affecting HRQoL of primary caregivers....26
2.5.1 Policies and guidelines....26
2.5.2 Human resource....27
2.5.3 Cancer diagnosis....27
2.5.4 Length of hospitalization....28
2.5.5 Care giving intensity and duration....29
2.5.6 Marital satisfaction....29
2.5.7 Caregiving self-esteem....29
2.6 Patient factors affecting HRQoL of primary caregivers....30
2.6.1 Types of cancer....30
2.6.3 Cancer diagnosis....30
2.6.4 Length of hospitalization....31
2.6.5 Caregiving intensity and duration....32
2.6.6 Marital satisfaction....32
2.6.7 Caregiving self-esteem....32
2.7 Research gap....33
CHAPTER THREE:METHODOLOGY....34
3.0 Overview....34
3.1 Study Design....34
3.2 Study Site....34
3.3 Study Population....35
3.4 Measurable variables....35
3.5 Inclusion and Exclusion Criteria....35
3.5.1 Inclusion:....35
3.5.2 Exclusion....35
3.6 Sampling....35
3.7 Sample size determination....36
3.8 Data Collection Instruments....37
3.9 Pre-test....39
3.10 Validity....39
3.11 Reliability....40
3.12 Data analysis....41
3.13 Ethical Considerations....42
3.13.1 Beneficence....42
3.13.2 Respect for Human Dignity....43

3.13.3 Justice 43
3.13.4 Confidentiality 44
3.13.5 Informed Consent 44
CHAPTER FOUR:RESULTS 45
4.0 Overview 45
4.1 Socio-demographic information of caregivers 45
4.1.1 Place of Residence 47
4.1.2 Caregiver's information about family cancer history and current care provided 48
4.1.3 Socio-economic factor's influence on health-related quality of life of primary caregivers of cancer patients 50
4.1.4 Family support's influence on health-related quality of life of primary caregivers of cancer patients 53
4.1.5 Caregiver's knowledge on cancer and its influence on health-related quality of life of primary caregivers of cancer patients 54
4.1.6 Multiple regression analysis on Socio-Demographic Information of Caregivers associated with health-related quality of life 59
4.2 To determine the patient factors associated with HRQoL among primary caregivers of cancer patients in Kakamega County 61
4.2.1 Patient socio-demographic characteristics 61
4.2.2 Patient's medical History 62
4.2.3 Type of cancer 63
4.2.4 Patient factor's influence on health-related quality of life of primary caregivers of cancer patients 63
4.2.5 Multiple regression analysis on Patient factors associated with health-related quality of life 66
4.3 To evaluate psychological factors affecting HRQoL among primary caregivers of cancer patients in Kakamega County 67
4.3.1 Descriptive statistics of variables ..... 674.3.2 Relationship between depression, anxiety and health-related quality of life 71
4.3.3 Multiple regression analysis on psychological factors associated with health-related quality of life 73
CHAPTER FIVE:DISCUSSION 75
5.0 Overview 75
5.1 Socio- economic factor's influence on HRQoL among primary caregivers of cancer patients in Kakamega County 75
5.2 Patient Factors influencing HRQoL among primary caregivers of cancer patients in Kakamega County 79

5.3 Caregiver's knowledge and its influence on health-related quality of life of primary caregivers of cancer patients 82
5.5 Psychological factors affecting health-related quality of life of primary caregivers of cancer patients 85

CHAPTER SIX:CONCLUSION AND RECOMMENDATION 87
6.1 Overview 87
6.2 Conclusions 87
6.3 Recommendations 88
6.4 Suggestions for future research 90

REFERENCES 91
APPENDIX I: INFORMATION SHEET 99
APPENDIX II: CONSENT FORM 100
APPENDIX III: QUESTIONNAIRE 101
APPENDIX IV: FOCUS GROUP DISCUSSION WITH PRIMARY CARE GIVERS OF CANCER PATIENTS 110
APPENDIX V: RESEARCH PROPOSAL APPROVAL 114
APPENDIX VI: COUNTY RESEARCH AUTHORIZATION 115
APPENDIX VII: RESEARCH LICENCE 116
APPENDIX VIII: INSTITUTIONAL ETHICS REVIEW COMMITTEE (IERC). 117

LIST OF TABLES

TABLE **PAGE**

Table 3. 1: Cronbach tests....41

Table 4. 1: Socio-demographic information of caregivers....46

Table 4. 2: Caregiver's information about family cancer history and current care provided....49

Table 4.3: Socio-economic factor's influence on health-related quality of life of primary caregivers of cancer patients....52

Table 4. 4: Family support's influence on health-related quality of life of primary caregivers of cancer patients....54

Table 4. 5: Caregiver's knowledge on cancer and its influence health-related quality of life of primary caregivers of cancer patients....56

Table 4. 6: Multiple regression analysis on Socio-Demographic Information of Caregivers associated with health-related quality of life....61

Table 4. 7: Patient socio-demographic characteristics....62

Table 4. 8: Patient's medical History....63

Table 4. 9: Patients factor's influence on health-related quality of life of primary caregivers of cancer patients....66

Table 4. 10: Multiple regression analysis on patient factors associated with health-related quality of life....67

Table 4. 11: Descriptive statistics of variables....69

Table 4. 12: Relationship between depression, anxiety and health-related quality of life....73

Table 4.13 The number of caregivers with depression and anxiety....73

Table 4. 14: Multiple regression analysis on psychological factors associated with health-related quality of life....75

LIST OF FIGURES

FIGURE **PAGE**

Figure 1.1 Conceptual framework 9

Figure 4.1: Place of Residence 47

Figure 4.2: Type of cancer 63

LIST OF ABBREVIATIONS AND ACRONYMS

GAD7	-	Generalized Anxiety Disorder
GLOBOCAN	-	Global Cancer data
W.H.O	-	World Health Organization
HRQoL	-	Health Related Quality of Life
IARC	-	International Agency for Research on Cancer
JOOTRH	-	Jaramogi Oginga Odinga Teaching and Referral Hospital
KCTRH	-	Kakamega County Teaching and Referral Hospital
KDHS	-	Kenya Demographic and Health Survey
MOH	-	Ministry of Health
NCD	-	Non-communicable Diseases
PHQ9	-	Patient Health Questionnaire
SDGs	-	Sustainable Development Goals
WHOQoL-BREF	-	World Health Organization Quality of Life Assesment Tool

OPERATIONAL DEFINITIONS OF KEY TERMS

Anxiety- The feeling of tiredness, overburdened and worrying all the time**.**

Cancer patients - This is a person who has been diagnosed with malignant cells and is receiving medical treatment for a malignant growth

Depression- It is a mental disorder that is generally characterized by loss of interest or pleasure, decreased energy, feeling of guilt or low self-esteem, difficulty sleeping, decreased appetite, feeling of tiredness, lack of concentration and a constant feeling of sadness

Health- The WHO defines health as "a state of complete physical, mental and social well-being, and not merely the absence of disease and infirmity"

Health-related quality of life (HRQoL) - It is a multi-dimensional concept that includes domains related to physical, mental, emotional, and social functioning or well-being. A related concept of HRQoL is well-being, which assesses the positive aspects of a person's life, such as positive emotions and life satisfaction. The variables that was measured in physical domain include; personal appearance, pain and weight loss and sleep disturbance. In mental/psychological domain, the variables that were measured include; stress, depression, anxiety, and emotional support. Economic domain includes; standard of living, financial independence and job /unemployment.

Hope-It is a reflection of future oriented motivational process where the caregiver has an expectation towards attaining a desirable goal.

Primary caregivers – Primary caregivers where be a person who most often helps the person with cancer and is not paid to do so. In most cases, the main (primary) caregiver is a spouse, partner, parent, or an adult child. When family is not around, close friends,

co-workers, or neighbours may fill this role. The caregiver has a key role in the patient's care.

Quality of life- It is defined as an overall general well-being that comprises objective descriptors and subjective evaluations of physical, material, social, and emotional well-being together with the extent of personal development and purposeful activity, all weighted by a personal set of values. It includes everything from physical health, family, education, employment, wealth, safety, and security to freedom, religious beliefs and the environment.

Satisfaction- Feeling of contentment with life.

CHAPTER ONE

INTRODUCTION

1.0 Overview

The background information, problem statement, study justification, research objectives, research questions, conceptual framework, and study scope are all presented in this chapter.

1.1 Background to the Study

As the primary cause of disease and death globally, cancer is currently acknowledged as a pandemic. There are no restrictions related to geography, economy, ethnicity, or society (WHO & IARC, 2018). One in six women and one in five men worldwide are predicted to develop cancer at some point in their lives, with 18.1 million new cases and 9.6 million deaths from the disease in 2018. Additionally, statistics indicate that the illness claims the lives of one in eight males and one in eleven women (Bray et al., 2019). According to the World Cancer Report, there might be a 50% increase in cancer rates, or 15 million new cases, by 2020. (WHO & IARC, 2018).

Cancer in Africa is an emerging public health problem. Approximately 25-30% of all cancers in Africa are caused by or associated with infections. Africa and other low- and middle-income regions account for more than half of cases and nearly two-thirds of mortality (Plummer et al., 2021). Kenya's population is also seeing an increase in the cancer rate. With an expected 29,000 new cases and 24,000 cancer deaths recorded in 2018, cancer ranks third nationally in terms of causes of mortality, behind infectious and cardiovascular diseases (MOH, 2018).

Cancer diagnoses have an impact on primary caregivers' quality of life in addition to the patients' health (Hadi et al., 2020). A cancer diagnosis has far-reaching effects on the person receiving the diagnosis as well as their family and the larger community (McKeague et al., 2021). Because cancer is a chronic condition, family members frequently take on the majority of the patient care (Akpan-Idiok et al., 2020). Research indicates that providing treatment to

individuals with cancer can be more difficult due to inadequate diagnosis, delayed identification, and the requirement for a high standard of patient care (Abdullah et al., 2019). The majority of family caregivers for cancer patients are ill-equipped to handle the caregiving responsibilities (Shamsuddin et al., 2019). Because of the stress that comes with being a caregiver, family caregivers of cancer patients frequently experience a reduction in their quality of life (QOL) (Idris et al., 2019). As a result of this declining quality of life (QOL), the caregiver may eventually experience more psychological consequences and a higher chance of dying (Üzar-ÖzçetiŇn et al., 2020).

Cancer burden in western Kenya is a significant health problem and probably affects a larger number of patients and their caregivers (MOH, 2017) as incidence of cancer is seen to be on the rise with an estimated 600 new cancer cases in 2018 to 1800 cancer cases in 2020 as this number is expected to rise by three fold in 2023 (KHIS and MOH, 2019). Aswani and Joyce M. (2022) conducted a study in western Kenya and found an increase in the number of patients with Kaposi's sarcoma associated with the HIV/AIDS pandemic. However, there is a dearth of information regarding studies on the health-related quality of life of primary care providers for cancer patients in western Kenya.

The majority of research done in Western populations has demonstrated a link between higher caring stress and poorer mental and physical health as well as earlier death among family caregivers.

In spite of the increasing incidence of cancer in Kenya, western Kenya included, with attendant burden on caregivers, Data on HRQoL determinants among primary caregivers of cancer patients are few. As a result, by aiming to assess the health-related quality of life of primary caregivers of cancer patients in Kakamega County, this study closes these gaps in the Kenyan literature on cancer research.

1.2 Statement of the problem

The diagnosis of cancer affects not only the health-related quality of life of the patients but also that of primary caregivers (Guerra-Martín *et al.,* 2023). Although caregiver's health is

important and requires attention from healthcare providers, there is lack of support which negatively affects their health and lead to illness (Idris *et al.,* 2019).

The ramifications of cancer diagnosis go far beyond the individual who has been diagnosed to the family and society at large (McKeague et al., 2021). While environmental and lifestyle interventions have greatly increased life expectancy and have greatly improved cancer control, many experts in the field of preventative healthcare believe that not enough has been done to support family caregivers of cancer patients, who frequently experience a reduced quality of life (QOL) as a result of stress related to their caregiving responsibilities. (María Dolores, 2023). It has been reported that being a caregiver for a patient with cancer is associated with anxiety (Sharma *et al.,* 2024), depression (Hossain *et al.,* 2024), sleep disturbance (Rebeka J 2024), fatigue (Haque *et al.,* 2024), impaired quality of life, impact on work, and economic burden (Bed P *et al.,* 2024).

An rising number of cancer patients in Kakamega County are being cared for by family members, who shoulder the majority of the emotional and physical demands of their care. On the other hand, taking on the position of caregiver and the corresponding caregiving responsibilities cause modifications to the structure and dynamics of the family and are a substantial cause of stress for caregivers, who may shoulder heavy responsibilities that have an adverse effect on their own health. There is a dearth of information on HRQoL among western Kenyan cancer patients' primary caregivers. Determining the factors that influence the Health-Related Quality of Life of primary caregivers for cancer patients in Kakamega County is therefore crucial.

1.3 Justification of the study

In countries like the China, studies show that the HRQOL of Spousal caregivers were linked to the patients' symptoms intensity, caregiving-related variables, and the spouses' demographics. (Wang *et al.,* 2020). This study gave recommendations for further research to be done in other third world countries.

Though there are several guidelines, such as national cancer treatment guidelines and WHO guidelines on cancer treatment, which are intended to help reduce the incidence and mortality of cancer and improve the quality of life for cancer patients, there are no guidelines currently available regarding the improvement of primary caregivers' quality of life. Family caregivers have taken on an increasingly larger role in providing home care for cancer patients. (WHO, 2018).

Kenya's constitution, in accordance with the World Health Organization, states that everyone has the basic human right to health care, and Vision 2030 lists universal health care as a prerequisite for turning Kenya into a middle-income country.

In this sense, progress toward reaching Goal 3 of the Sustainable Development Goals (SGDs) and the World Health Organization's (WHO) Global Action Plan 2013–2025 for the prevention and control of noncommunicable diseases (NCDs) has been made possible in large part by the identification and prevention of risk factors for poor health related quality of life among caregivers.

Little study has been carried out in Kenya on HRQOL of caregivers thus creating a research gap for this study. In addition, policies and guidelines on cancer management in Kenya only focus on support of the construction of lodging facilities, regardless of the caregiver's HRQoL, for patients and caregivers undergoing cancer treatment services (NCCS, 2017–2022).

There is a dearth of information in Kakamega County about the quality of life of primary caregivers. Determining the health-related quality of life for family caregivers of cancer patients in Kakamega County is therefore crucial. The cancer registry for the area is housed in the County General Teaching and Referral Hospital, making it an appropriate location for this function. In western Kenya, the planned study aimed to determine the factors that influence the health-related quality of life of those who care for cancer patients. The results would play a crucial role in informing medical professionals about the health requirements of primary caregivers in order to enhance their HRQOL. The results can serve as a starting point for creating future interventions that will help caregivers enhance their HRQOL.

1.4 Main Objective

To identify factors that Kakamega County primary caregivers of cancer patients use to predict their health-related quality of life.

1.4.1 Specific objectives

i. To evaluate how socioeconomic factors affect primary caregivers' HRQoL among cancer patients in Kakamega County.

ii. To identify the patient characteristics linked to HRQoL among Kakamega County main caregivers for cancer patients.

iii. To assess the psychological elements influencing HRQoL in Kakamega County main caregivers of cancer patients.

1.5 Research Questions

i. What socioeconomic variables affect the HRQoL of Kakamega County main caregivers of cancer patients?

ii. Among Kakamega County main caregivers of cancer patients, what patient variables are linked to HRQoL?

iii. What psychological variables influence HRQoL in Kakamega County main caregivers of cancer patients?

1.6 Limitations of the study

STUDY DESIGN

The primary caregivers of cancer patients provided data, which was analyzed using a cross-sectional analytical study design at a particular point in time.

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SAMPLE SIZE

The sample size was small and could not be generalized to all primary caregivers of cancer patients.

SAMPLING TECHNIQUE

Sampling technique was simple random sampling method from the cancer patient registry record though it was time consuming and bias could still occur under certain circumstances.

1.7 Conceptual framework

The proposed study included Ferran's and Power Models for quality of life. Accepting an individualistic viewpoint, which recognizes that every person's quality of life is a product of their own particular life experiences, is the foundation of the notion. Since everyone has different values, only that person is able to assess their own quality of life. For this reason, quality of life was defined as a person's degree of satisfaction with the parts of life that are important to them. The theory identifies the following four dimensions of quality of life: family, social and economic, psychological/spiritual, and physical/health (Ferrans, Zerwic, Wilbur, & Larson, 2005). Greater scores in the functional or physical domains indicate an improved situation, while higher values in the symptom

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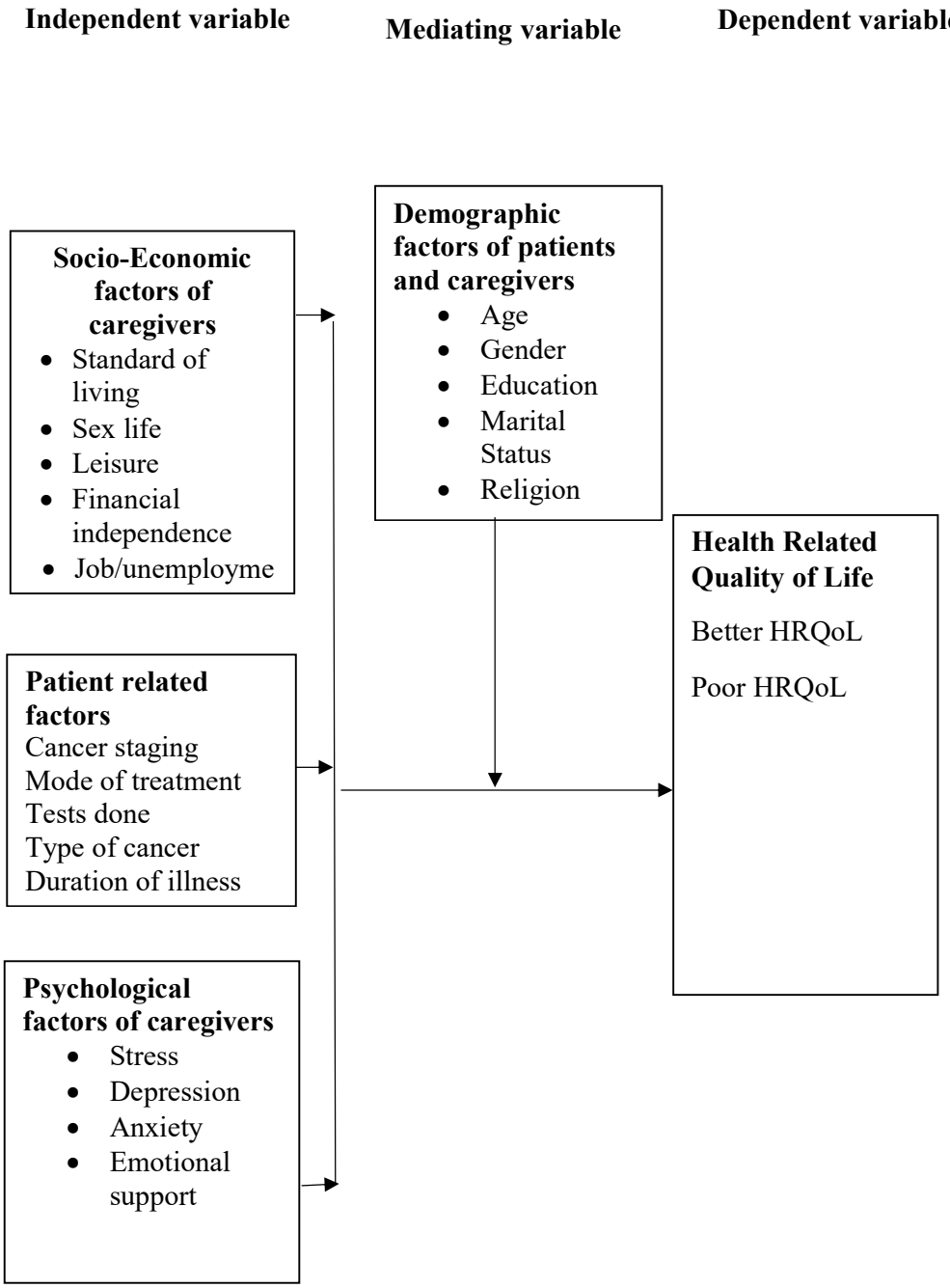

Figure 1.1 Conceptual framework

Source: Ferrans, (2007)

CHAPTER TWO

LITERATURE REVIE

2.0 Overview

This chapter reviewed the literature in accordance with the stated research objectives and the study problem's context. The chapter discusses the cancer burden on a global and regional level. It addresses the following topics: cancer incidence Sociodemographic, economic, and cultural aspects that impact primary caregivers, as well as health-related quality of life (HRQOL) among caregivers of cancer patients, physical and psychological factors affecting primary care givers of cancer patients.

2.1 Cancer and its burden on caregivers

With an anticipated 9.6 million deaths from the disease in 2018, cancer is the second greatest cause of mortality worldwide. Cancer is the cause of around 1 in 6 deaths worldwide. About 70% of cancer-related deaths take place in low- and middle-income nations. In 2017, the percentage of low-income nations with widely available pathology services in the public sector was only 26%. Compared to less than 30% of low-income nations, over 90% of high-income countries reported having access to treatment services. Cancer has a substantial and growing financial impact. It is estimated that the annual economic cost of cancer is almost $1.16 trillion. Cancer burden is expected to rise globally as risk factors like high BMI and other life style risks increase (Chakraborty *et al.,* 2023); IARC, 2019; (Plummer *et al.,* 2021).

In Africa, cancer is becoming a more serious public health issue. Infections are the cause of or a contributing factor in 25–30% of all cancer cases in Africa. Africa and other low- and middle-income regions accounted for more than half of the cases and over two-thirds of the deaths, respectively (Plummer et al., 2021). By 2030, it is anticipated that these figures will increase to over 22 million cases (60 percent in low- and middle-income countries) and 13 million deaths (70 percent in low- and middle-income countries). Patients and their families are suffering greatly as a result of the unfavorable cancer statistics for Africa, which are also placing a burden on national and regional health budgets.

(Omotoso, Olabode *et al.,* 2019). This poses a challenge where the governments in African countries are least prepared to improve on the health facility infrastructure and employment of qualified human resource that would provide qualified care and adequate support to an increasing number of primary caregivers (Omotoso, Olabode *et al.,* 2019; WHO, 2018).

McMaughan, *et al.,* (2020) reported the link between new issues and demands in the contexts of socioeconomics, cultures, and healthcare, as well as the population's growing aging and dependency, which is creating new difficulties. Support for "primary family caregivers" has become even more crucial as a result of older persons with numerous pathologies, dementia, or advanced chronic diseases needing long-term care. Most of the physical and mental responsibilities of care are supported by these caregivers, who are typically family members (Perpiñá-Galvañ et al., 2019). According to WHO (2018) and NCD country profile (2018), cancer is the second most common cause of death in Kenya, accounting for 7% of all deaths attributable to NCDs, after cardiovascular diseases. It is expected to be the third greatest cause of death in Kenya, behind infectious and cardiovascular illnesses. Ferlay et al. (2019) state that the yearly incidence.

The cancer burden in western Kenya is a significant health problem and is likely affecting a larger number of patients and their caregivers (MOH, 2018). Breast, oesophageal, and cervical cancers are the most common cancers in women. The most prevalent cancers in men are Kaposi sarcoma, prostate, and oesophageal cancers. According to data from the Nairobi Cancer Registry from 2002, of all malignancies registered, 23.3% were breast cancer, 20% were cervical cancer, and 9.4% were prostate cancer. About 2,354 women were given a cervical cancer diagnosis in 2006, and 65% of them passed away as a result of the illness.

Signs and symptoms of cancer Depending on the exact kind and stage of the cancer, patients may experience the following general signs and symptoms, which are not particularly specific: exhaustion, weight loss, pain, skin changes, altered bowel or bladder function, unusual bleeding, persistent coughing or voice changes, fever, lumps, or tissue masses (WHO 2018).Pathology, medical imaging, laboratory medicine, immunology, microbiology,

chemistry, immuno-haematological, haematological, biophysical, cytological, pathological, and other examinations of materials derived from the human body for the purpose of providing information for the diagnosis are all included in the diagnostic services for cancer. Early cancer diagnosis depends on having laboratory services that are easily accessible, readily available, reasonably priced, and effective. However, developing nations, like Kenya, face difficulties with the following:

The burden of cancer on caregivers

Recognizing caregiver burden helps improve patients' and caregivers' quality of life. The difficulties involved in providing care for someone who is frequently ill might be referred to as caregiver burden (Guerra-Martín et al., 2023). When cancer patients are not admitted to the hospital during their sickness and treatment, family caregivers play a vital role in providing support to the patients. As long as the patient requires assistance with even the most basic activities of daily living because of the disease's consequences, the therapies, or the co-occurrence of cancer and comorbidities, providing care does not end once the patient is in the hospital and instead becomes a full-time job (Yuxuan et al., 2023). Additionally, there is a strong correlation between caregivers' perceived (2021). These findings suggest setting specific findings when it comes the overall outcome of care burden in cancer caregiving by primary care givers.

2.2 Health Related Quality of Life (HRQOL) among primary caregivers

Recently, Health Related Quality of Life (HRQOL) has emerged as a critical component of medical care. The World Health Organization (WHO) describes predictors as variables like physical, mental, emotional, and social functioning that are used to observe how they affect some other variable, which is Health Related Quality of Life (Barbosa et al., 2022). HRQOL is defined as "an individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards, and concerns relating to wellbeing."

Although more recent study focuses on the caregiver's HRQOL, many HRQOL investigators have historically concentrated on the individual diagnosed with an illness or condition realizing how treating caregiver stress can significantly improve the course of treatment (Guerra-Martín et al., 2023). Although HRQOL assessments have been applied to other aspects of healthcare practice, caregivers of cancer patients are frequently not given an HRQOL evaluation. According to Sherman et al. (2019), evaluating the health and well-being of the primary caregivers may help identify and address physical, psychological, and social issues within the family more effectively.

Cancer patients are living longer thanks to ongoing medical advancements, necessitating long-term care from caregivers. Caretakers' HRQOL may be greatly impacted by their long-term commitment to these patients, as they are frequently tasked with providing 24-hour care to address the patient's medical, physical, and social demands. Sima Sadat. *et. al,* (2022).

The health-related quality of life (HRQOL) of family caregivers who are giving care to cancer patients has received relatively little specialized research attention (Fagerström et al. 2020). On the other hand, providing care for cancer patients has generally been linked to higher burden and lower HRQOL for caregivers. The severity of a chronic disease increases caregiver stress (Mishraet et al., 2021).

WHOQoL-BREF has been developed to measure the subjective dimension of QOL through single item and multi item scales while applying both generic and disease specific questionnaires. This is done in order to assess the health-related quality of life (HRQoL) of primary caregivers of cancer patients (Aujla & Needham, 2019).

2.3 Predictors of Health-Related Quality of Life (HRQOL) among primary caregivers

Predictors of HRQoL among primary caregivers include the following; social demographic factors, economic factors, physical factors and psychological factors.

2.3.1 Socio-demographic and economic factors affecting Health Related Quality of Life of primary caregivers of cancer patients

Several studies have identified the following socio-demographic factors being associated with HRQoL of cancer patients' caregivers: age, sex, marital status, and education and are discussed as follows;

2.3.1.1 Age

The caregiver's HRQOL is correlated with their age. Compared to younger caretakers, older caregivers are more likely to be dealing with chronic conditions. Caregiving demands, age-related biological vulnerabilities, and psychological factors like feelings of distress and loss can all have an adverse effect on an older caregiver's physical health. Other factors that contribute to poor HRQOL among caregivers of patients with chronic diseases include having a lower monthly income and being the care recipient's spouse. Previous research has indicated that the age of the caregiver has an impact on the burden of care (Sun, Haiyan, Yang Qin, and Pornpat Hengudomsub, 2021).

2.3.1.2 Sex

Gender of a caregiver is further connected to HRQOL. For instance, compared to males, women who provide care report worse levels of well-being or health status, especially in relation to mental health, and higher rates of depression. In comparison to female caregivers, male caregivers frequently reported higher levels of physical and emotional well-being. Moreover, regardless of the condition of the care recipient, female caregivers are more likely to experience comorbidities and chronic illnesses.prognosis and stage (Yoshiko *et al.,* 2023).

2.3.1.3 Marital status

Research has demonstrated that the quality of life (QOL) of spouses who care for cancer patients is influenced by the relationship between the couples (Lin et al., 2020). In addition, spouses deal with concerns about their capacity to offer physical and emotional assistance as well as the possibility of losing their life partner to cancer (Mbozi et al., 2020).

A study conducted by Jeong et al. (2020) found that older spousal caregivers who reported caregiver stress had a mortality rate that was 63% greater than that of non-caregivers of the same age. Furthermore, within the year following the cancer diagnosis, there were noticeable alterations in neurohormonal and inflammatory processes, according to data gathered from salivary biomarkers of caregivers for cancer patients (Mitchell et al., 2021).

2.3.1.4 Level of education

Research indicates that primary carers with greater educational attainment have reported lower levels of wellbeing because they are more aware of the effects and prognosis of cancer than their less educated counterparts (Molassiotis, A., & Wang, M. 2022). Better quality of life for both couples was linked to a relatively low level of education for both the patient and the caregiver, according to a long-term study that evaluated the QOL of prostate cancer patients and their spouses (Andreas Ihrig et al., 2022).

When family caregivers take on the duties of a sick family member in addition to their own, they bear a greater burden. According to reports, primary caregivers require not only the support of family members but also their vocal encouragement

Health status of the caregiver affecting their HRQoL

The HRQOL of a caregiver is impacted by their personal health (Hemphill et al., 2020). According to reports, caregivers are more likely to become seriously ill and are less likely to participate in preventive health activities (Forsythe et al., 2020). About half of caregivers report having at least one chronic disease, 20% characterize their health as fair or poor, and 17% feel that providing care has negatively impacted their health and the quality of care provided to cancer patients.Compared to non-family caregivers, family caregivers of cancer patients suffer from more severe impairments Zhong, Yaqin, Jian Wang, and Stephen Nicholas (2020)

2.3.2 Economic factors affecting Health Related Quality of Life of primary caregivers of cancer patients

Alam, S., & Zimmermann, C. (2020) found that caregiver burden has been linked to the caregiver's own poor health status, a decline in health-maintaining behaviors, an increase in health-risk behaviors, and prescription drug use. The following three economic determinants have an impact on caregiver HRQoL: job/unemployment, standard of living, and financial independence.

2.3.3.1 Financial independence

When caring for a sick family member, caregivers can have to pay for care out of their own pockets. Over 40% of caregivers in the United States paid $5,531, or roughly 10% of their yearly household income, out of their own pockets on average in 2007. The reduction in social security benefits, retirement savings, and salary and benefits were not included in the cost (Collins & Swartz, 2019). Limited financial and social resources prevent caregivers from hiring home care and transportation services to relieve onerous caregiving duties, and friends and family may not be able to assist because of their own commitments to their own families and jobs. Minority patients and their carers may reside in underprivileged areas with little access to healthcare resources, particularly those pertaining to prohibited substances.

2.3.3.2 Standard of living

According to Erhunmwunsee et al. (2019), nearly one-fifth (18%) of caregivers said they had lost all or most of the family savings, and another 18% said a family member had drastically changed their life—for example, by quitting their job—in order to take care of the patient. In a related study, Mazanec et al. (2011) examined 70 caregivers of patients receiving palliative care. They found that the sample's overall job productivity loss was 22.9%, which was marginally higher than the figure (20.1%) that Giovannetti, Wolff, Frick, and Boult (2009) had previously reported.

2.3.3.4 Job/unemployment

Some literatures have reported relationships between increased job productivity loss and elevated levels of anxiety and depression, as well as increased caregiver burden reported as a result of health issues, schedule disruptions, and financial difficulties (Xiang, Ellen, et al., 2022).

Researchers looking at caregivers of people with Alzheimer's dementia found that, when it came to using acute care services, 24% of the caregivers (N=153) had at least one hospital stay or ER visit in the six months before study enrollment (Afonso-Argilés et al., 2023). Furthermore, caregivers with higher load levels also had higher risks of all-cause mortality and Framingham stroke (Swartz, Kristine, and Lauren G. Collins 2019).

2.4 Psychological factors affecting Health Related Quality of Life of primary caregivers of cancer patients

Over the course of the patient's and caregiver's care, confusing issues such as fear, uncertainty, and a lack of hope that come with receiving a cancer diagnosis persist (Lewandowska, Anna, et al., 2021). The discovery of brain metastases may intensify these psychological reactions. Given that providing care for a loved one with cancer shares characteristics with a chronic stress experience (Maina, Geoffrey, et al., 2021), it makes sense that the psychological and emotional dimensions would include the majority of the negative health effects of this role. These domains include the following variables: emotional support, depression, anxiety, and stress among caregivers.

2.4.1 Primary caregiver’s Stress

Caregivers experience stress from providing care, which has a negative impact on their health. Feliciano, L., and Broxson, J. (2020). It has been shown that stress level is a strong predictor of caregiver load. It has been noted that a caregiver's stress level rises in tandem with their caregiving load. In addition to high levels of stress, caregivers' health is also impacted by the caregiver burden itself. Several studies have demonstrated that caregiver stress can exacerbate

caregivers' pre-existing depressive conditions, and that caregiver burden is associated with symptoms of depression (Chakraborty et al., 2023). According to a different meta-analysis, stress is brought on by caregiver burden, and finding the right support systems is crucial to reducing stress (Shi, Jing, et al, 2020).

Out of 116 caregivers in the sample

2.4.2 Primary caregiver's Depression

According to the National Alliance for Caregiving, there is a correlation between providing care and increased rates of depression and insomnia. In fact, rates of depression have been shown to reach 91%, with 60% of cases classified as moderate or severe (National Alliance for Caregiving, 2019). Furthermore, a study involving 152 caregivers of cancer patients in Italy revealed a high prevalence of psychological distress in caregivers; more than half of the caregivers tested positive for mood disorders, over 10% had severe cases of post-traumatic stress disorder, and 37% tested positive for emotionally disturbed patients that needed to be treated clinically (Sullivan, Matthew C., et al., 2022).

The findings of a cross-sectional, descriptive, and correlational study with 410 community-recruited caregivers show that all of them experience high levels of hardship and sadness. Notable

2.4.3 Primary Caregiver's Anxiety

Researchers have examined the negative reactions of anxiety and despair in those who care for patients with Kim, Y. (2022). Fewer studies, meanwhile, concentrated on a certain group of patients' caregivers who had brain metastases. According to reports, providing care for patients with advanced cancer can cause emotional stress, depression, and increased anxiety in the caregivers (Belapurkar, Parth, et al., 2023). It has also been noted that, in comparison to the general population, caregivers of patients with brain tumors have higher levels of anxiety and depression symptoms (Shah et al., 2023). According to Kilic, S. T., and Oz (2019), there is evidence to suggest that the affective symptoms experienced by caregivers of cancer patients

differ over the illness continuum and may be impacted by factors associated to the patient's declining health.

2.5.4 Primary Caregiver's emotional support

According to research conducted by Akpan-Idiok et al. (2020), first-degree relatives, such as siblings or children, provide care for the majority of patients in need of primary care providers. Additionally, they found that the caregiver burden scale point falls with an increase in the number of assistants providing support to main caregivers (Stavas et al., 2019). It is thought that the presence of caregiver support workers lessens the primary caregivers' caregiving burden. The carer burden is greater for caregivers who reside in large households. Contrary to expectations that caregiver load would reduce as obligations would be divided among family members, this data demonstrates that an increase in family size would result in women having more responsibilities.

2.5. Hospital factors affecting HRQoL of primary caregivers

Hospital factors affects the HRQoL of primary caregivers either negatively or positively and they include policies/guidelines and human resource.

2.5.1 Policies and guidelines

Although there are several guidelines, such as the National Cancer Treatment Guidelines and WHO Guidelines on Cancer Treatment, which are intended to help reduce the incidence and mortality of cancer and improve the quality of life for cancer patients, family caregivers have taken on an increasing amount of responsibility for providing home care for cancer patients. However, there are no guidelines available regarding the improvement of primary caregivers' quality of life. It is anticipated that following the standards will enhance early identification, prompt diagnosis, and standardize cancer therapy. Furthermore, this increased availability of high-quality and secure cancer treatment and enhance capacity in all fields of cancer management (Who, 2012).

2.5.2 Human resource

Poor diagnosis, hospitalized detection delays, and the requirement for a high standard of patient care make caring for cancer patients more difficult (Abdullah et al., 2019). The health of caregivers is vital and has to be attended to by healthcare professionals; yet, a lack of assistance has a detrimental effect on their health and can result in disease (Idris et al., 2019). Due to a lack of hospital support, the majority of family caregivers for cancer patients are ill-prepared to handle the load of caregiving (Shamsuddin et al., 2019). According to earlier research, the following variables affected the overall quality of life (QOL) of patients and caregivers: the cancer diagnosis, hospital stay duration, intensity and duration of caregiving, marital satisfaction, and caregiving self-esteem. (Guerra-Martín *et al.,* 2023)**.**

2.5.3 Cancer diagnosis

In addition to the illness and its treatment, a cancer diagnosis presents a person with a number of obstacles, including the possibility of physical disability, risks to their social and familial relationships, and concerns for their own lives (Chen et al., 2020).

Pathology, medical imaging, and laboratory medicine for biological, microbiological, immunological, chemical, immune-haematological, haematological, biophysical, cytological, pathological, and other examinations of materials derived from the human body are among the services that provide information for the diagnosis of cancer. Early cancer diagnosis depends on accessible, affordable, efficient laboratory services; nevertheless, in poor nations—Kenya included—diagnosis-related issues are common, contributing to the lengthy time it takes to diagnose cancer (ACS).

2.5.4 Length of hospitalization

Cancer does not only affect the cancer patient only not to mention their main caretakers. The majority of cancer treatments occur in outpatient settings, where the primary caregiver assumes greater responsibility, especially in terms of continuous, round-the-clock care (Tsai, et al., 2019). It has been demonstrated that the lengthening of time spent providing care and

the associated stress experienced by family caregivers of patients with brain tumors have a detrimental effect on the caregiver's physical health (Heffernan et al., 2020).

2.5.5 Care giving intensity and duration

Cancer patients face difficulties related to both the disease and its treatment, as do family members, particularly the primary caregiver who is in charge of providing the patient with care and support (Xu, Ling, et al., 2021). Sadly, the majority of new cases of cancer are often diagnosed at an advanced stage in developing nations, including Kenya. This late diagnosis of cancer and the scarcity of treatment options in these nations may result in poor prognoses for cancer, which may then have an impact on the health-related quality of life (HRQOL) of cancer patients. together with that of their primary caregivers as well as increasing the caregiving burden (Agyemang-Duah *et al.,* 2024).

2.5.6 Marital satisfaction

Marital satisfaction can be negatively impacted by the difficulties associated with receiving a cancer diagnosis and treatment, as well as by changes in the dynamics of the relationship between cancer patients and their spouses. This is because each partner's HRQoL can have an effect on the other (Oh, S., & Ryu, E. (2019)

2.5.7 Caregiving self-esteem

The experience of providing care is frequently viewed as a chronic stressor, and primary caregivers are too concerned and preoccupied with providing appropriate care and support, which can have a detrimental psychological, behavioral, and physiological impact on their everyday life and health.

to the cancer patients until they neglect their own health leading to deterioration of their own health hence reducing the self-esteem of the primary caregivers (Li *et al.,* 2020).

2.6 Patient factors affecting HRQoL of primary caregivers

The type of cancer, the length of the illness, the cancer diagnosis, the length of hospitalization, the intensity and duration of caregiving, marital satisfaction, and the caregiver's self-esteem are among the patient factors that impact the HRQoL of primary caregivers.

2.6.1 Types of cancer

Research from the literature has demonstrated that because upper GI cancer has a poor prognosis, caregivers of patients with this type of cancer are more likely to experience psychological distress than those caring for tumors with longer illness trajectories (Abdullah et al., 2019). Better quality of life for both partners was linked to localized cancer at baseline, according to a long-term study that evaluated the QOL of prostate cancer patients and their spouses (Kilic, S. T., & Oz, F. (2019)

2.6.2 Duration of illness

It has been demonstrated that the lengthening of time spent providing care and the associated strain experienced by family caregivers of patients with brain tumors have a detrimental effect on the caregiver's physical health (Brenner, et al., 2022). Research from the literature also reveals that because upper GI cancer has a bad prognosis, caregivers for patients with that type of cancer are more likely to experience psychological anguish than those caring for tumors with longer illness trajectories (Abdullah et al., 2019).

2.6.3 Cancer diagnosis

A cancer diagnosis presents a person with many obstacles in addition to the illness and its management, including the possibility of physical disability, risks to their social and family relationships, and concerns for their own well-being (Chen et al., 2020).

Cancer diagnostic services include pathology, laboratory medicine, and medical imaging for biological, microbiological, immunological, chemical, immune-haematological, haematological, biophysical, cytological, pathological, and other examinations of materials derived from the human body in order to provide information for the diagnosis. The ability to obtain laboratory services that are efficient, affordable, conveniently accessible, and quickly

available is essential for early cancer detection. Nonetheless, diagnosis-related problems are frequent in developing countries—Kenya included—which prolongs the turnaround times.

2.6.4 Length of hospitalization

Cancer affects not just the patient but also the key caretakers for the patient. The majority of cancer treatments occur in outpatient settings, where the primary caregiver assumes greater responsibility, especially in the area of continuous, round-the-clock care (Oh, S., & Ryu, E. (2019). It has been demonstrated that the lengthening of time spent providing care and the associated strain experienced by family caregivers of patients with brain tumors have a detrimental effect on the caregiver's physical health (Brenner, Keri, et al. 2022).

2.6.5 Caregiving intensity and duration

Both the illness and its treatment present challenges for cancer patients and their family members, especially the primary caregiver who is responsible for the patient's care and support (Oh, S., & Ryu, E. (2019). The prognosis for cancer patients and their primary caregivers may be poor due to delayed diagnosis and limited treatment options in developing nations like Kenya. This could result in an increased caregiving burden and negatively impact the patients' health-related quality of life (HRQOL). Regretfully, most newly diagnosed instances of cancer in these nations are often diagnosed at an advanced stage (Agyemang-Duah et al.,

2.6.6 Marital satisfaction

Marital satisfaction can be negatively impacted by the difficulties associated with receiving a cancer diagnosis and treatment, as well as by changes in the dynamics of the relationship between cancer patients and their spouses. This is because each partner's HRQoL can have an effect on the other. Ryu, E., and Oh, S. (2019)

2.6.7 Caregiving self-esteem

The experience of providing care is frequently viewed as a chronic stressor, and caregivers frequently experience detrimental psychological, behavioral, and physiological effects on their daily lives and health. Primary caregivers are often overly concerned with meeting the

needs of cancer patients to the point where they neglect their own health, which deteriorates their own health and lowers their self-esteem (Li et al., 2019).

2.7 Research gap

The diagnosis of cancer affects not only the health-related quality of life of the patients but also that of primary caregivers. Although caregiver's health is important and requires attention from healthcare providers, there is lack of support which negatively affects their health and lead to illness.

In countries like the China, studies show identified factors connected to caregiving, the degree of patients' symptoms, and the spouses' demographics were all linked to the quality of life of those who provide spousal care.

This study gave recommendations for further research to be done in other third world countries which has informed the proposed study. Hence necessity for further research to address this variable to have more conclusive findings. In addition, policies and guidelines on cancer management in Kenya only focuses on the diagnosis and management cancer patients and not capturing anything on caregivers.

CHAPTER THREE

METHODOLOGY

3.0 Overview

The research design employed by the investigator is presented in this chapter. The study's assumptions are covered, along with the study site, study population, target population, sample size calculation, sampling procedure, data scheduling, data analysis, presentation, and dissemination.

3.1 Study Design

This cross-sectional analytical study design employed a variety of data collection techniques. Since the research involved gathering and comparing data from the phenomenon at the same time of investigation, this specific design is perfect.

3.2 Study Site

In Kakamega County, Western Kenya, at the Kakamega County Referral Hospital, this study was carried out. The county is home to 34 health centers, 86 dispensaries, 1 county referral hospital, 12 subcounty hospitals, and a number of facilities run by for-profit and religious organizations.

The cancer registry centre serves an estimate of 6550 patients from western region, it has a work force of one consultant pathologist, one consultant oncologist, one medical officer, one pharmacist, one oncologist nurse, two oncologists' master's student nurses, one higher diploma nurse, two palliative nurses, one nutritionist, one research registrar and one cancer registrar. Averagely the registry centre reports an estimate of 120 new cases monthly. The centre has a psychosocial support group for patients but none available for the primary caregivers. Yet the caregivers are the ones who accompany the cancer patients to the hospital, offer daily care to the patients and even administer their medication and even if they fall sick during the care, they have to cater for their own treatment.

3.3 Study Population

The research was carried out among primary caregivers of cancer patients in Kakamega County Referral Hospital Cancer centre.

3.4 Measurable variables

The independent variables in this research have been clustered as individual socio- economic, psychological, and demographic aspects. Primary care providers' health-related quality of life is the dependent variable.

which was assessed based on outcome of individual physical independence whether better or poor.

3.5 Inclusion and Exclusion Criteria

3.5.1 Inclusion:

- Caregivers who have stayed with the patients for at least one month and ≥18 years old.
- Caregivers who provided unpaid care to cancer patients

3.5.2 Exclusion

- Caregivers who are not mentally stable
- Those who did not give consent to participate in the study

3.6 Sampling

The area of study, Kakamega County was purposively sampled as it has the hospital with western region cancer centre. The cancer centre at Kakamega County Referral Hospital was a sampling frame from which the sample was drawn. The sampling unit was the patients but the interviewees were the caregivers of the patients sampled. The patients were randomly sampled using simple random sampling method until the sample size is achieved and primary caregivers of these patients were the interviewees.

3.7 Sample size determination

Using the Cochran's formula for sample size determination, the sample size was determined. Since there has never been a national or regional estimate of the prevalence of cancer in Kenya, a 50% prevalence is taken as given. This calculation assumes that, according to the sample frame, every cancer patient has a primary caregiver (MOH, 2017).

n_o=(〖z⇩2〗 pq)/e^2

The sample size can be computed using the formula

where p is the expected 50% population-based cancer prevalence in Kenya.

With α = 0.05, the standard normal distribution curve value for 95% confidence interval (z^2) is 1.96. q = 1-p e = Margin of error n- Sample size

$$n_o = \frac{(1.96^2)(0.5)(0.5)}{0.05^2}$$

$n_o = 384 + (10\%\ attrition) = 422\ p\text{rimary care givers}.$

The 10% is the loading population to take care of possible refusals.

3.8 Data Collection Instruments

The interviewers noted the patients' primary site of disease, comorbidities (hypertension, coronary heart disease, diabetes mellitus, and other conditions), and demographic and socioeconomic factors (gender, age, marital status, and educational attainment). Information about the specific patient-caregiver relationship was also documented, including the patient's spouse, parent, or child, if they shared a residence and whether the patient was the primary caregiver) and this means that patient data was collected for each caregiver.

The questionnaire tool has four section; Section (a) Socio-demographic factors which has the following independent variables; age, sex marital status, religion, education and ethnicity. Section (b) Psychological/ Physical factors and this include; stress, depression, anxiety, personal appearance, pain, weight loss and emotional support, section (c) Economic factors which cover the following: standard of living, financial independence, house, neighborhood, employment and unemployment, and friends. Then, in section (d), an independent variable

called Health Related Quality of Life (HRQoL) is discussed. This includes physical independence, one's own health, pain, energy and fatigue, stress and worries, and sexual life. A QoL questionnaire like the Personal Wellbeing Index (PWI) can be compared to the HRQoL dimensions discussed above (Aujla & Needham, 2019). A number of satisfaction-related questions are included in the PWI, including questions about future security, relationships, personal safety, achievement, health, and standard of life. While not commonly included in HRQoL surveys, each of these dimensions is probably impacted by poor health. Each of the seven satisfaction items on the PWI scale corresponds to a quality of life domain, such as standard of living.

The WHOQOL-BREF is a streamlined version of the WHOQOL-100 developed by the WHOQOL Group. Kenya has validated the WHOQOL-BREF questionnaire as valid and trustworthy (Kondo et al., 2023). This questionnaire comprises 26 items that assess general health and overall quality of life. Four categories include the remaining 24 questions: social connection, physical, psychological and environmental with six questions in each and every category, a scale from 1-5 used to grade each item.

Every item is rated on a 5-point scale. Next, a linear scale from 0 to 100 is created using the results, where 100 represents the best possible quality of life. The descriptive system assesses five variables: pain or discomfort, mobility, self-care, routine activities, and anxiety or depressed symptoms. The respondent is asked to select the option that most accurately represents their current state of health after each component is further divided into three severity levels. The result of this decision is a 1-digit number that represents the level selected for that dimension. Combining these answers results in a 5-digit health status profile that represents the respondent's current state of health.

3.9 Pre-test

The tools were pretested among primary care givers of cancer patient in Cancer registry of Jaramogi Oginga Odinga teaching and referral hospital, it was chosen because it has an active cancer registry centre in the region offering both outpatient and inpatient services, the centre

is well equipped with diagnostic equipment and drugs for cancer management. The pre-test was done to assess if the data collection tool was stated clearly and had the same meaning to all research respondents. The questions were thereafter fine-tuned for clarity and validity. As observed by Alam, T. G. M. R. (2019), this exercise reduces the amount of incorrect data that is collected; in a similar vein, the validity and integrity of the tools were determined. The purpose of the pre-test was to train the research assistants and evaluate the validity and reliability of the questionnaire. Care was made to make sure that the questionnaire questions weren't excessively long or worded in a way that would make it difficult for responders to understand them. To identify any gaps, data from the pre-test was double reviewed. As a result, adjustments and changes were made to address any irregularities found on the instrument prior to administration.

3.10 Validity

Validity, according to Alam (2019), is the precision, dependability, or efficacy with which an instrument measures the things it is supposed to measure. According to Alam (2019), the standard practice for evaluating a measure's content validity is to have a professional or expert in the topic do the assessment. To make sure that the questionnaire's format and content match the study variables, the instrument (questionnaire) in this study was validated. In this instance, department specialists evaluated the questionnaire's architecture, content, and face validation. Before the device was deployed in the field, the experts' feedback was integrated into it. A small number of questionnaires were given out during the pre-test, and the data were analyzed to determine the construct validity.

3.11 Reliability

The study employed strategies related to internal consistency to enhance the tool's reliability. This required comparing a score from one item in the instrument with scores from other items. In this instance, the Kuder-Richardson (K-R) 20 formula in general form, known as Cronbach's alpha, was applied (Sürücü, L., & Maslakçi, A. (2020). According to academics, the Cronbach Alpha coefficient is a better measure of dichotomous test items than the Kuder-Richardson

Formula 20 (KR-20). Scale reliability is measured by Cronbach's alpha, which is defined as the average of all potential split-half coefficients. Version 26.0 of the Statistical Package for Social Sciences was used to administer the test. Keep in mind that "acceptable" is defined as having a Cronbach reliability coefficient of.70 or higher.

test results for WHOQOL-BREF ($\alpha = 0.816$), PHQ-9 ($\alpha = 0.833$) and GAD-7 9 $\alpha = 0.79$) was satisfactory.

Table 3. 1: Cronbach tests

Type of instrument	Domain	Cronbach Coefficient Alpha
WHOQOL-BREF	All the four domains	0.816
Patient Health Questionnaire (PHQ-9)	Depression	0.833
Generalized Anxiety Disorder (GAD-7)	Anxiety	0.798

3.12 Data analysis

The dependent variables in the WHOQOL-BREF were the four domains: physical, psychological, social connection, and environmental. Kruskal Wallis was used to compare the QOL scores between the two groups. We investigated the relationships between the caregivers' QOL (four domains), patient characteristics, levels of knowledge and support systems, depression, anxiety, and sociodemographic traits, and each of the four WHOQOL-BREF dimensions. The four QOL domains served as dependent variables in the multiple regression models containing the variables that demonstrated a significant correlation ($p < 0.05$) with QOL. Prior to being incorporated into the multiple regression models, each independent variable was either coded or converted into a category measurement except for depression, anxiety and Hearth Hope Index (HHI) which were included as interval scale variables. A p value ≤ 0.05 was used to reject the null hypothesis between the independent variable and the

outcome variables. Using Pearson correlation analysis, the association between the WHOQOL-BREF domains and Herth Hope Index variables was examined to determine the relationship between variables. Statistical significance was defined as $p \leq 0.05$ for all processes. For HHI, items #2 and #6 were reversed during analysis to give positive statements in line with the rest of the other 10 items.

3.13 Ethical Considerations

Ethical considerations were followed to prevent ethical dilemmasThe Institutional Ethical Review Committee of Masinde Muliro University of Science and Technology was consulted in order to guarantee the study was conducted ethically. Prior to conducting any research, the researcher was required by law in Kenya to get a research permit from the National Commission for Science, Technology, and Innovations (NACOSTI). It was requested from Kakamega County Referral and Teaching Hospital for permission to carry out the study.

After explaining the goal of the study, the instrument to be used, and the information to be requested, the respondents were asked for their consent to participate in the research. No one was forced to take part in the study; only those who were eager to did so. Participants in the study were advised of their right to withdraw at any time.

3.13.1 Beneficence

This idea made sure that individuals wouldn't suffer any negative effects on their bodies, minds, finances, or social standing. This was reduced by: asking thoughtful, considerate, and nonjudgmental inquiries. The respondents were advised that they might leave the interview at any time if it made them uncomfortable and that a new date would be arranged if feasible. To guarantee their freedom from exploitation, participants would not be placed in circumstances for which they were unprepared. The responder received a thorough explanation of the study protocol prior to the interview. The study's participants were advised that while their involvement would not yield immediate advantages, it would yield information that could help policymakers and healthcare professionals devise plans to enhance the health-related quality of life for cancer patients' primary caregivers.

3.13.2 Respect for Human Dignity

The right to full disclosure and the right to self-determination both express the ethical concept of respect for human dignity. Participants in this study had the freedom to ask questions as well as the choice to freely select whether to engage in the study without running the risk of punishment. They were entitled to make free and informed judgments about participating in the study, which calls for complete disclosure. This was amply covered in the informed consent form that was completed prior to the interview.

3.13.3 Justice

This idea covers both the right to privacy and the right to be treated fairly. By conducting a non-discriminatory participant selection process, following established protocols, providing participants with the researcher's contact information for information clarification at any point during the study, and guaranteeing polite and respectful treatment at all times, the study ensured equitable treatment. By ensuring that codes rather than respondent names were written on the questionnaire, the right to privacy was upheld through anonymity. As a result, the data remained anonymous and the informants were not linked. Only the lead investigator had the key to access the completed questionnaires, which were kept locked away.

3.13.4 Confidentiality

The study safeguarded the confidentiality of the information provided by respondents by assigning identification numbers to each participant in place of names or other identifiers, and by requiring all research assistants who worked with the study data to sign a confidentiality agreement. The questionnaires were encrypted, and the only people who had access to the completed forms were the lead investigator, interviewers, and data reviewers.

3.13.5 Informed Consent

The four components of informed consent—voluntary involvement, understanding the information, disclosure of pertinent information to participants, and the freedom to withdraw at any time without consequence—were all applied in this study.

CHAPTER FOUR

RESULTS

4.0 Overview

The study looked at main caregivers of cancer patients in Kakamega County to find indicators of health-related quality of life. In the study, both descriptive and inferential statistics were employed. The frequency distributions, means, and standard deviations are among the descriptive statistics that were employed. Multiple regressions and Pearson correlation were utilized in the study's inferential statistics.

4.1 Socio-demographic information of caregivers

Four hundred and twenty-two cancer patient caregivers were eligible for the study and all their questionnaires were fully completed and analysed giving 100% response rate. The profiles of the caregivers are presented in Table 4.1. One-third (33.6%) were in the age group of 25 – 34 years with a mean age of 38.7 ± 11.7 (SD) ranging between 19 – 89 years. Over half (62.1%) were women, 39.3% had attained secondary education, most were married (66.6%), majority being rural residents (93.4%). Slightly more than half (53.1%) were farmers, majority were Christians (94.3%) and more than a third (36.7%) had an income of between KSh. 5000 – 9999.

Table 4. 1: Socio-demographic information of caregivers

Variables	Categories	n	%
Age group in years	15 – 24	29	6.9
	25 – 34	142	33.6
	35 – 44	124	29.4
	45 – 54	88	20.9
	≥ 55	39	9.2
Mean age ± SD (Range)		38.7 ± 11.7 (19.0 – 89.0)	
Gender	Male	160	37.9
	Female	262	62.1
Level of education	None	31	7.3
	Primary	80	19.0
	Secondary	166	39.3
	Tertiary	145	34.4
Marital status	Single	107	25.4
	Married	281	66.6
	Divorced	9	2.1
	Widow	25	5.9
Type of area of residence	Urban	28	6.6
	Rural	394	93.4
Occupation	Housewife	14	3.3
	Farmer	224	53.1
	Casual	42	9.9
	Employed	108	25.6
	Unemployed	28	6.6
	Other	6	1.4
Religion	Christian	398	94.3
	Muslim	20	4.7
	Other	4	1.0
Income	< 5000	78	18.5
	5000 – 9999	155	36.7
	10,000 – 14,999	90	21.3
	≥ 15,000	99	23.5

Eight Focus group discussions (FGDs) were conducted, eight focus group discussions with participants implying each FGD has seven discussants. There were nine distinct caregivers, mothers, husbands, sisters, fathers, wives, children, daughters, brothers and mother in laws. Further, the study identified 8 distinct type of cancers, cervical and Oesophageal accounting 17.4% each, breast, liver, lung and prostate accounting 13.0% while stomach cancer accounted for 8.7% and ovarian accounted for 4.3%.

Preliminaries results indicated that care givers offered all kind of support to their cancer patients. One of the respondents in Focus Group Discussion I said that:

> "*With me I do take care of her but at least I get assistance from my siblings but when it comes to her medication, I do it personally from administration of drugs, bringing her to hospital, taking her for investigations even if it means outside the county and I tell you it needs commitment*"

4.1.1 Place of Residence

An equal proportion (11.6%) was residents of Butere, Matungu and Shinyalu sub-counties in Kakamega County (Figure 4.1). Less than 10% were from Vihiga and Uasin Gishu counties.

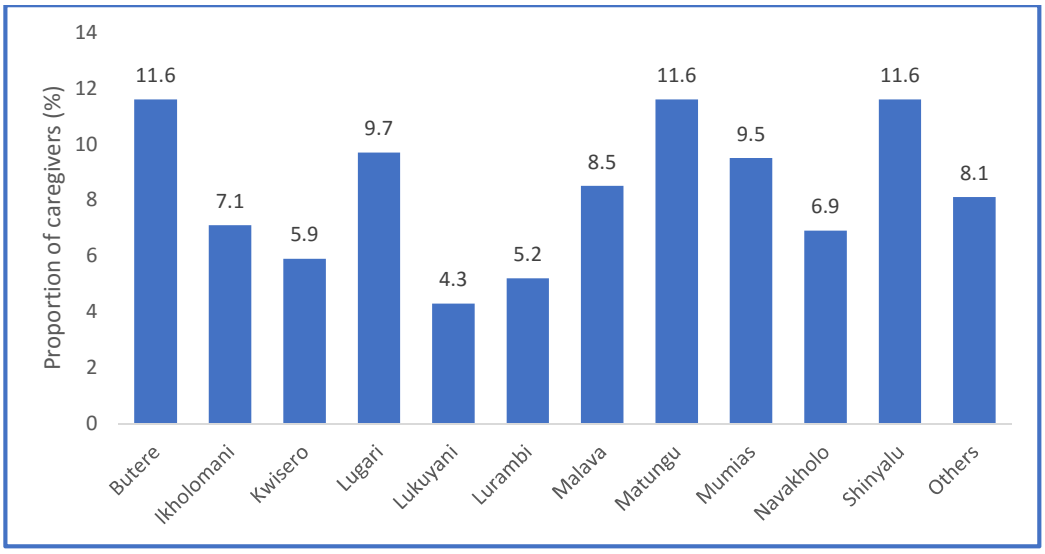

Figure 4. 1: Place of Residence

4.1.2 Caregiver's information about family cancer history and current care provided

Table 4.2 presents caregiver's information on family cancer history. About half (48.6%) were patient siblings and other significant others this was followed by 43.6% who were spouses with less than 10% being mothers (6.6%) or fathers (1.2%). Majority had heard of cancer before the patient was diagnosed with cancer (96.2%) most of whom perceived cancer as a serious disease (91.5%) and severe (97.4%). Only 13.7% had had a member of the family having had cancer. Most of the caregivers spent 6 – 12 hours daily caring for their patient (71.3%) with another quarter (25.6%) spending more than 12 hours. More than three-quarters (79.9%) were also supported by others for care provision. More than 59.7% reported other family members suffering for other chronic illnesses.

Generally, 58.5% of the caregivers had a positive attitude towards the disease with a smaller proportion (16.3%) fully understanding the disease. Over half (54.7%) reported their patients having had the disease from between 4 months and 2 years with an overwhelming majority (96.2%) being still on treatment.

On average, each household had four members ranging between 1 – 9 and over half (54%) having between 4 – 5 members. More than three-quarters (78%) lived in house with 3 to 4 rooms.

Table 4. 2: Caregiver's information about family cancer history and current care provided

Variables	Categories	n	%
Relationship to patient	Mother	28	6.6
	Father	5	1.2
	Spouse	184	43.6
	Sibling, Other	205	48.6
Ever heard of cancer before the patient was diagnosed with cancer	Yes	406	96.2
	No	16	3.8
Is cancer a serious disease	Yes	386	91.5
	No	36	8.5
Perceived severity of the disease	Mild	3	0.7
	Moderate	8	1.9
	Severe	411	97.4
Other family members have had cancer	Yes	58	13.7
	No	364	86.3
Daily care time in hours	< 6	13	3.1
	6 – 12	301	71.3
	> 12	108	25.6
Others help with care	Yes	337	79.9
	No	85	20.1
Other family members with chronic illness	Yes	252	59.7
	No	170	40.3
Care giver attitude towards the disease	Positive	247	58.5
	Negative	175	41.5
Caregiver's understanding of the disease	Fully	69	16.3
	Partially	353	83.6
Duration patient has had the disease	0 – 3 months	15	3.6
	4 months – 2 years	231	54.7
	> 2 years	176	41.7
Treatment options	Still on treatment	406	96.2
	Untreated	16	3.8
Mean number of household members (Range)		4.2 (1 – 9)	
Number of household members	1	14	3.3
	2 - 3	102	24.2
	4 - 5	228	54.0
	≥ 6	78	18.5
Number of rooms	1 - 2	37	8.8
	3 - 4	329	78.0
	≥ 5	56	13.3

4.1.3 Socio-economic factor's influence on health-related quality of life of primary caregivers of cancer patients

Table 4.3 shows results on the impact of socioeconomic variables on the health-related quality of life of cancer patients' carers, Higher satisfaction scores were correlated with younger age groups (less than 35 years old).

with their health ($\bar{x}$= 40.9; p = 0.02) Males enjoyed higher mean scores on HRQOL in the three sub-domains that is social, psychological and environmental except on physical sub-domain where the association had borderline statistically significant results (p = 0.07). Males compared to females presented with significantly higher mean scores on psychological ($\bar{x}$= 56.7; p = 0.006), social relationship ($\bar{x}$= 21.2; p = 0.004) and environment ($\bar{x}$= 73.4; p < 0.0001). Equally, their mean score on perceived quality of life ($\bar{x}$= 37.7; p 0.007) and level of satisfaction with health ($\bar{x}$= 41.5; p = 0.01) was relatively higher than that of females. On the other hand, caregivers with secondary or tertiary education compared with their counterparts with none or primary education, had lower mean level of satisfaction with health ($\bar{x}$= 34.9, p = 0.005), physical ($\bar{x}$= 53.3, p = 0.0006), social relationship ($\bar{x}$= 18.9, p = 0.04) and environment ($\bar{x}$= 66.4, p = 0.003) score. Caregivers who were single, divorced or widowed got lower mean score on HRQOL under environment sub-scale ($\bar{x}$= 67.0, 0.002) as opposed to those who were married. Living in rural area resulted in higher mean scores on HRQOL on perceived QOL ($\bar{x}$= 36.2, p = 0.004) and psychological ($\bar{x}$= 55.2, p = 0.008) sub-scales but lower scores under physical sub-domain ($\bar{x}$= 57.1, p = 0.009). Being employed was statistically associated with higher mean scores on physical, ($\bar{x}$= 64.2, p < 0.0001) psychological ($\bar{x}$= 58.7, p = 0.0001), social relationship ($\bar{x}$= 22.0, p 0.0005) and environment ($\bar{x}$= 75.0, p < 0.0001) HRQOL. Those who were Christians had lower mean scores level of satisfaction with health ($\bar{x}$= 38.1, p 0.02) compared to non-

Christians. Caregivers earning less than KSh 10,000 per months were significantly associated with poor HRQoL on their perceived QoL ($\bar{x}$= 34.2, p 0.01), satisfaction with health ($\bar{x}$= 37.0, p = 0.01) and all the four sub-domains of HRQOL (p < 0.0001). Number of household members did not yield significant association with HRQOL in all the areas assessed. However, having fewer number of rooms (1 – 2) was statistically related to lower means scores in perceived quality of life ($\bar{x}$= 29.2, p 0.0005), level of satisfaction with health ($\bar{x}$= 33.5, p = 0.01), physical ($\bar{x}$= 52.4, p 0.04), psychological ($\bar{x}$= 48.3, p = 0.0002) and environment ($\bar{x}$= 64.3, p 0.02) sub-domains of HRQOL.

Table 4.3: Socio-economic factor's influence on health-related quality of life of primary caregivers of cancer patients

Variable	Categories	n	QoL	Satisfaction	Physical	Psychological	Social relationship	Environment
			$\bar{x}$	$\bar{x}$	$\bar{x}$	$\bar{x}$	$\bar{x}$	$\bar{x}$
Age group in years	< 35	171	36.9	40.9	57.7	55.2	19.9	69.0
	≥ 35	251	34.9	37.1	57.5	54.6	20.0	70.1
	P value		0.10	**0.02**	0.92	0.68	0.54	0.55
Gender	Male	262	37.7	41.5	60.0	56.7	21.2	73.4
	Female	160	34.5	36.9	56.1	53.7	19.2	67.3
	P value	262	**0.007**	**0.01**	**0.07**	**0.006**	**0.004**	**< 0.0001**
Level of education	Secondary / Tertiary	311	33.5	34.9	53.3	53.7	18.9	66.4
	None / Primary	111	36.6	40.0	59.1	55.3	20.4	70.8
	P value		0.07	**0.005**	**0.0006**	0.33	**0.04**	**0.003**
Marital status	Single / Others	141	35.5	38.7	56.7	54.8	19.3	67.0
	Married	281	36.4	38.6	58.0	54.9	20.4	71.0
	P value		0.59	0.91	0.78	0.96	0.14	**0.002**
Type of area of residence	Rural	394	36.2	38.9	57.1	55.2	19.9	69.6
	Urban	28	29.3	35.7	63.3	49.4	21.0	70.0
	P value		**0.004**	0.13	**0.009**	**0.008**	0.22	0.65
Occupation	Employed	108	35.4	39.6	64.2	58.7	22.0	75.0
	Others	314	36.8	38.3	55.3	53.6	19.3	67.8
	P value		0.39	0.59	**< 0.0001**	**0.0001**	**0.0005**	**< 0.0001**
Religion	Christians	398	35.6	38.1	57.3	55.1	20.1	69.8
	Others	24	38.3	48.3	62.2	51.5	19.2	67.0
	P value		0.48	**0.02**	0.07	0.12	0.69	0.44
Income in KSh	< 10,000	233	34.2	37.0	53.5	52.1	18.7	66.3
	≥ 10,000	189	37.7	40.7	62.5	58.2	21.6	73.8
	P value		**0.01**	**0.01**	**< 0.0001**	**< 0.0001**	**< 0.0001**	**< 0.0001**
Number of household members	< 4	116	37.9	38.1	58.0	54.7	20.5	69.0
	≥ 4	306	34.9	38.9	57.4	54.9	19.8	69.9
	P value		0.22	0.61	0.96	0.72	0.22	0.59
Number of rooms	1 – 2	37	29.2	33.5	52.4	48.3	18.6	64.3
	≥ 3	385	36.4	39.2	58.0	55.5	20.1	70.1
	P value		**0.0005**	**0.01**	**0.04**	**0.0002**	0.32	**0.02**

4.1.4 Family support's influence on health-related quality of life of primary caregivers of cancer patients

Table 4.4 shows survey findings on influence of family support on HRQL of caregiver of cancer patients in the study area. Caregivers who were being supported by other family members in care provision and whose daily care time was less than 12 hours received higher mean score in satisfaction with health ($\bar{x}$= 39.2, p = 0.01; $\bar{x}$ = 39.6, p = 0.006), social relationship ($\bar{x}$= 20.3, p = 0.04; $\bar{x}$= 20.7, p = 0.0002) and environment ($\bar{x}$= 70.4, p = 0.004; $\bar{x}$= 70.6, p 0.003), the relationship being statistically significant. In addition, those providing daily care for less than 12 hours also registered better HRQL in their perception of quality of life ($\bar{x}$= 37.1, p = 0.0002) and psychological ($\bar{x}$= 55.7, p 0.006) sub-domains. On the contrary, caregivers who were spouses had significantly lower mean score on physical sub-scale ($\bar{x}$= 56.3, p = 0.03) on HRQOL. The same has been confirmed by several studies (Barben, Jérémy, *et al.,* 2023)) that social support, such as support from friends and family, can have a positive impact on caregivers' mental HRQOL. A plausible explanation for this finding is that when there are more family members, they are better able to offer emotional support to caregivers, which lowers their psychological stress.

Table 4. 4: Family support's influence on health-related quality of life of primary caregivers of cancer patients

Variable	Categories	N	QoL	Satisfaction	Physical	Psychological	Social relationship	Environment
			$\bar{x}$	$\bar{x}$	$\bar{x}$	$\bar{x}$	$\bar{x}$	$\bar{x}$
Relationship to patient	Spouse	184	35.5	37.7	56.3	54.8	19.7	70.4
	Mother, Father, etc	238	35.9	39.4	58.6	54.9	20.2	69.1
	P value		0.74	0.24	**0.03**	0.87	0.88	0.55
Other family members also provide care	Yes	337	35.8	39.2	57.2	54.9	20.3	70.4
	No	85	35.3	36.7	59.0	54.9	18.7	66.3
	P value		0.30	**0.01**	0.09	0.94	**0.04**	**0.004**
Care giver attitude towards the disease	Positive	247	36.4	38.8	58.5	55.2	20.2	70.0
	Negative	175	34.7	38.5	56.2	54.4	19.8	69.1
	P value		**0**.33	0.85	**0.07**	0.52	**0.26**	0.79
Daily care time in hours	≤ 12	314	37.1	39.6	58.1	55.7	20.7	70.6
	> 12	108	31.7	35.9	55.9	52.5	18.0	66.8
	P value		**0.0002**	**0.006**	**0.15**	**0.006**	**0.0002**	**0.003**

4.1.5 Caregiver's knowledge on cancer and its influence on health-related quality of life of primary caregivers of cancer patients

As displayed in Table 4.5, having heard of cancer before patient was diagnosed with cancer ($\bar{x}$= 39.1, p = 0.003) and patient having had the disease for two years or less since diagnosed, ($\bar{x}$= 40.0, p = 0.003) was related to higher mean level of satisfaction scores. Duration patient has had the disease was also associated with higher scores on

caregiver's perceived quality of life ($\bar{x}$= 37.7, p = 32.9). Perception that cancer is a serious disease resulted in higher mean score on psychological sub-domain ($\bar{x}$= 55.9, p < 0.0001) while caregiver's fully understanding of the disease was significantly associated with higher mean score on the physical sub-domain ($\bar{x}$= 60.8, p = 0.02) compared to those who partially understood the disease.

Results also show that other family members having had cancer ($\bar{x}$= 32.4, p = 0.05), caregiver's full understanding of the disease ($\bar{x}$= 33.6, p = 0.02) and patient being still on treatment ($\bar{x}$= 35.1, p = 0.0009) were associated with lower mean scores on caregiver's perceived quality of life. Other family members having chronic illness ($\bar{x}$ = 35.5, p < 0.0001) and caregiver's understanding fully the disease ($\bar{x}$= 34.2, p = 0.001) negatively influenced level of satisfaction with health resulting in lower mean score. The former was also negatively associated with lower mean physical score ($\bar{x}$= 54.6, p < 0.0001). Under environment sub-scale, lower mean scores were reported caregiver perceived cancer as serious ($\bar{x}$= 69.2, p = 0.02) and where other family members had had cancer before ($\bar{x}$= 65.7, p = 0.02).

Table 4. 5: Caregiver's knowledge on cancer and its influence health-related quality of life of primary caregivers of cancer patients

Variable	Categories	N	QoL	Satisfaction	Physical	Psychological	Social relationship	Environment
			$\bar{x}$	$\bar{x}$	$\bar{x}$	$\bar{x}$	$\bar{x}$	$\bar{x}$
Heard of cancer before patient diagnosed with cancer	Yes	406	35.6	39.1	57.5	55.1	19.0	69.6
	No	16	40.0	28.7	58.0	50.0	21.7	69.5
	P value		0.58	**0.003**	0.94	**0.07**	0.61	0.82
Cancer is a serious disease	Yes	386	35.7	38.5	57.8	55.9	19.9	69.2
	No	36	35.6	40.0	55.1	44.0	21.1	73.7
	P value		0.95	0.98	0.29	**< 0.0001**	0.24	**0.02**
Cancer severity	Severe	411	35.8	38.6	57.6	55.0	20.0	69.6
	Mild, Moderate	11	34.5	41.8	54.9	50.5	20.0	71.3
	P value		0.93	0.91	0.63	0.26	0.78	0.67
Other family member has had cancer	Yes	58	32.4	40.0	60.6	54.2	18.9	65.7
	No	364	36.3	38.5	57.1	55.0	20.2	70.3
	P value		**0.05**	0.99	**0.03**	0.54	0.28	**0.02**
Other family members have chronic illness	Yes	252	35.2	35.5	54.6	54.1	19.9	69.3
	No	170	36.5	43.4	61.9	56.0	20.1	70.1
	P value		**0.17**	**< 0.0001**	**< 0.0001**	**0.15**	0.81	0.92
Caregiver's understanding of the disease	Fully	69	33.6	34.2	60.8	53.9	19.3	68.3
	Partially	353	36.1	39.5	56.9	55.1	20.1	69.9
	P value		**0.02**	**0.001**	**0.02**	0.26	0.25	0.36
Duration patient has had the disease	0 -2 years	246	37.7	40.0	57.7	55.1	20.2	70.6
	> 2 years	176	32.9	36.8	57.3	54.5	19.7	68.3
	P value		**0.0002**	**0.003**	0.56	0.31	0.40	0.13
Treatment options	Still on treatment	406	35.1	38.7	57.6	54.9	20.0	69.5
	Untreated	16	52.5	37.5	57.8	53.7	19.5	72.0
	P value		**0.0009**	0.99	0.71	0.78	0.97	0.35

In relation to information seeking, the discussants sought information about cancer from various sources which are not limited to health care providers, internet, family and friends. The information mostly sought after are information on various management of cancer, side effects of the various types of management. One of the respondents further said that "*The most common thing that I usually look for in an interest is where cancer came from and if there is a drug that can completely treat cancer and especially breast canc*er". One of the discussant indicated that:

> "*I do get information about cancer from the internet and how the hospital could organize some lessons for us the caregivers on how to take care of the cancer patients because like me, I found myself in this without any knowledge on how to take care of my husband leave alone taking care of myself."*

However, not all care givers trust and got their information from the internet. Two of the discussants indicated that they rely on health care provider for any information pertaining their patients. One of the discussants stated that:

> *"About information seeking, I only trust the one I get from the medical team, I have never tried internet because I don't know anything about it. I don't trust information given to me by word of mouth from peers or friends because most of the time they mislead people. My children also advice accordingly and I trust their input in the management of their sister but any other source of information from anyone apart from medical team and my children, I don't trust."*

The study also sought to find out information regarding healthcare information from the discussants. The results revealed that health care provider communicated with the care givers although the communication was not consistent. The researcher noted that communication is very key in management of cancer patients. One of the respondents stated that:

> *"what I have learned during this period that I have nursed my husband is that the most important people to communicate with about my husband's illness are the medical team, those are the once with first-hand information about my husband. Other people can at times mislead you because there was time a friend introduced me to a herbalist who made me almost lose my husband because he became worse than before. The only problem with the medical team is that you have to ask or prompt to get more information about the patient's progress, though they are very friendly but they are overwhelmed because we are many compared to the few providers available."*

Health care communication is important for the care givers since it improves their quality of life. The results revealed that healthcare communication especially with the healthcare providers is closely associated with social relationship and psychological support. Communication with family member has also been associated better quality of life. This was supported by one of the respondents who said that; "*In our family since mother started ailing we have really embraced communication. This communication has made the burden bearable amongst the family members*" However, one of the discussants had contrary opinion as indicated below.

"I feel that my brother's health information is safe with the immediate family members and the health care team. At times, we share the health information with our church pastors and other few ordained servants of God, we don't like sharing with other people because we need people who are contributing positively, and they worsen the situation spreading false information about the illness."

4.1.6 Multiple regression analysis on Socio-Demographic Information of Caregivers associated with health-related quality of life

Table 4.6 displays HRQL predictors. Regression models were constructed using the variables that were found using the Kruskall Wallis statistics. After adjusting for other confounding variables in the multivariate model, the gender of the caregiver did not substantially correlate with any of the four sub-scales of HRQOL among the sociodemographic characteristics included in the regression model. The model found a positive correlation between the marital status of the caregiver and the environmental sub-scales of HRQOL ($\beta = 3.216$, $p = 0.043$). The caregiver's residence had a favorable correlation with psychological well-being ($\beta = 4.624$, $p = 0.005$). A profession that was categorized as employed as opposed to other occupations was positively correlated with the environment ($\beta = 4.3874$, $p = 0.011$), psychological ($\beta = 2.764$, $p = 0.016$), and physical ($\beta = 4.398$, $p = 0.043$). Physical ($\beta = -2.641$, $p = 0.043$) and psychological ($\beta = -2.156$, $p = 0.027$) factors were inversely correlated with income. Caregiver awareness of

Table 4. 6: Multiple regression analysis on Socio-Demographic Information of Caregivers associated with health-related quality of life

Predictors	Physical			Psychological			Social relationship			Environment		
	Adj β	T	P	Adj β	T	P	Adj β	T	p	Adj β	T	p
Gender of caregiver: Male vs Female	-0.123	-0.10	0.919	1.362	1.51	0.132	0.833	1.24	0.214	2.552	1.88	0.061
Caregiver: Married vs Single, etc	1.998	1.42	0.158	-0.434	-0.41	0.681	0.754	0.96	0.336	3.216	2.03	**0.043**
Residence: Rural vs urban	-4.071	-1.85	0.066	4.624	2.81	**0.005**	-2.181	-1.79	0.075	-1.603	-0.65	0.518
Occupation: Employed vs Others	4.398	2.89	**0.004**	2.764	2.43	**0.016**	1.334	1.58	0.115	4.387	2.56	**0.011**
Income:< 10,000 vs ≥ 10,000	-2.641	-2.03	**0.043**	-2.156	-2.22	**0.027**	-0.946	-1.31	0.191	-2.576	-1.76	0.079
Cancer a serious disease: Yes vs No	3.037	1.60	0.120	12.162	8.61	**< 0.0001**	-0.375	-0.36	0.721	-4.397	-2.07	**0.039**
Other family members have cancer: Yes vs No	-1.400	-0.85	0.396	-1.541	-1.26	0.209	-2.084	-2.29	**0.022**	-5.386	-2.92	**0.004**
Other family members help with care: Yes vs No	-2.387	-1.73	0.084	-1.391	-1.35	0.177	1.589	2.08	**0.038**	2.618	1.69	0.092
Other family members have chronic illness: Yes vs No	-5.287	-4.49	**< 0.0001**	-1.352	-1.54	0.124	0.279	0.43	0.668	-0.339	-0.26	0.798

4.2 To determine the patient factors associated with HRQoL among primary caregivers of cancer patients in Kakamega County

4.2.1 Patient socio-demographic characteristics

Table 4.7 shows results on patient characteristics. A comparable proportion of patients aged 35 – 44 (28%) and 45 – 54 (27.5%) years and a mean age of 49.9 ± 11.8 (SD) years ranging from 10 to 99 years. More than half (56.6%) were females, married (68.2%) with more than a third (35.1%) having completed secondary education most whom were farmers (50.2%).

Table 4. 7: Patient socio-demographic characteristics

Variables	Categories	n	%
Age group in years	< 25	3	0.7
	25 – 34	29	6.9
	35 – 44	118	28.0
	45 – 54	116	27.5
	≥ 55	156	37.0
Mean age ± SD (Range)		49.9 ± 11.8 (10.0 – 99.0)	
Gender	Male	183	43.4
	Female	239	56.6
Marital status	Single	34	8.1
	Married	288	68.2
	Divorced	24	5.7
	Widow	76	18.0
Level of education	None	63	14.9
	Primary	109	25.8
	Secondary	148	35.1
	Tertiary	102	24.2
Occupation	Housewife	19	4.5
	Farmer	212	50.2
	Casual	9	2.1
	Employed	86	20.4
	Unemployed	96	22.7

4.2.2 Patient's medical History

Table 4.8 reveals results on patient disease information. Over half (54.7%) had had the disease for at least 1 year since diagnosed and another 40.3% having had it for two years. Two-thirds (66.6%) were in stage 4 with almost all having been on chemotherapy (99.5%). All had had CT Scan with an equally higher proportion (98.6%) having had biopsy done. Overall, all had spent over KSh. 100,000 on treatment. Majority of the patients had the following complications as a result of the disease: hair loss (98.3%), anaemia (97.9%), nausea and vomiting (95.3%) and body weakness (98.6%).

Table 4. 8: Patient's medical History

Variables	Categories	n	%
Number of years since diagnosed	0 -1	231	54.7
	2	170	403
	≥ 3	21	5.0
Stage of cancer	1	6	1.4
	2	21	5.0
	3	114	27.0
	4	281	66.6
Mode of treatment	Surgical	374	88.6
	Chemotherapy	420	99.5
	Radiation	302	71.6
Tests done	CT scan	422	100.0
	Biopsy	416	98.6
	Ultrasound	310	73.4
	Tumour analysis	124	29.4
Cost of treatment in KSh.	> 100,000	422	100.0
Complications due to cancer	Hair loss	415	98.3
	Anaemia	413	97.9
	Nausea and vomiting	402	95.3
	Body weakness	416	98.6

4.2.3 Type of cancer

Figure 4.2 illustrates type of cancer that patients presented with. The top three were oesophageal (26.1%), breast (23.7%) and prostate (13.3%) cancer. Of the 110 with oesophageal cancer 69.1% were males. Males were also leading number of those presenting with lung cancer (77.8%, n = 18), stomach cancer (78.9%, n = 19), colon cancer (90%, n = 10) and bone cancer (100%, n = 9). The least common types of cancer were leukemia (0.7%), skin cancer (0.5%) and liver cancer (0.5%), the two latter cases being males.

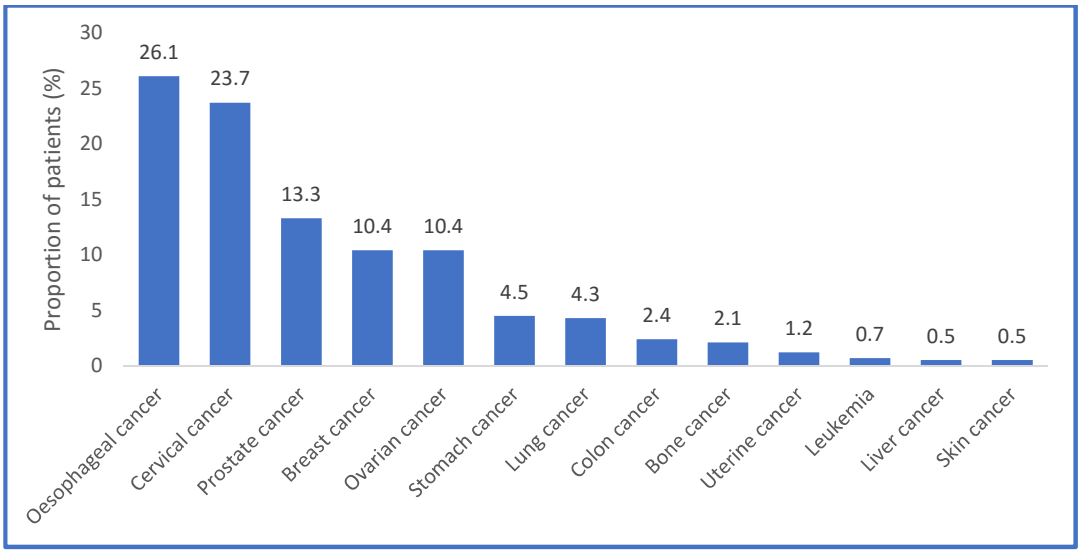

Figure 4. 2: Type of cancer

4.2.4 Patient factor's influence on health-related quality of life of primary caregivers of cancer patients

Table 4.9 depicts study findings on the influence of patient factors on HRQOL of caregivers for cancer patients. Caregivers who had patients who were on radiation ($\bar{x}$ = 36.9, p = 0.006) reported higher mean score on perceived quality of life. On

physical sub-scale higher mean scores were associated with younger patients (< 35 years) ($\bar{x}$= 62.9, p = 0.01) and those in stage 1, 2 or 3 ($\bar{x}$= 58.3, p = 0.05). Higher mean scores on psychological sub-scale were significantly associated with younger patients (< 35 years) ($\bar{x}$=58.6, p = 0.03) and those who were on radiation mode of treatment ($\bar{x}$= 55.6, p = 0.03, this findings was contradicting According to a Korean study by Choi et al. (2015), younger patients result in a higher care load, which lowers family caregivers' quality of life. The reduction in function, degree of independence, and stress levels experienced by patients are factors that influence the quality of family caregivers.

There was negative association between male gender ($\bar{x}$= 34.1, p = 0.03), cancer stage of 1 – 3 ($\bar{x}$= 33.9, p = 0.02) and caregiver's perceived quality of life as indicated by comparatively lower mean scores. As regards caregiver's level of satisfaction, patients secondary / tertiary level of education ($\bar{x}$= 37.1, p = 0.02) and patient being employed ($\bar{x}$= 35.8, p = 0.04) were associated with lower mean scores, the relationship being statistically significant. Being male ($\bar{x}$= 56.3, p = 0.03) was associated with lower HRQOL mean score on the physical sub-scale. Similarly, where tumour analysis test was done on a patient ($\bar{x}$= 19.0, p = 0.03), posted lower means scores social relationship suggesting poor performance on HRQOL on that sub-scale.

None of patient factors assessed had any statistically significant association with environment sub-scale. In the same manner none of the different types of cancer yielded any statistically significant association with any of the HRQOL sub-scales.

Table 4. 9: Patients factor's influence on health-related quality of life of primary caregivers of cancer patients

Variable	Categories	N	QoL	Satisfaction	Physical	Psychological	Social relationship	Environment
			$\bar{x}$	$\bar{x}$	$\bar{x}$	$\bar{x}$	$\bar{x}$	$\bar{x}$
Age group in years	< 35	32	35.0	39.4	62.6	58.6	21.4	70.5
	≥ 35	390	35.8	38.6	57.1	54.6	19.9	69.6
	P value		0.58	0.82	**0.01**	**0.03**	0.29	0.71
Gender	Male	183	34.1	38.0	56.3	54.7	20.0	69.3
	Female	239	37.0	39.2	58.5	55.0	20.0	69.9
	P value		**0.03**	0.71	**0.03**	0.83	0.72	0.83
Marital status	Single / Others	134	34.0	39.0	59.2	54.3	20.0	68.3
	Married	288	36.5	38.5	56.8	55.1	20.0	70.0
	P value		**0.07**	0.62	0.13	0.42	0.41	0.23
Level of education	Secondary / Tertiary	250	36.0	37.1	57.3	54.6	20.1	70.0
	None / Primary	172	35.3	40.9	58.0	55.3	19.8	69.0
	P value		0.80	**0.02**	0.77	0.44	0.47	0.60
Occupation	Employed	86	33.9	35.8	59.0	54.8	20.5	68.9
	Others	336	36.2	39.4	57.2	54.9	19.9	69.8
	P value		**0.09**	**0.04**	0.48	0.86	0.17	0.47
Cancer stage	1 – 3	141	33.9	37.0	58.3	53.4	19.1	68.9
	4	281	36.6	39.5	57.2	55.6	20.5	70.0
	P value		**0.02**	0.22	**0.05**	**0.08**	0.25	0.64
Mode of treatment	Radiation	302	36.9	39.5	57.8	55.6	20.0	69.5
	Others	120	32.8	36.5	57.0	53.0	20.1	70.0
	P value		**0.006**	0.16	0.58	**0.03**	0.40	0.57
Tests done	Tumour analysis	124	34.5	39.7	57.8	54.5	19.0	69.7
	Others	298	36.2	38.2	57.5	55.0	20.4	69.6
	P value		0.25	0.56	0.86	0.51	**0.03**	1.00
Type of cancer	Oesophageal	110	35.6	38.9	56.8	55.0	20.2	70.0
	Others	312	35.8	38.6	57.8	54.8	19.9	69.5
	P value		0.97	0.66	0.22	0.91	0.89	0.79

4.2.5 Multiple regression analysis on Patient factors associated with health-related quality of life

Table 4.10 presents predictors of HRQL. Kruskall Wallis statistics was used to identify variables to include in regression models. Out of the patient factors that were entered into the regression model, only cancer severity was not significantly associated with any of the four sub-scales of HRQOL after controlling for other confounding factors in the multivariate model. In this model, Mode of treatment which was classified as Radiation vs Surgery and other was positively associated with psychological (β =2.000, p = 0.022). Type of test done classified as Tumour analysis vs Others of life was negatively associated with social relationship (β = -1.360, p = 0.033).

Table 4. 10: Multiple regression analysis on patient factors associated with health-related quality of life

Predictors	**Physical**			**Psychological**			**Social relationship**			**Environment**		
Patient Factors	**Adj β**	**T**	**P**	**Adj β**	**T**	**P**	**Adj β**	**T**	**p**	**Adj β**	**t**	**p**
Mode of treatment: Radiation vs Chemotherapy, etc	1.402	0.46	0.643	2.000	2.29	**0.022**	-0.340	-0.53	0.600	-0.421	-0.32	0.749
Type of test done: Tumour analysis vs Others	-0.595	-0.52	0.604	-0.896	-1.05	0.295	-1.360	-2.14	**0.033**	0.517	0.40	0.688
Cancer severity: Severe vs Mild Moderate	4.105	1.22	0.223	1.941	0.77	0.440	0.584	0.31	0.754	-0.004	-0.00	0.100

4.3 To evaluate psychological factors affecting HRQoL among primary caregivers of cancer patients in Kakamega County

4.3.1 Descriptive statistics of variables

Table 4.11 shows results on descriptive statistics on four instruments used in the study. The mean score for Hearth Hope Index was 32.8 ± 2.8 (range: 41.0 – 41.0) out of a maximum score of 48 suggesting higher mean score on Hope Index. However, means scores for depression (19.1 ± 4.7; range: 3.0 – 27.0) and anxiety (17.1 ± 3.6; range; 4.0 – 21.0) were more than half the maximum score for both indicating higher number of caregivers with depression and anxiety. All the four sub-domains of health-related quality of life namely: physical (57.6 ± 14.4; range: 32.0 – 112.0), psychological (54.9 ± 10.7), social relationship (20.0 ± 6.2; range: 12.0 – 48.0) and environment (69.6 ± 13.0; range: 40.0 – 112.0) had mean score of the less than half the maximum score in each sub-scale indicating poor health-related quality of life. The same was true of caregivers' perceived quality of life (35.7 ± 13.5; range: 20.0 – 80.0) and their level of satisfaction with their health (38.7 ± 15.4; range: 20.0 – 100.0) both of which had a mean less than half total expected score.

Table 4. 11: Descriptive statistics of variables

Variable	$\bar{x}$	SD	Minimum	Maximum	Expected Maximum
Hearth Hope Index					
Hope	32.8	2.8	24.0	41.0	48.0
Depression and Anxiety					
Patient Health Questionnaire	19.1	4.7	3.0	27.0	27.0
Generalized Anxiety Disorder	17.1	3.6	4.0	21.0	21.0
Health-related quality of life					
Perceived quality of life	35.7	13.5	20.0	80.0	100.0
Level of satisfaction with health	38.7	15.4	20.0	100.0	100.0
Physical	57.6	14.4	32.0	112	140
Psychological	54.9	10.7	32	88.0	120
Social relationship	20.0	6.2	12.0	48.0	60
Environment	69.6	13.0	40.0	112.0	160

In regards to care giver isolation and care giver social nature, the study established that care givers have been isolated from the rest of the community due to intense nature of taking care of their cancer patients. It was evident the quality of life of all the 56 care givers is negatively affected. This was not limited to physical, spiritual, psychological

but also social relationship and environment. They are supposed to accompany their cancer patients to all errands related to their which has not only isolated them, but they have been forced to cut short their participation in socio-economic activities. This was well summarized during FGD 1 by the fourth discussants who stated that:

> "*My husband does not understand the magnitude of my sister's illness, so he married a second wife because most of the time I am taking care of my sister. I miss my family so much but I also have to be with my sister. I no longer attend church, women group or any other leisure activity because my sister needs me so much. Financially I am down. I am a business woman and most of my businesses have collapsed and it is not easy to make ends meet. I am not at peace with my mind, I am always stressed and sometimes I fear that I might lose my sister.*"

This was also reported by Respondents 5 in the second focus group discussion who said that:

> "*The issues affecting care givers include both physical, emotional and social burden and there is no one to help because I started nursing my daughter two years ago and no one has ever talked to us like you are doing today. How I wish someone could be concerned about us like you are doing today. At least the hospital could have known our challenges/ problems and may be see how to help us together with our patients."*

In the fourth focus group discussion, the sixth discussant stated that

> "*as a care giver, we face several issues for instance, since I started taking care of my wife I have had a lot of issues. Psychologically I am not okay, physically my body is worn out and I have developed ulcers and hypertension due to care giving. I have to ensure that children are stable and remain strong for everyone and yet personally I also don't feel okay and I have no one to turn to not even the service providers."*

From the above results, it is clear that sampled care givers have been isolated and this is negatively affecting their quality of life. During the focus group discussion, various discussants brought forward various ways that can address isolation and social nature challenges of the primary care givers of cancer patients. This was well stated by one of the respondents from the second focus group discussion who stated that:

> "*the issues affecting care givers include both physical, emotional and social burden and there is no one to help because I started nursing my daughter two years ago and no one has ever talked to us like you are doing today. How I wish someone could be concerned about us like you are doing today. At least the hospital could have known our challenges/ problems and may be see how to help us together with our patients."*

From the above statement, it is clear that care givers need support but from the results of this study, no support has been accorded to the care givers as must of the support is directed towards their cancer patients. This was evident by one the of the discussant

said that "Personally I have never been engaged in any social network, we have social network for cancer patients but not for caretakers". Therefore, all the discussants affirmed that there is need for social support directed towards the giver since caring for cancer patients has negatively affected their quality of life. One of the discussants who took part in this study indicated that:

> "*I wish the hospital could organize for us a support group where we share our challenges and know how to cope with the burden or challenges we face will need to be done for periodic medical examination especially for screening of cancer so that in any case will test positive we can be helped in an earlier stage."*

Respondents six in focus group II stated that

> "*the services that would be helpful for care giver include psychosocial support group for caregivers. At least in this forum we can be able to share with others who have the same burden and so will not feel all alone. Secondly, how I wish the financial charges for cancer management could be subsided as this could relieve the financial burden we are facing as care givers.".*

4.3.2 Relationship between depression, anxiety and health-related quality of life

As shown in Table 4.13, depression was highly statistically significantly associated with caregiver perceived quality of life ($\bar{x}$= 34.2, $p < 0.0001$), level of satisfaction with health ($\bar{x}$= 35.8, $p < 0.0001$) and all the four sub-scales ($p < 0.0001$). In all these outcomes, severe depression posted lowest mean scores suggesting that caregivers

who presented with signs suggestive of severe depression performed poorly on HRQOL.

An assessment on relationship between anxiety and HRQOL revealed that statistically significant relationship between anxiety and caregiver perceived quality of life (($\bar{x}$= 34.2, p = 0.002), level of satisfaction with life, physical and psychological, each having a $p < 0.0001$). Again, among caregivers presenting with signs suggestive of severe anxiety, the mean scores were relatively lower indicating lower HRQOL. This was however, not the case with social relationship and environment sub-domains which resulted in non-statistically significant outcome.

Table 4. 12: Relationship between depression, anxiety and health-related quality of life

Variable	Categories	N	QoL	Satisfaction	Physical	Psychological	Social relationship	Environment
			$\bar{x}$	$\bar{x}$	$\bar{x}$	$\bar{x}$	$\bar{x}$	$\bar{x}$
Depression	Normal	2	50.0	50.0	82.0	74.0	32.0	98.0
	Mild	18	51.1	66.7	86.0	74.7	30.0	82.7
	Moderate	46	40.9	49.6	70.3	63.2	21.7	75.0
	Severe	356	34.2	35.8	54.3	52.7	19.2	68.1
	P value		**< 0.0001**	**< 0.0001**	**< 0.0001**	**< 0.0001**	**< 0.0001**	**< 0.0001**
Anxiety	Normal	2	50.0	60.0	92.0	68.0	24.0	82.0
	Mild	17	41.2	50.6	70.6	62.8	25.4	75.5
	Moderate	76	40.5	48.1	66.7	61.3	21.3	73.5
	Severe	327	34.2	35.7	54.5	52.9	19.4	68.4
	P value		**0.002**	**< 0.0001**	**< 0.0001**	**< 0.0001**	0.09	0.07

Table 4.13 The number of caregivers with depression and anxiety

Variable	Categories	N
Depression	Normal	2
	Mild	18
	Moderate	46
	Severe	356
	P value	
Anxiety	Normal	2
	Mild	17
	Moderate	76
	Severe	327
	P value	

4.3.3 Multiple regression analysis on psychological factors associated with health-related quality of life

Table 4.14 presents predictors of HRQL. Kruskall Wallis statistics was used to identify variables to include in regression models. Out of the psychological factors that were entered into the regression model, only hope and anxiety were not significantly associated with any of the four sub-scales of HRQOL after additional confounding variables were taken into account in the multivariate model. Depression was shown to be negatively correlated with the following variables in this model: psychological ($\beta = -0.880$, $p = 0.000$), physical ($\beta = -1.08$, $p = 0.000$), social relationships ($\beta = -0.343$, $p = 0.000$), and environment ($\beta = -0.711$, $p = 0.000$). Perceived quality of life was positively connected with the following factors: environment ($\beta = 0.218$, $p = 0.000$), social relationship ($\beta = -0.077$, $p = 0.003$), psychological ($\beta = 0.169$, $p = 0.000$), and physical ($\beta = 0.121$, $p = 0.011$). Health satisfaction and physical well-being had a positive correlation ($\beta = 0.200$, $p = 0.011$).

Table 4. 14: Multiple regression analysis on psychological factors associated with health-related quality of life

Psychological factors	Physical			Psychological			Social relationship			Environment		
	Adj B	**T**	**P**	**Adj β**	**T**	**P**	**Adj β**	**T**	**p**	**Adj β**	**t**	**p**
Hope	-0.127	-0.66	0.508	0.267	1.86	0.063	-0.042	-0.40	0.690	0.358	1.66	0.098
Depression	-1.08	-7.00	**<0.001**	-0.880	-7.65	**<0.001**	-0.343	-4.02	**<0.001**	-0.711	-4.11	**<0.001**
Anxiety	-0.358	-1.85	0.065	-0.189	-1.31	0.192	0.017	0.16	0.873	0.238	1.10	0.274
Perceived quality of life	0.121	2.57	**0.011**	0.169	4.79	**<0.001**	0.077	2.95	**0.003**	0.218	4.11	**<0.001**
Being satisfied with one's health	0.200	4.46	**<0.001**	0.018	0.54	0.588	0.013	0.51	0.610	-0.048	-0.96	0.337

CHAPTER FIVE

DISCUSSION

5.0 Overview

The results of the study on the factors predicting Health-Related Quality of Life among primary caregivers of cancer patients in Kakamega County are discussed in this chapter. The chapter is divided into several sections, such as the relationship between psychological factors and HRQoL among primary caregivers of cancer patients, socioeconomic factors influencing HRQoL among primary caregivers of cancer patients in Kakamega County, and patient factors associated with HRQoL among primary caregivers of cancer patients in Kakamega County. in Kakamega County.

5.1 Socio- economic factor's influence on HRQoL among primary caregivers of cancer patients in Kakamega County

Primary caregivers who were younger in age below 35 years had a better score on the overall level of satisfaction with life than their counterparts. It has been reported in other studies that the caregiver's age has an impact on the care load (Sezgin et al., 2022). The results of the study can be explained by the fact that aging and the physiological changes that occur in the body have a significant impact on health and the perceived quality of life in old age. Aging can also have a negative impact on caregivers' HRQoL due to the strain that it can place on their lives.

According to the study, there were more female caregivers than male caregivers, which is consistent with findings from earlier research (Waldron, 2022; Stenberg et al., 2020) and the National Family Caregivers Association report (National Family Caregiver Association, 2018). According to the reports, women still make up 63% of caregivers, despite the fact that men do participate. This result may be explained by the

conventional responsibilities that women play, since they are primarily responsible for providing care.

With the exception of the physical sub-domain, where the association produced results that were only marginally statistically significant, men had higher mean HRQOL ratings in the current study throughout the three sub-domains: social, psychological, and environmental. Findings from a cross-sectional study on primary caregivers' HRQoL for gastrointestinal cancer affecting their HRQoL in the four sub-domains. Veenstra *et al.,* (2022) reported that, once a member of the family has been diagnosed with cancer, the primary caregiver is at risk for missed work, job loss, and financial burden that negatively impact their HRQoL.

From the current study, caregivers who were single, divorced or widowed had lower mean score on HRQOL under environment sub-scale as opposed to those who were married. This was also confirmed in a study conducted by Shang-Yu (2021). This could be explained by the fact that married caregivers had a better score due to the support they receive from their partners and family members.

Christians had lower mean scores in level of satisfaction with health compared to non-Christians. Ying *et al.,* (2021) found out that Islamic religion assisted primary caregivers, who, in contrast to Christians, were taking care of family members with disabilities or health concerns, in managing their own physical and mental well-being. Family members' caregiving responsibilities are part of Islam's holistic teachings in all spheres of life, and this has benefited believers' relationships with their families and relatives. Islamic religious views, which see sick relatives as gifts from God and provide them a feeling of purpose, also assisted primary caregivers in accepting their ailing relatives Asano et al., (2021). The results may be explained by Christians seeing their circumstances as unfair, unjust, God's retribution, or God's desertion, which

exacerbates their psychological and spiritual effects. and lower mean scores on their overall HRQoL.

Number of household members did not yield significant association with HRQOL in all the areas assessed. However, having fewer number of rooms (1 – 2) was statistically related to lower means scores in perceived quality of life, level of satisfaction with health, physical, psychological and environment sub-mains of HRQOL. In the current study, those living in houses with more than 3 rooms were doing better than their counterparts. During COVID-19, as people were instructed to stay at home, According to Tinson and Clair (2020), 39% of those residing in overcrowded families had symptoms of both physical trauma and psychological anguish. According to Mornis et al. (2020), people who live in cramped quarters have a greater impact on their well-being than people who live in safe, roomy homes. Environmental issues including noise disruption from subpar housing caused anxiety to rise by 18% (Bowel et al., 2021).

5.2 Patient Factors influencing HRQoL among primary caregivers of cancer patients in Kakamega County

Primary caregivers of younger patients (< 35 years) had a higher mean score on physical and psychological domain which was incongruent with (Mokhzan *et al.,* 2023). The findings could be explained by the fact that elderly patients wholly depend on their caregivers on many aspects of their care unlike their younger counterparts who can perform some activities by themselves.

Caregivers of male patients had a lower mean score on QoL and physical sub-domain. This is consistent with Israeli study which reported that male colorectal cancer patient's caregivers had a higher level of stress than their counterparts (Akpan-Idiok *et al.,* 2020). This could be explained by the fact that male patients only relied more

on spousal support and less on others, while their female counterparts had more external support even from friends. Contrary to the finding, a study conducted in Thailand found that the caregivers of male cancer patients had better HRQOL than those caring for female patients (Üzar-Özçetin *et al.,* 2020). This because female patients may feel distressed by needing to care for others even when they are unwell, due to their social role and this distress on the part of the patient may negatively impact the caregiver's HRQOL.

In regards to the level of education, primary caregivers whose patients had none or primary level of education scored higher in overall satisfaction with HRQOL than those with higher level of education this was in agreement with the findings in longitudinal study that assessed the QOL of caregivers of prostate cancer patients by Raghupathi (2020). This finding could be explained by the fact that, the more a person is educated, the more knowledge and skills he will acquire with increased awareness of his condition and with poor prognosis of cancer cases and being aware on their condition may lead to increased anxiety which negatively impacts on the caregiver.

Primary caregivers of employed cancer patients have reported low level of satisfaction and poor QoL. This is confirmed by the report of a study conducted by Tamminga *et al.,* (2022). This finding could be explained by the fact that cancer patients discontinue work after cancer diagnosis as a result of fatigue, nausea and unfavourable prognosis. This eventually reduces the family income flow hence negatively affecting the HRQoL of primary caregivers.

In cancer staging, the caregivers whose cancer patients were in stage 1-3 were doing poorly on HRQoL than those in stage 4. This was in agreements with the findings in study conducted by Mwangi, (2022). The finding could explain that, during early

stages after diagnosis, patients experience the side effects of treatments, such as headache, fatigue, nausea and dizziness. The severity of the patient's symptoms and behavioral disturbances result in a greater “burden” to primary caregivers leading to their poor HRQoL . Cancer changes the lives of the patients and their loved ones causing both physical and psychological suffering as well as negative social and spiritual experience (Avancini *et al.,* 2020). Once diagnosed with cancer, patients have to deal not only with physical ailment resulting from the illness and its treatment, but also permanent health impairment, disability, fatigue and pain which affects the HRQoL of their primary caregivers. Poor patient performance status and cohabiting with the patient are also associated with caregiver poor HRQoL (Adele *et al.,* 2019).

Caregivers who had patients on radiation reported higher mean score on perceived quality of life. Higher mean scores on psychological sub-scale were significantly associated with those who were on radiation mode of treatment, this was in agreement with a study conducted by (Lawrie, Theresa A., *et al* 2019) . This could be explained by the fact that chemotherapy treatment kills/destroys cancer cells all over the body not only at the primary site and at times destroying normal cells, making the patient suffers serious side effect of the treatment. Radiation, on the other hand, involves giving high doses of radiation beams directly into a tumor. The radiation beams change the DNA makeup of the tumor, causing it to shrink or die. This type of cancer treatment has fewer side effects than chemotherapy since it only targets one area of the body.

Several tests were done on cancer patients but those who underwent tumours analysis were doing poorly on social domain, the results concurred with (Belapurka *et al.,* 2023). The study findings could be explained by the fact that the pain/stress experienced by cancer patients during surgery and post-surgery leads to a decline in

the quality of life of the primary caregivers especially in their social domain. Patients with a new cancer diagnosis can experience distress as a result of the impending financial burden associated with the expected long-term treatment.

5.3 Caregiver's knowledge and its influence on health-related quality of life of primary caregivers of cancer patients

Caregivers who already heard of cancer before their patients were diagnosed with cancer were doing better on the overall satisfaction with life. Lack of information and awareness about cancer before diagnosis leads to increased anxiety and stress among the primary caregivers (McCarthy, 2011). The author further reported that family caregivers who have not heard of cancer before tend to neglect their own wellbeing unlike those who had heard of cancer before diagnosis. Having knowledge on how to care for their patients improves their overall satisfaction with life.

Reports also show statistically significant association between psychological and environmental sub-domains among primary caregivers and HRQOL with regard to caregivers who considered cancer as a serious disease. The results are similar to Kilic and Fatma (2018) study conducted in Turkey for general cancer patients. Their argument was that regardless of the type of cancer, the mere diagnosis of cancer alone brings multi-factorial stresses that reduce the HRQol of the primary caregivers.

The findings also revealed that caregivers with history of cancer in their family were doing better on physical domain but poor on environmental domain. Liu (2014) in his study demonstrated that caregivers of cancer patients who had other family members diagnosed with cancer before appeared much stronger compared to those without family history of cancer. This probably could be because such caregivers had already adopted a coping mechanism.

On the contrary, caregivers with chronic illnesses were doing poorly on HRQOL's overall satisfaction with life, physical and psychological sub-domains. (Kilic, S. T., & Oz, F. (2019) reported that primary caregivers with chronic illnesses had lower score on the level of satisfaction as their health status hindered them from offering care to the cancer patient. Care giving itself is major role and having a condition that hinders the provision of care role is bound to bring stress therefore reducing the HRQoL of the primary caregivers (Jadalla, Ahlam, *et al.,* 2020).

Caregivers who understood cancer fully were doing better on physical domain but poor on overall satisfaction with life. When primary caregiver is equipped with cancer disease information, disease management, modes of therapy and the likely complications, it reduces the fear of the unknown and will be able to manage burnout associated with caregiving hence better performance on the physical domain Mwangi (2020). However, the poor performance on overall satisfaction with life can be ascribed to the multi-factorial stress as a result of cancer which negatively affects their HRQoL (Mulugeta *et al.,* 2023).

Duration that the patient had taken with the disease since diagnosis was associated with higher mean score on overall HRQOL. Caregivers whose patients had stayed with the disease for 0 to 2 years were doing better on the overall satisfaction with life sub-domain. Longer duration with the cancer disease is associated with increased burden in terms of the demand for care (Sun, H., Qin, Y., & Hengudomsub, P. (2021)

Results also revealed that primary caregivers whose patients were still on treatment option were doing poorly on HRQoL. During treatment, cancer patients usually experience and suffer from the side effects of treatments, such as headache, fatigue, nausea, dizziness and many more. Greater severity of the patient's symptoms and behavioural disturbances result in a greater "burden" to primary caregivers leading to caregivers poor HRQoL (Mwangi, 2022).

5.4 Family support's influence on HRQoL of primary caregivers of cancer patients

In this study, spousal caregivers were doing poorly in physical sub-domain compared to caregivers taking care of other family members. A similar finding was reported in a study which revealed that the relationship between the couples influences the HRQOL of the spousal caregivers of cancer patients Kilic, S. T., & Oz, F. (2019). Spouses also face challenges such as worries about their ability to provide emotional and practical support, and the potential loss of their life partner from cancer (Sevcan Toptas *et al.,* 2019). In one study of older spousal caregivers, those who reported caregiver stress had a 63% higher mortality rate than non-spousal caregivers of the same age (Schulz, Beach, *et al.,* 2021) which may explain why spousal caregivers scored poorly in physical domain.

Primary caregivers receiving caring support from other family members had a higher mean score on overall satisfaction with life, social and environmental sub-domains. The results are similar to previous studies conducted in Uganda and Vietnam which showed significant difference on caregivers HRQoL based on receiving support in provision of care (Kizza and Kanaabi.,2019, Nguyen *et al.,* 2019). When care is provided by more family members, it means that less time will be spent by the caregiver leaving more time for the main caregiver to relax. Stavas *et al.,* (2018)

reported that as the number of helpers who support primary caregivers' increases, caregiver burden scale point decrease.

Caregivers offering care to cancer patients for less than 12 hours in a day had higher mean score on overall satisfaction with life, physics, psychological, social and environmental Sub-scales. Caregiving activities are varied and numerous and they include personal care, mobility, transportation, communication, administration of medications and therapies, among many others (Fisher *et al.,* 2021). More than half of caregivers in another study reported having more things to do than they could handle (Schofield *et al.,* 2021) leading to poor HRQoL.

5.5 Psychological factors affecting health-related quality of life of primary caregivers of cancer patients

Depression was highly statistically significantly associated with caregiver perceived quality of life, level of satisfaction with health and all the other four sub-scales. In all these outcomes, severe depression posted lowest mean scores suggesting that caregivers who presented with signs suggestive of severe depression performed poorly on HRQOL. Several studies have revealed that caregiver burden is linked to depressive disorder symptoms. Caregiving stress can worsen caregivers' existing depressive situations (Hanzawa *et al.,* 2013; Fitzmaurice *et al.,* 2017; Geng *et al.,* 2018).

An assessment on relationship between anxiety and HRQOL revealed statistically significant relationship between anxiety and caregiver perceived quality of life, level of satisfaction with life, physical and psychological sub-domains. Again, among caregivers presenting with signs suggestive of severe anxiety, the mean scores were relatively lower indicating lower HRQOL. This was however, not the case with social relationship. Studies have reported that caregivers presented with higher levels of

anxiety symptoms if they were heavily burdened by caregiving. This is because they experienced more disruptions in schedules, greater health deterioration, stronger sense of family abandonment, and lower caregivers' esteem (Tang *et al.,* 2012; Mazzotti *et al.,* 2013; Papastavrou *et al.,* 2012).

CHAPTER SIX

CONCLUSION AND RECOMMENDATION

6.1 Overview

The study's conclusions are presented in this part in accordance with its goals. The chapter concludes with recommendations and prospects for additional research based on the study's findings.

6.2 Conclusions

The study found a strong relationship between the HRQoL of main caregivers of cancer patients in Kakamega County and socioeconomic characteristics such as age, gender, income, number of rooms, occupation, marriage status, and housing. The younger caregivers scored better on the satisfaction scale for their health. With the exception of the physical sub-domain, men's mean HRQoL scores were higher in the social, psychological, and environmental sub-domains. A higher mean score on the physical, psychological, social relation, and environmental domains was linked to employment. Married caregivers have higher quality of life scores in relation to environmental health. Rural caregivers' quality of life is superior in terms of psychological health. Caregivers who are employed demonstrate superior quality of life in terms of physical, psychological, and environmental health. Conversely, however, caregivers who have secondary.

The study found that among main caregivers of cancer patients in Kakamega County, patient-related characteristics such as the type of test performed and the modality of therapy were substantially correlated with HRQoL. Caregivers of patients receiving radiation therapy report improved psychological health and overall quality of life. Caregivers of patients who had their tumors analyzed showed poor quality of life in terms of social relationships and health.

The study found that among main caregivers of cancer patients in Kakamega County, psychologically related characteristics such as depression and anxiety were substantially connected with HRQoL. Depressed caregivers showed lower quality of life in terms of psychological, physical, social interaction, and environmental health. Better psychological, physical, social connection, and environmental health-related quality of life was demonstrated by caregivers who felt that their quality of life was higher.

6.3 Recommendations

The study made the following recommendations based on the findings.

Low income negatively affected care giver health-related quality of life among primary caregivers of cancer patients in Kakamega County, therefore, the study recommended that the national and county government should come up with a financial scheme that will help subsidise the financial charges for cancer management as this could relieve the financial burden care givers are facing. .

Other family members having cancer and chronic illness negatively affected care giver health-related quality of life. In this regards, the study recommended that other family members should support primary care givers not only financially, but also psychologically to ease the burden of the primary care givers. Health care providers should develop a program focused on reducing burden, enhancing caregivers' support and family hardiness, and helping them to maintain their quality of life. Knowledge on cancer as serious disease negatively affected care giver health-related quality of life among primary caregivers of cancer patients in Kakamega County. The study recommended that the cancer regulatory body to come up with a policy that allow the health care providers to create sometime to educate caregivers on various types of

cancer their management, side effect of the drugs and how to assist their patients at home thereby easing the burden of cancer, as a serious disease.

Nurses should endeavour to identify primary caregivers at risk in order to institute tailored health information about cancer and teach them ways & techniques of promoting the HRQol. Nurses should deploy HRQol scale- family version as tool to identify primary caregivers at risk in order to offer training that may include modern way of digital networking through social groups & organisations that support cancer patients & their care givers for example Kenya Network of Cancer Organisation (KENCO).

In regards to policy, there is need for government and other state actors to initiate psychosocial counselling services to cancer care givers. Depression negatively affected care giver health-related quality of life among primary caregivers of cancer patients in Kakamega County. Therefore, the study recommended that the hospital management in collaboration with the cancer governing body to establish a psychosocial support group networks for caregivers through multiple communication channels thereby reducing the mental and psychological burden experienced by caregivers.

6.4 Suggestions for future research

The primary caregivers of cancer patients at the Kakamega County Referral Hospital Cancer Center were the subject of the study. Additional research ought to be carried out at other medical facilities from different areas.

Furthermore, since the study only looked at socioeconomic, patient-related, and psychological characteristics, more research is required to identify other predictors of health-related quality of life among primary caregivers of cancer patients.

This study did not include caregivers whose patients were admitted to private hospitals in Kakamega County. To further understand how hospital-related factors affect primary caregivers' health-related quality of life, comparable studies in private hospitals should be conducted in the future.

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APPENDIX I: INFORMATION SHEET

The following information is to enable you to give voluntary, informed consent to participate in this study. Please read the information carefully before signing the consent form (part B). To be verbally read for those who are not able to read.

Study title: Predictors **of** Health-Related Quality of Health of primary caregivers of cancer patients in Kakamega County.

Investigators Names: Hellen Aoko Odeny

Address County Government of Kakamega,
Lurambi Sub-County,
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Tel: 0728475932

Aim and Significance of the study

This study aims at determining the Predictors of Health-Related Quality of Life amongst primary care givers of cancer patients in Kakamega County. The findings will therefore be instrumental in educating health care providers on the health needs of primary care givers so as to improve their HRQOL and as well be used as baseline for developing future intervention to support care givers towards improving their HRQOL.

What participation will involve

Participation in the research is dependent upon signing the informed consent form. Upon signing the consent form, you will be asked detailed questions on social, economic and demographic information concerning Health Related Quality of Life of primary care givers of cancer patients. This information will be recorded onto forms. The participant in this study will be required to give honest information to their level best.

Data Security

All information you provide will remain confidential. Only the study team will have access to this information and will be treated with confidentiality unless your express permission is obtained.

You may withdraw from participating in this study at any time without giving reasons. This will not affect services you are receiving.

APPENDIX II: CONSENT FORM

Please read the previous information sheet (or have the information read to you) carefully before completing and signing this consent form. Should you have any questions about the study please feel free to ask the investigator prior to signing your consent

Consent Form for the Study

Health Related Quality of Life of primary care givers of cancer patients in Kakamega County Teaching and Referral Hospital.

Investigators Names: Hellen Aoko Odeny

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Tel: 0728475932

FOR COMPLETION BY PARTICIPANTS

I have read (or the enumerator has read to me) the following sheet concerning this study and I understand what will be required of me if I take part in the study.

I understand that at any time I may withdraw from the study without giving a reason and this will not affect the care am receiving.

I AGREE TO TAKE PART IN THE STUDY:

Name Initials of participant: ……

Signed……. (Or thumb print)

Date: ……...

APPENDIX III: QUESTIONNAIRE

Inclusion criteria: (Male and female individuals)

RESPONDENT ID

Health facility name_____ Initials of respondent: _____
Serial #: _____ Date: _____
Name of Interviewer: _____ Signature: _____

A. Clinical
Cancer patient clinical information's

#	Question	Response	Code
1	Patient has been diagnosed with cancer?	1.Yes 2. No	
2.	Date when patient was diagnosed _ _/_ _/_ _ _ _(DD/MM/YYYY		
3	PT. Initials or Hosp. No.		
4	What type of cancer	…….	
	What's the age of patient		
	Indicate gender of patient	1. Male 2. Female	
	Indicate patient's marital status	1. Single 2. Married 3. Divorced 4. Widowed 5. Others (specify)	
	Patient's level of education	1. Did not go to school 2. Primary education 3. Secondary education 4. Tertiary education 5. Others (specify)	
	Patient's employment status	1. Employed 2. Unemployed 3. House wife 4. Farmer 5. Any other (specify)	
5.	Stage of cancer at diagnosis	1. Stage 1 2. Stage 2 3. Stage 3 4. Stage 4	

6.	Mode of treatment	1. Surgical 2. Chemotherapy 3. Radiation 4. Others (specify)	
7	Tests done	1. CT-Scan 2. Biopsy 3. Ultrasound 4. Tumours analysis 5. Others (specify)	
8	Cost of treatment	1. <Ksh50,000 2. 50,000-100,000 3. >Ksh 100,000	
9	Complications due to cancer/treatment	1. Hair loss 2. Anaemia 3. Nausea/Vomiting 4. Body weakness 5. Others (specify)	
B. SOCIO-DEMOGRAPHIC CHARACTERISTICS OF THE PRIMARY CAREGIVER			
10.	What is your age please?	……	
11.	Indicate gender of the respondent.	1. Male 2. Female	
12.	What is the highest level of education that you have attained? (Don't read the options)	1.Did not go to school 2.Primary education 3.Secondary 4. Tertiary	
13.	What is your current marital status?	1.Single 2.Married 3.Divorced 4.Widowed	
14.	Where do you stay (Name of the S/County)	**……**	
15.	Which type of area do you come from?	1.Urban 2.Rural 3. Don't know?	
16.	What is your job status?	1.Housewife 2.Farmer 3.Casual 4. Employed 5. Unemployed 6.Any other (please specify) _____	
17	Religious belief	1.Christian 2.Hindu 3.Islamic 4.Others	
18	Relationship to patient	1.Mother 2.Father 3.Spouse 4.Other	

19	Perceived disease severity	1.Mild 2.Moderate 3.Severe	
20	Whether other family members have cancer.	1.Yes 2.No	
21	Daily care time	1. < 6 hrs. 2. 6-12 hrs. 3. >12 hrs.	
22	Whether others help with caregiving	1.Yes 2.No	
23	Chronic illness	1.Yes 2.No	
24	Caregiver attitude	1.Positive 2.Negative	
25	Understanding of disease	1.Full 2.Partially	
29	Patient's duration since diagnosis	1.0 – 3 months 2.4months- 2 years 3.> 2 years	
30	Treatment options	1.Treated 2. Un treated	
31.	Please tell me the number of your family members you are currently living with? (just enter the number in the box provided) _____	……	
32.	Please tell me the number of rooms in your house? (just enter the number in the box provided) _____	……	
33.	What is your personal monthly Income (KShs)?	1. <5000 2. 5000 – 9999 3. 10000 to 14999 4. More than 15000 5. Don't know	

Perceived Health Status of primary care givers

Please read each question, assess how you perceive your HRQoL, and circle the number on the scale for each question that gives the best answer for you.

		V. Poor	Poor	Neither poor/Good	Good	V. Good
1	How would you rate your quality of life?	1	2	3	4	5

		V. Dissatisfied	Dissatisfied	Neither satisfied/dissatisfied	satisfied	v. satisfied	
2.	How satisfied are you with your health?	1	2	3	4	5	

The following questions ask about how much you have experienced certain things in the last four weeks

		Not at all	A little	A moderate amount	Very much	An extreme amount
3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	5	4	3	2	1
4.	How much do you need any medical treatment to function in your daily life?	5	4	3	2	1
5.	How much do you enjoy life	1	2	3	4	5
6.	To what extent do you feel your life to be meaningful?	1	2	3	4	5
7.	How well are you able to concentrate	1	2	3	4	5
8.	How safe do you feel in your daily life	1	2	3	4	5
9	How healthy is your physical Environment	1	2	3	4	5

The following questions refers to how completely you experience or were able to do certain things in the last two weeks.

		Not at all	A little	Moderately	Mostly	Completely	

10	Do you have enough energy for everyday life?	1	2	3	4	5
11	Are you able to accept your bodily appearance?	1	2	3	4	5
12	Have you enough money to meet your needs	1	2	3	4	5
13	How available are you to the information that you need in your day to day life?	1	2	3	4	5
14	To what extent do you have the opportunity for leisure activities	1	2	3	4	5

		Very poor	poor	Neither poor nor	Good	Very good
15	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither dissatisfied nor satisfied	Satisfied	Very satisfied
16	How satisfied are you with your sleep?	1	2	3	4	5
17	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18	How satisfy are you with your capacity at work?	1	2	3	4	5
19	How satisfied are you with yourself?	1	2	3	4	5
20	How satisfied are you with your personal relationship?	1	2	3	4	5

21	How satisfied are you with your sex life?	1	2	3	4	5
22	How satisfied are you with the support you get from friends?	1	2	3	4	5
23	How satisfied are you with the condition of your living place?	1	2	3	4	5
24	How satisfied are you with your access to health services?	1	2	3	4	5
25	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite often	Very often	Always
26	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

27.	Had you ever heard of cancer before your patient was diagnosed?	1.Yes 2.No	
28.	In your opinion is cancer a serious disease?	1.Yes 2.No	

Adapted from (Ferrans, 2010; Ferrans *et al.,* 2005)

Listed below are a number of statements. Please place a tick in the box that describes how much you agree with that statement right now.

Herth Hope Index

		Strongly disagree	Disagree	Agree	Strongly agree
1.	I have a positive outlook towards life.				
2.	I have short/long range goals				
3.	I feel all alone				
4.	I can see possibilities in the midst of difficulties				
5.	I have a faith that gives me comfort				
6.	I feel scared about my future				
7.	I can recall happy/joyful times				
8.	I have deep inner strength				
9.	I am able to give and receive caring /love				
10	I have a sense of direction				
11	I believe that each day has potential				
12	I feel life has value and worth				

PHQ-9 is a multipurpose instrument used for measuring the severity of depression.

Please tick [√] the option that best describe your mental health.

0= Not at all +1 = several days +2 = More than half the days +3 = nearly every day 99 = I prefer not to answer the question

Choose one number from each line

No.	Over the last 2 weeks, how often have you been bothered by any of the following problems?	0	+1	+2	+3	99
1.	Little interest or pleasure in doing things.					
2.	Feeling down, depressed, or hopeless.					
3.	Trouble falling asleep, staying a sleep or sleeping too much.					
4.	Feeling tired or having little energy.					
5	Poor appetite or over eating					
6	Feeling bad about yourself or that you are a failure or have let yourself or your family down					
7	Trouble concentrating on things such as reading the newspaper or watching television					
8	Moving or speaking so slowly that other people could have noticed. Or the opposite being fidgety or restless that you have been moving around a lot more than usual					
9	Thoughts that you would be better off dead or of hurting yourself in some way.					

PART M: GENERALIZED ANXIETY DISORDER 7 – ITEM (GAD-7)

The Generalized Anxiety Disorder 7-item (GAD-7) is tool for generalized anxiety disorderPHQ-9.

Please tick [√] the option that best describe your mental health.

0= Not at all +1 = several days +2 = More than half the days +3 = nearly every day
99 = I prefer not to answer the question

Choose one number from each line.

No	Over the last 2 weeks, how often have you been bothered by any of the following problems?	0	+1	+2	+3	99
1	Feeling nervous, anxious or on edge					
2	Not being able to stop or control worrying					
3	Worrying too much about different things					
4	Trouble relaxing					
5	Being so restless that it is hard to sit still					
7	Becoming easily annoyed or irritable					
8	Feeling afraid as if something awful might happen					

APPENDIX IV: FOCUS GROUP DISCUSSION WITH PRIMARY CARE GIVERS OF CANCER PATIENTS

All information collected in the group discussion is confidential and will only be used for the purpose of research to assist with improving the quality of life of primary care givers.

Focus Group Guide
Questions will be asked from an Interview Guide. Not all questions will be asked for each group.

Cancer Caregiving Interview Guide
I. Introduction and Warm-Up: 10 minutes
1. Purpose and agenda.

2. Audiotaping information.

3. Introductions and ground rules.

II. Caregiver Needs
We would like to understand:

- What are your roles as a primary caregiver of cancer patient in your day to day life?
- How has caregiving affected your life physically, that is your appearance/grooming, sleep, appetite and pain/weight loss?
- How has your quality of life been affected psychologically as a result of caregiving? How have you managed your emotions during this period?
- Have has your standard of living and financial independence been affected as a result of being a primary caregiver?
- What are your most important needs as a caregivers?" "Are they being met?" If so, "How?"
- What are your unmet needs as a caregivers?"
- How does the family unit supports and coordinate care needs and appointments of the cancer patient?"

Caregiver Isolation and Caregiver Social Network

- Generally what are the issues affecting caregivers and how do you resolve them?"
- What services are available in the facilities for caregivers to take care of themselves?"
- What support services would be helpful for caregivers?" "How do you find them and how would you like to be handled?"
- Have you engaged in social networks for support during this period of caregiving?" "What has been your experience like?"

III. Information Seeking

We are interested in understanding how you look for information, specifically health information?"

- Health Domains
- What information do you think would help caregivers be better able to offer caregiving services better?
- Legal/Social Issues
- What questions have you had about legal planning related to health? Where you would you look for that information? For example advanced directives, living will, and health care proxy.
- Utility of Different Resources
- Tell us how you look for information. For instance, how do you use the following resources?" "What was the experience like?"
    - Internet?
    - Peers/friends/word of mouth?
    - Children?
    - Other people (doctors, social workers)?
- **Prompt**: What tools are most useful?" "What tools are least useful?"
    - Tell us about something you were looking for but had a hard time finding."
    - Tell us about a search for medical information that went really well."
- Trustworthiness of Information
- Tell us how you decide what information to believe. For example Internet, books, peers and your doctor.

- Internet
- If you used the Internet:
    - How easy is it for you to use the Internet?"
    - What was the experience like?"
    - What is hard?" "What is easy?"
- If you did not use the Internet:
    - Why not? What barriers exist?

IV. Health Care Communication

- Communication
- **Prompts:** In your life, who are important types of people to communicate with about your health?" "Who would you want to be aware of your health updates? For example
    - How does your family communicate among themselves?"
    - How are family member involved in discussions of the patient's progress with their clinicians?"
    - What are the communication barriers that exist between patients and their providers?
- Privacy and Control of Personal Health Information
- Who do you want to control your information?" "How do you decide when that should change?" "When might you give control to someone else?"
- **Example:** Specific questions/prompts about communication:
    - Specialists versus primary care doctors.
    - Children, children-in-law.
    - Visiting nurses.
    - Physical therapy, other providers.
    - Spiritual support: priests, rabbis, imams, etc.

V. Privacy

The group has discussed privacy as a theme throughout; we want to make sure that specific areas are addressed if not already covered:

- Caregiver Communication With Clinicians
- Caregiver Review of Medical Records
- Handing Off Rights
- End-of-Life Decisions

VI. Closing

1. Do you have any additional comments or questions?

2. Please may you provide a brief evaluation of the focus group discussion experience?

APPENDIX V: RESEARCH PROPOSAL APPROVAL

COUNTY GOVERNMENT OF KAKAMEGA

E-mail: wpgh15@yahoo.com
Telephone: Kakamega 0702930346
When replying, please quote:

REF: CGH/KAK/ERC/VOL.I/108

COUNTY GENERAL HOSPITAL
P.O. Box 15-G.P.O-50100
KAKAMEGA

DATE: 31st August, 2021

MINISTRY OF HEALTH SERVICES

HELLEN AOKA ODENY
LICENCE NO. NACOSTI/P/21/11895

RE: RESEARCH PROPOSAL APPROVAL – NO. ERC/130-08/2021

This is to inform you that **Kakamega County General Hospital Ethics Review Committee (KCGH ERC)** has approved your research proposal titled: ***"Predictors of Health-Related Quality of Life Among Primary Caregivers of Cancer patients in Kakamega County, Kenya".*** The approval period is 31st August 2021 – 21st July, 2022

This approval is subject to compliance with the following requirements:

i. Only approved documents including informed consent, study instruments, MTA will be used.
ii. All changes including amendments, deviations and violations are submitted for review and approval by the **KCGH ERC.**
iii. Death and life-threatening problems and serious adverse events or unexpected adverse events whether related or unrelated to the study must be reported to **KCGH ERC** within 24 hours of notification.
iv. Any changes, anticipated or otherwise that may increase the risks or affected safety of welfare of the study participants and others or affect the integrity of the research must be reported to **KCGH ERC** within 24 hours.
v. Clearance for export of biological specimens must be obtained from relevant institutions.
vi. Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. Attach a comprehensive progress report to support the renewal.
vii. Submission of an executive summary report within 90 days upon completion of the study to **KCGH ERC**.

This approval should be attached to your research license from National Commission for Science, Technology and Innovation (NACOSTI) and also other necessary clearances.

KAKAMEGA COUNTY GEN. TEACHING & REFERRAL HOSPITAL
MEDICAL SUPERINTENDENT
31 AUG 2021
P.O. BOX 15-50100, KAKAMEGA

DR. AJEVI AUSTINE
CHAIRMAN
ETHICS AND RESEARCH COMMITTEE
CGH - KAKAMEGA

APPENDIX VI: COUNTY RESEARCH AUTHORIZATION

REPUBLIC OF KENYA
COUNTY GOVERNMENT OF KAKAMEGA

DEPARTMENT OF HEALTH SERVICES

Telephone: 056 31125
E-mail: pdmswestern@gmail.com
Website : www.kakamega.go.ke
When replying please quote

THE COUNTY DIRECTOR
P O BOX 2309- 50100
KAKAMEGA

DATE: 5TH AUGUST, 2021

Ref : CGK/MOH/CDH/2021/8/2

To

The Medical Superintendent,
Kakamega County General Hospital.

RE: RESEARCH AUTHORIZATION – PREDICTORS OF HEALTH-RELATED QUALITY OF LIFEAMONG PRIMARY CAREGIVERS OF CANCER PATIENTS IN KAKAMEGA COUNTY, KENYA

Mrs. Hellen Aoko Odeny of Masinde Muliro University, Department of Clinical Nursing and Health Informatics is hereby approved by the County Department of Health Services to carry out the aforementioned research. She is instructed to remain within the confines of the research protocol as has been underscored in the ethical approval. She will submit an executive summary report within 90 days upon completion of the study to my office. Kindly accord her the necessary assistance she carries out the research.

DR. JOHN OTIENO,
05 AUG 2021
Ag. COUNTY DIRECTOR FOR HEALTH SERVICES
KAKAMEGA

APPENDIX VII: RESEARCH LICENCE

REPUBLIC OF KENYA

NATIONAL COMMISSION FOR SCIENCE,TECHNOLOGY & INNOVATION

Ref No: **993371**

Date of Issue: **21/July/2021**

RESEARCH LICENSE

This is to Certify that Ms.. Hellen Aoko Odeny of Masinde Muliro University of Science and Technology, has been licensed to conduct research in Kakamega on the topic: PREDICTORS OF HEALTH-RELATED QUALITY OF LIFE AMONG PRIMARY CAREGIVERS OF CANCER PATIENTS IN KAKAMEGA COUNTY, KENYA for the period ending : 21/July/2022.

License No: **NACOSTI/P/21/11895**

993371

Applicant Identification Number

Director General
NATIONAL COMMISSION FOR SCIENCE,TECHNOLOGY & INNOVATION

Verification QR Code

NOTE: This is a computer generated License. To verify the authenticity of this document, Scan the QR Code using QR scanner application.

APPENDIX VIII: INSTITUTIONAL ETHICS REVIEW COMMITTEE (IERC)

MASINDE MULIRO UNIVERSITY OF SCIENCE AND TECHNOLOGY
Tel: 056-31375
Fax: 056-30153
E-mail: ierc@mmust.ac.ke
Website: www.mmust.ac.ke
P. O. Box 190-50100
Kakamega, Kenya

Institutional Ethics Review Committee (IERC)

Ref: MMU/COR: 403012 Vol 4 (01)

Date: 14th July, 2021

Hellen Aoko Odeny,
HNR/G/01-53028/2018
Masinde Muliro University of Science and Technology,
P.O. Box 190-50100, Kakamega.

Dear Ms Odeny,

RE: Predictors of Health-Related Quality of Life among Primary caregivers of Cancer Patients in Kakamega County, Kenya. - MMUST/IERC/201/2021

Thank you for submitting your proposal entitled as above for initial review. This is to inform you that the committee conducted the initial review and approved (with no further revisions) the above Referenced application for one year.

This approval is valid from **14th July, 2021** through to **14th July, 2022**. Please note that authorization to conduct this study will automatically expire on by **14th July, 2022.** If you plan to continue with data collection or analysis beyond this date please submit an application for continuing approval to the MMUST IERC by **14th June, 2022.**

Approval for continuation of the study will be subject to submission and review of an annual report that must reach the MMUST IERC Secretariat by **14th June, 2022.** You are required to submit any amendments to this protocol and any other information pertinent to human participation in this study to MMUST IERC prior to implementation.

Please note that any unanticipated problems or adverse effects/event resulting from the conduct of this study must be reported to MMUST IERC. Also note that you are required to seek for research permit from NACOSTI prior to the initiation of the study.

Yours faithfully,

Dr. Gordon Nguka (PhD)
Chairman, Institutional Ethics Review Committee

Copy to:
- The Secretary, National Bio-Ethics Committee
- Vice Chancellor
- DVC (PR&I)