FACTORS CONTRIBUTING TO ROLE STRAIN AMONG FAMILY CAREGIVERS OF ADULT PATIENTS SUFFERING FROM CANCER AT KENYATTA NATIONAL HOSPITAL

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Factors contributing to Role Strain among Family Caregivers of Adult Patients Suffering from Cancer at Kenyatta National Hospital

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DECLARATION

This thesis is my own original work and has not been presented for a degree in any other university

Signature……………………………………………… Date………………………

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This thesis has been submitted for examination with our approval as university Supervisors

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DEDICATION

This work is dedicated to the family caregivers and all healthcare workers who strive against all odds to make the challenging cancer journey bearable to the patients under their care.

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ABBREVIATIONS AND ACRONYMS

ADLs:	Activities of daily living
CTC	Cancer Treatment Centre
ECOG-PS	Eastern Cooperative Oncology Group of Performance Status
FCG	Family Caregiver
FCGs	Family Caregivers
GFC	Adult Outpatient Chemotherapy clinic
GFD	Adult Oncology ward
JKUAT	Jomo Kenyatta University of Science and Technology
K.I	Key Informant
KNBS	Kenya National Bureau of Statistics
KNH	Kenyatta National Hospital
LMICs	Low and Middle Income Countries
MCSI	Modified Caregiver Strain Index
MOH	Ministry Of Health
NACOSTI	National Commission for Science, Technology and Innovation
RAM	Roy’s Adaptation Model
U.S	United States of America
WHO	World Health Organisation

OPERATIONAL DEFINITION OF TERMS

Activities of daily living (ADLs)	Comprises all daily activities that the patient is not able to perform by self due to altered functional status and may require help in execution of such functions.
Caregiving	Refers to the unpaid care and support provided by a family caregiver to another person due to illness, disease or disability. Also includes support care comprising of assistance with ADLs, clinic attendance, psycho-social and financial support.
Chemotherapy	Refers to any anti-neoplastic drugs including hormonal therapies.
Cancer staging classification	Cancer stage I and II were classified as early cancer while cancer stage III and IV were classified as late. According to Rosen and Sapra (2022) both cancer stage I (localized cancer) and stage II (locally advanced cancer) are early stage cancer while stage III (locally advanced cancer) and stage IV (metastatic cancer) are late stage cancer.
Coping skills	Refers to specific efforts, both behavioural and psychological that family caregivers employ to tolerate, reduce or minimize stressful experiences of caregiving.
Family caregiver (FCG)	A person who is involved in caregiving or who assists the patient in performing activities of daily living free of charge. He or She may be a relative, spouse, a friend or a neighbour.
GFC	Refers to where the outpatient adult oncology treatment clinic is located at Kenyatta National Hospital.

Hours of care provision	Refers to approximated time spent per day by the FCG in caregiving. For this research it has been categorized as either less than 5 hours or more than 5 hours.
KNH cancer treatment clinic	Refers to the outpatient adult oncology treatment clinic.
Not married	Refers to a family caregiver who is Single, Separated or Widowed.
Patient performance or functional status	Refers to the patient's ability to execute certain activities of daily living (ADLs) without being helped by significant others. For this research it was estimated using Eastern Cooperative Oncology Group of Performance Status (ECOG-PS) and was categorized as follows; a grade of less than 2 reflected a good patient functional status while a grade of more than 3 reflected poor patient functional status.
Role strain	Refers to caregiving strain encompassing physical strain, psychological strain, social strain and financial strain experienced by family caregivers as a result of caregiving. Role strain also means family caregiver burden.
Stressors	Refers to situations, activities or experiences which overwhelm the family caregiver and cause strain. These can be physical, psychological, social and economic stressors.

ABSTRACT

Cancer is a global health burden which is affecting every region in terms of socio-economic, psychological and physical strain placed on patients and their families. Many family caregivers are thrust into cancer caregiving without any training or healthcare system support, yet the services they render could affect the patient treatment outcomes. Therefore, the purpose of this study was to assess the level of role strain and its contributing factors among family caregivers of adult patients suffering from cancer at Kenyatta National Hospital outpatient cancer treatment clinic. This study adopted analytical cross-sectional design involving 255 systematically sampled family caregivers and their corresponding adult cancer patients attending Kenyatta National Hospital outpatient cancer treatment clinic between February and March 2020. Specialized nurses in cancer care and medical social workers were also recruited as key informants through census. Both quantitative and qualitative data was collected. Quantitative data from structured questionnaire, Modified Caregiver Strain Index (MCSI) tool and ECOG-PS scale for performance status was analyzed by deriving descriptive statistics and ordinal logistic regression was performed to derive the relationship between the independent variables and the dependent variable. Quantitative data was presented by use of tables and chart. SPSS software version 25 was utilized in data analysis. Qualitative data from 3 focus group discussions involving purposefully selected family caregivers and 6 key informants were transcribed verbatim and analyzed thematically. The study findings revealed that 44.3% of family caregivers had moderate role strain. The study further revealed that family caregiver related factors influencing family caregiver role strain included being married (OR=0.49, p=0.038), being unemployed (OR=3.29, p=0.001), <5 hours of caregiving per day (OR 0.40, p=0.002), social isolation (OR=0.20, p=0.001) and transportation costs (OR=0.32, p=0.017), In addition, qualitatively; the following themes emerged; lack of social support, costly transportation and accommodation services. The patient related factors influencing family caregiver role strain included patient's county of residence (OR=0.54, p=0.028), good functional status (OR=0.33, p=0.001), patient's current treatment modality (OR=0.21, p=0.001) and current interpersonal relations with the patient (OR=0.30, p=0.001). The institutional related factors influencing family caregiver role strain included physical strain during navigation (OR=0.39, p=0.033), shortage of cancer drugs (OR=0.30, p=0.005) and traversing long geographical distance (OR=0.38, p=0.008). In addition, qualitatively; the following themes emerged; physical strain, costly cancer treatment services, geographical disparity and treatment process challenges. In conclusion, role strain among family caregivers of adult patients with cancer is prevalent and there are various factors (family caregiver, patient and institutional) which influence the role strain. Therefore, this study recommends that healthcare practitioners should screen family caregivers for role strain and pro-actively consider them for psychological counselling, social support

groups, caregiving skills training, health education and provision of literature materials on self-care, self financial empowerment and referal for respite care if available.

CHAPTER ONE

INTRODUCTION

1.1 Background information

Cancer is a global health burden touching every region and socio-economic group exerting tremendous physical, emotional and financial strain on individuals, families, communities and health systems (WHO, 2017). Globally cancer incidence and mortality is on the increase; an estimated 19.3 million new cancer cases and 10.0 million cancer deaths occurred in 2020 and globally cancer burden is projected to hit 28.4 million cases by 2040 representing a 47% rise from 2020 (Sung *et al*., 2021).

In Africa cancer is the third leading cause of death; after infectious and cardiovascular diseases. Cancer incidence is also projected to increase by more than 85% in Sub-Saharan Africa by 2030 (Wambalaba *et al*., 2019). In Kenya based on GLOBOCAN 2020 report; the annual estimate of new cancer cases were 42, 116 while deaths due to cancer were 27, 092 (Sharma, 2022).

Cancer is a major life-limiting chronic disease which advegrsely affects the patient and their family members who are the main caregivers. Family caregivers (FGCs) play a very vital role in the care of patients with cancer (Hiremath *et al*., 2017) and their care constitutes a huge support to the patients; lack of which can greatly compromise patient’s health and capacity to benefit from homebased care (Hudson *et al*., 2015).

Family caregivers are responsible for performance of numerous tasks pertaining to care (WHO, 2016) which includes self-care, ability to walk, household chores, shopping, settling financial needs, transport, organizing clinic appointments, communication and social activities (Karabulutlu, 2014). The support provided by family caregivers (FCGs) touch on every aspect of the patient’s life, ranging from helping with basic activities of daily living to providing emotional, social, and financial support (Borges *et al*., 2017). In addition, family caregivers play vital roles such as monitoring and management of therapy side effects, drug administration, wound dressing and making decisions like whether to seek medical attention or whether the drugs need to be administered (Van Ryn *et al.*, 2011, Ullgren *et al.*, 2018). Family caregivers also help their patients in navigating the complex healthcare systems (Lilleheie *et al.*, 2020). Moreover, there are better patient outcomes when FCGs are integrated in the unit of care. Indeed, Rodakowski *et al.* (2017) conducted a metanalysis and established that FCGs integration in discharge care planning was associated with reduced readmission rates among the patients.

The positive aspects of caregiving also positively impact the FCGs where they experience enhanced intimacy and affection, personality growth, good relations, social support, self-satisfaction and self-respect (Karabulutlu, 2014). Family caregivers also experience self-satisfaction, personal growth, and discover personal meaning (Henriksson *et al.*, 2015) as well as appreciation of life and support by others in caregiving (Akpan-Idiok & Anarado, 2014).

Caregiving negatively impacts the FCGs resulting in physical strain, psychological strain, and socio-economic strain (Karabulutlu, 2014). This is because caregiving leads to problems such as burn-out syndrome, poor physical health, anxiety, depression, social isolation and financial strain which further amplify the role strain experienced by FCGs (Kahriman & Zaybak, 2015). In addition, FCGs experience cancer-related strain which is almost equal to or even worse than what the patients experience (Gropper *et al.*, 2016).

Patients with end stage cancer have multiple needs (Akpan-Idiok & Anarado, 2014) and FCGs sometimes take up roles that are usually performed by nurses or other healthcare professionals (National Alliance for Caregiving, 2016). However, despite the complex roles that family caregivers play, the healthcare professionals focus only on addressing patient’s needs while the family caregiver’s needs are not addressed (Borges *et al.*, 2017). Further, family caregivers are not offered any skills training to enhance their caregiving roles (Van Ryn *et al.*, 2011). Since there is no framework to guide implementation of support programmes, many cancer treatment centers do not provide comprehensive programmes to support family caregivers (Northouse *et al.*, 2012).

In addition, majority of family caregivers experience role strain related to caregiving (Yakubu & Schutte, 2018). There is also a problem of integrating FCGs in the unit of care and healthcare systems do not share vital information with FCGs and excludes them from care planning which makes them feel unprepared in their caregiving role, hence need for psychosocial care to address the psycho-social and financial strain that patients and their family members experience (WHO, 2016). To lessen the role strain that FCGs of adult patient with cancer experience, it is important to assess role strain and its predictor factors as a first step to inform development of strategies to mitigate the role strain.

1.2 Problem Statement

Cancer is a chronic condition that has taken a big toll on population health in terms of socio-economic, physical and psychological strain placed on families and family caregivers leading to role strain (MOH, 2017). Moreover, not much is known about the caregiving challenges faced by the FCGs in Africa (O'Neil *et al*., 2018). Similarly, Johansen *et al*. (2018) posited that not much is known regarding how patient characteristics impact the caregiving strain experienced by FGCs.

There are also many family caregiver demographic and socio-economic factors which are contributing to increased role strain especially in least developed and developing countries (Yakubu & Schutte, 2018), with Kenya being in this category. African countries have inadequate medical resources and ill equipped healthcare systems (Oleribe *et al*,. 2019) and as a result, many patients suffering from cancer lack access to timely high-quality cancer treatment and care services (WHO, 2017). Inadequately resourced healthcare systems have contributed to too many patients being diagnosed and accessing cancer treatment when it is too late with extra load of care being borne by the family caregivers who according to Petrovic and Gaggioli (2020) offer a valuable support in filling the gap between meeting the patient needs and what can be offered by the healthcare institutions.

Family caregivers as the main source of support to patients suffering from cancer face enormous challenges in their caregiving role (Muliira and Kizza, 2019) and this predisposes them to role strain. Moreover, many Kenyans can not afford the exorbitant cost of cancer treatment in addition to traveling long geographical distances in search of cancer treatment services (Malloy *et al.*, 2017). Simiraly, Ronniey (2019) established that missed or delayed treatment is still common and patients face a myriad of challenges in accessing cancer treatment services at K.N.H which includes huge costs related to cancer treatment, transportation to point of treatment and accommodation services within Nairobi city.

Despite the important roles played by FCGs and role strain that they experience, health care workers main focus is on addressing patients' health needs while little attention is paid to their FCGs. There is also no documented literature related to the role strain experienced by FCGs of adult patients with cancer. In addition, the healthcare system lacks policies of integrating family caregivers in the therapeutic unit of care, how to assess the role strain family caregivers experience, as well as factors contributing to the role strain. Moreover, understanding the nature and extent of family caregiver role strain in developing countries is necessary to guide development of appropriate interventions to mitigate the strain (Kusi *et al.*, 2020). These issues raised the researcher's desire to assess role strain and determine its contributing factors among family caregivers of adult patients suffering from cancer at Kenyatta National Hospital cancer outpatient clinic.

1.3 Study Justification

This study aimed to assess the role strain experienced by FCGs of adult patients suffering from cancer and the factors contributing to the role strain. Assessing the role strain among family caregivers is important since it can adversely affect the quality of care that family caregivers offer to patients with cancer, hence putting patients at great risk. Indeed, according to Lkhoyaali *et al.* (2015) FCGs make treatment decisions of over 86% patients with cancer and their involvement in treatment decision making significantly influences association between patient activation and treatment adherence (Acquati *et al.*, 2021). Further, Given (2019) posited that cancer care systems should champion formal inclusion of FCGs together with their patients in the unit of care for better patient outcomes. Role strain can also negatively affect the general health of family caregivers. This study was conducted at KNH which is the main public cancer treatment centre which offers comprehensive cancer treatment services and serves patients from across the country who face a myriad of challenges in search of cancer treatment services.

The study findings provide crucial information to healthcare workers, health care institutions, and policy makers on family caregiver role strain and it's contributing factors. This information is also critical in designing programmes or strategies to address the role strain and how family caregivers can be integrated in the therapeutic unit of care by the healthcare system. Supporting FCGs in caregiving can greatly improve family caregiver's general health as well as that of the patient under their care. The study results may also form a foundation for undertaking related research quest in future. This study is also in line with universal health coverage and provides information on areas of empowerment among FCGs as they take care of persons with chronic conditions in the community.

1.4 Research questions

i. What is the level of the role strain experienced by family caregivers of adult patients suffering from cancer at KNH cancer treatment clinic?
ii. What are the family caregiver related factors that contribute to the role strain experienced by family caregivers of adult patients suffering from cancer at KNH cancer treatment clinic?
iii. What are the patient related factors that contribute to the role strain experienced by family caregivers of adult patients suffering from cancer at KNH cancer treatment clinic?
iv. What are the institutional factors that influence the role strain experienced by family caregivers of adult patients suffering from cancer at KNH cancer treatment clinic?

1.5 Hypothesis

i. There is no relationship between the family caregiver related factors and the role strain experienced by family caregivers of adult patients suffering from cancer at KNH cancer treatment clinic.
ii. There is no relationship between the patient related factors and the role strain experienced by family caregivers of adult patients suffering from cancer at KNH cancer treatment clinic.
iii. There is no relationship between the institutional factors and the role strain experienced by family caregivers of adult patients suffering from cancer at KNH cancer treatment clinic.

1.6 Study Objectives

1.6.1 Main Objective

To determine the factors contributing to role strain experienced by family caregivers of adult patients suffering from cancer at the KNH cancer treatment clinic.

1.6.2 Specific Objectives

i. To assess the level of role strain experienced by family caregivers of adult patients suffering from cancer at KNH cancer treatment clinic.
ii. To determine the family caregiver related factors that contribute to the role strain experienced by family caregivers of adult patients suffering from cancer at KNH cancer treatment clinic.
iii. To determine the patient related factors that contribute to the role strain experienced by family caregivers of adult patients suffering from cancer at KNH cancer treatment clinic.
iv. To establish the institutional factors that influence the role strain experienced by family caregivers of adult patients suffering from cancer at KNH cancer treatment clinic.

1.7 Theoretical framework

Theoretical framework for this study was based on the Roy's Adaptation Model (RAM) by Roy (2009). The RAM views the human like a bio-psycho-social being who is always in constant interaction with an ever changing environment. Adaptation emanates from human-environment interaction. The RAM is an open system with stressors (stimuli) as its inputs. The internal environment of human person and external environment surrounding this bio-psycho-social being contribute to stimuli. Based on the RAM, stimuli can be classified as focal, contextual and residual stimuli (Smith & Parker, 2015).

Focal stimuli refer to stressors which can either be external or internal which are confronting the person and which he or she must develop adaptation, that is, the factor that causes the person to behave in a certain way; contextual stimuli refer to the other stressors involved in the situation that may strengthen focal stimuli effects or the behaviour while residual stimuli refer to all other factors emanating from the human external or internal environment which may influence focal stimuli but whose current influence are unclear. These three stimuli act together and influence the human ability to adapt positively in a situation (Mcewen & Willis, 2019).

For this study, as illustrated in figure 1.1, focal stimuli was role strain which is responsible for activating the available coping mechanisms of FCGs to seek physical and psychological resources to cope with this responsibility. Role strain emanates from the responsibility of providing care to the patient with chronic illness who depends partially or totally on the FCGs to meet their needs. Role strain among FCGs of patients suffering from cancer was the dependent variable which was under the influence of various independent variables. Contextual stimuli are the stressors that contribute to the effects of focal stimuli. For this study, contextual stimuli formed the independent variables of the conceptual framework. These included socio-demographic characteristics and strain in the following domains; psychological, social, physical, economic as well as other stressful life events as a result of caregiving. The residual stimuli are the intervening factors which for this study, referred to the FCG beliefs, behaviours, personal experiences and ill health.

The individual adapts to stimuli through two major subsystems (coping mechanism) which include cognator subsystem and regulator subsystem. Regulator subsystem is a physiological coping mechanism which involves chemical, neural, and endocrine coping mechanisms. The regulator subsystem has a feedback cycle of input (stimuli), throughput (control processes) and output (behaviors/ responses) and psychomotor responses. Cognator subsystem is a major coping process involving four cognitive-emotive mechanisms: perceptual and information processing, Learning, Judgment and Emotion. Adaptive responses are behaviours which support integrity of the person in terms of growth, reproduction, survival and mastery through the four adaptive modes (Physiological mode (Basic needs), Self concept (Psychological; beliefs, feelings & values), Role function mode (performance of duties), and Interdependence mode (relations and support systems) while ineffective responses are behaviours that compromise an individual integrity (Smith & Parker, 2015). In regard to this study, FCG adaptive responses lead to reduced role strain or enhanced role function while ineffective responses lead to high role strain or altered role function.

Application of the RAM among FCGs represents interaction of the different stimuli in the model, whether focal, contextual or residual; they trigger the systems of regulatory and cognitive coping, triggering behaviours that in turn will define the level of adaptation to the role of caregiving. Among the FCGs, the main focal stimulus is the responsibility to provide care to the patient with chronic illness who depends partially or totally on the FCGs to meet their needs. Focal stimulus, in this case role strain is responsible for activating the available coping mechanisms of FCGs to seek physical and psychological resources to cope with this responsibility. Contextual stimuli that contribute to the effects of focal stimuli on the family caregivers' situation include: demographic characteristics, physical strain, psychological strain, social strain, economic strain and other stressful life events as a result of caregiving. The first objective of this research aimed at assessing role strain while the other objectives were aimed at collecting data on factors influencing role strain among FCGs of patients suffering from cancer.

Roy Adaptation Model (RAM) in the context of caregiving

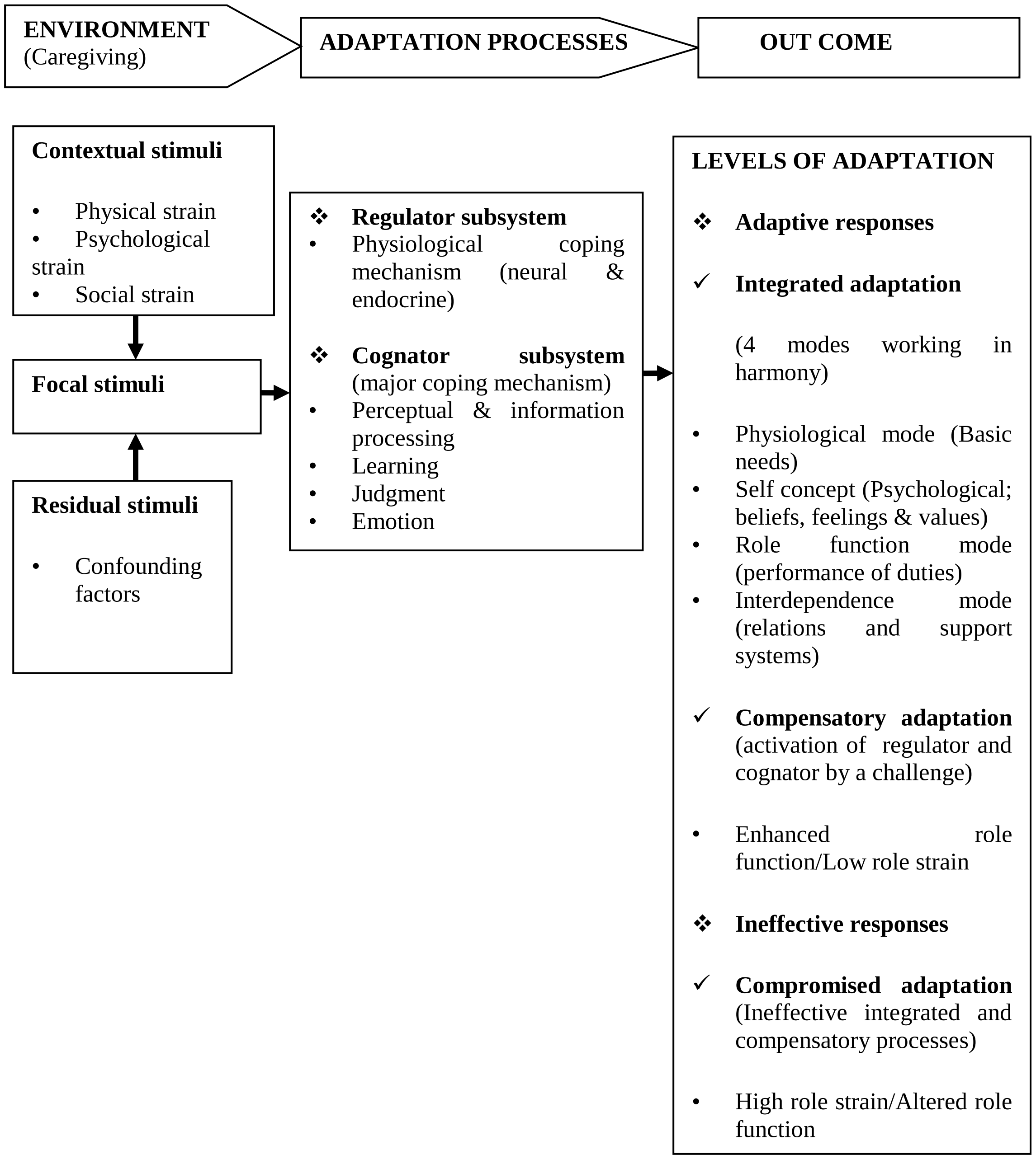

Figure 1.1: An illustration of Roy Adaptation Model (RAM) in context of caregiving (Author, 2022)

1.8 Conceptual framework

The conceptual framework (figure 1) shows the study variables and the arrows show the direction of interaction among the variables contributing to the role strain. The researcher’s construct was that there was an interaction between various characteristics of the main variables which included socio-demographic factors, family caregiver related factors, patient related factors and institutional factors and this interaction contributes to the role strain experienced by family caregivers of adult patients suffering from cancer at KNH cancer treatment clinic. The researcher assessed the level of role strain experienced by the family caregivers of adult patients suffering from cancer at KNH cancer outpatient treatment clinic as well as the associated predictor factors.

Conceptual framework

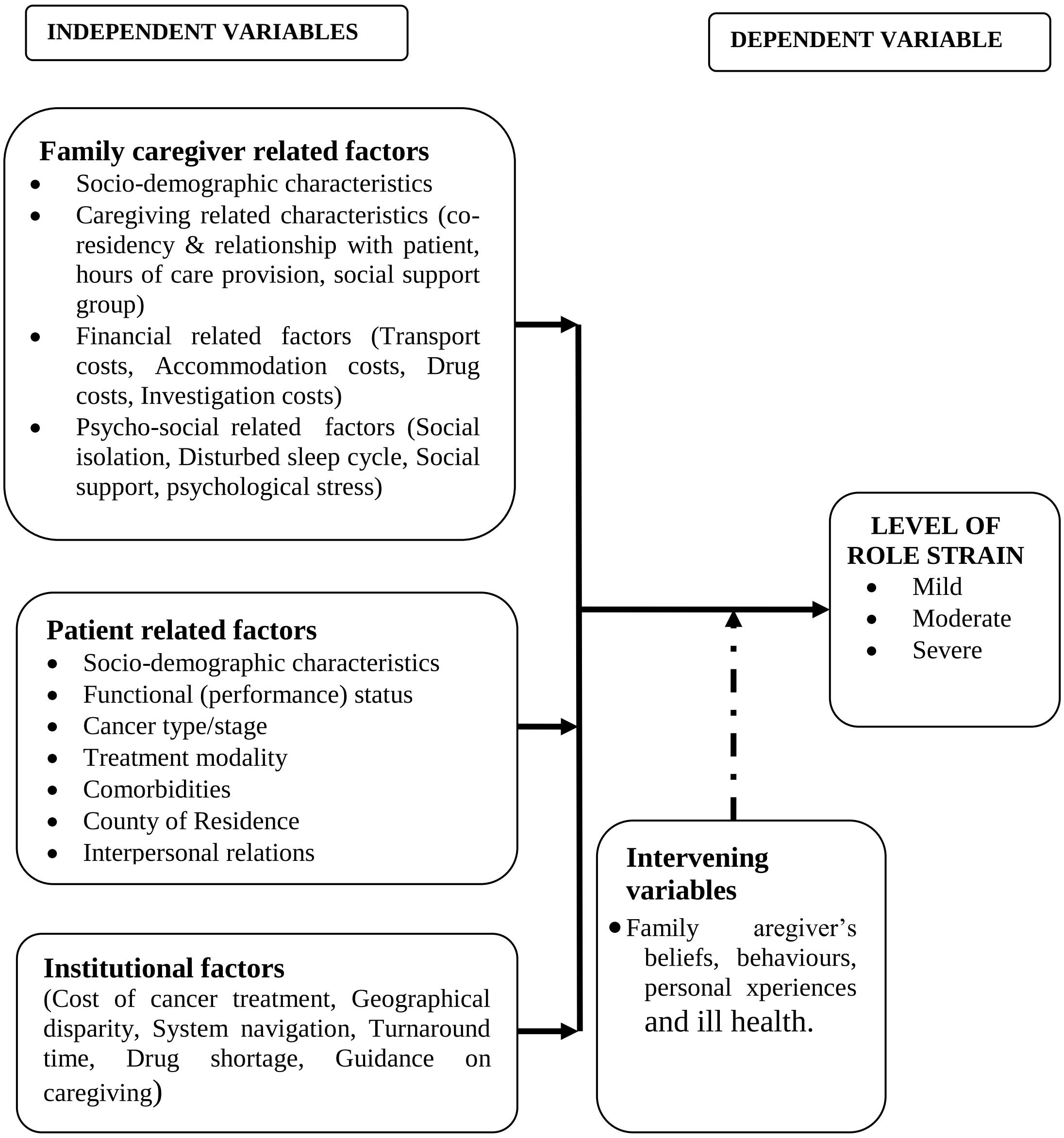

Figure 1.2: Conceptual framework (Author, 2022)

1.9 Study limitations

The study was conducted only in one care setting. It also adopted a cross-sectional design and as such the study results can not be generalized to the whole population. However, the study employed a large sample size. Also, the study setting chosen was the main national referral hospital where majority of patients suffering from cancer and their family caregivers access the comprehensive cancer treatment services from far and wide across the country.

Study was based on respondent’s experiences which are subjective and could be affected by recall bias. However, the researcher employed Modified Caregiver Strain Index (MCSI) tool which is a validated tool that scores well even when screening for family caregiver strain among long term family caregivers.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter covers literature review according to research objectives on role strain, family caregiver related factors, patient related factors and institutional related factors contributing to role strain experienced by family caregivers (FCGs) of adult patients suffering from cancer.

2.2 Role strain among family caregivers of adult patients suffering from cancer

Role strain refers to psychological, social, physical and financial strain that an individual experiences as a result of caregiving (Carpenito, 2013). Family caregivers provide care and crucial support to patients with cancer. They assist the patient with activities of daily living, psycho-social and financial support, accompany their patients during clinic appointments, make treatment decisions involving their patients and sometimes also perform advanced roles like stoma and colostomy care, monitoring and management of cancer treatment side effects while at home (National Alliance for Caregiving, 2016; Ullgren *et al*., 2018). As a result, family caregivers experience role strain which can have a toll on their physical health as well as compromise the care they provide to patients putting patient’s lives at risk. Indeed, Yakubu and Schutte (2018) in South Africa established that family caregivers experienced moderate to high role strain due to caregiving. Similary, Nortey *et al.* *(*2017) in Ghana established that 78% of family caregivers (FCGs) experienced a high level of caregiving strain. However, Dhandapani *et al.* (2015) in their study in India found out that majority (64%) of family caregivers experienced mild strain, while 31% experienced moderate strain and only 5% had severe strain.

2.3 Family caregiver related factors associated with role strain among family caregivers of adult patients suffering from cancer

Cancer is a global health burden exerting physical, psychological and financial strain (WHO, 2017). There are various socio-demographic and economic factors contributing to role strain in low income settings (Yakubu & Schutte, 2018).

Currently cancer care and treatment is largely being offered as an outpatient service than an inpatient service (Maguire *et al.*, 2016) and this has partly shifted the burden of care from healthcare professionals to patients and their FCGs (Kershaw *et al.*, 2015), setting stage for home based family caregiving. Indeed, Yakubu and Schutte (2018) established that family caregiving has become a full time task with majority of family caregivers (FCGs) providing care for over 40 hours per week while over 40% have been providing care for over 3 years.

Family caregivers (FGCs) play a critical role in taking care of cancer patients (Hiremath *et al.*, 2017) and assist patients with personal care, finances, transportation, emotional support and symptom management (Nipp *et al.*, 2016). Further, National Alliance for Caregiving (2016) in United States established that FCGs also undertake roles that are normally performed by nurses and other healthcare professionals which include catheter and colostomy care, tube feedings, administering injections and many other complex medical responsibilities. In addition, another study by Nortey *et al*. (2017) in Ghana established that 79% of FCGs co-resided with their patients while 52% of patients required help in at least one form of ADL.

There are a number of family caregiver related factors associated with the role strain that family caregivers experience when caring for adult patients with cancer. These factors include socio-demographic characteristics, psychological and financial factors. Indeed, a study conducted by Vahidi *et al*. (2016) in Iran established that financial status, level of education, activities of daily living (ADL) and gender contributed to caregiving strain. Likewise, a systematic review conducted by Ge and Mordiffi (2017) established that some of the socio-demographic factors associated with high caregiving strain included a male gender, marital status (being single), lower education level, poor perceived health status and being employed. In addition, Hsu *et al*. (2014) in Canada established that being employed and caring for patients requiring more assistance with activities of daily living contributed to high caregiving strain; while Dhandapani *et al*. (2015) in India established that unemployment and low income status among family caregivers contributed to caregiving strain.

Oboh and Adayonfo (2017) in Nigeria also established that being widowed, divorced or separated, poor patient-family caregiver relationship, poor communication skills, low and middle socio-economic class contributed to high role strain experienced by FCGs of adult patients with cancer. Further, Metzelthin *et al*. (2017) in Netherlands established that being a spouse to the patient (40.5%), poor family caregiver perceived health status, living together with the patient (40.3%) and more caregiving hours contributed to high caregiving strain.

Further, Litzelman *et al*. (2016) based on CanCORS data set established that college education or higher level of education is linked to greater social strain than lower level of education while older age is linked to less social stress. In addition, a study conducted by Amamou *et al*. (2019) in Tunisia established that family caregiver (FCG) related factors associated with role strain included sex (a male family caregiver), age (over 40 years), employment (employed full-time), caring for a parent, other family responsibilities and duration of caregiving (over one year).

Further, a study conducted by Longacre *et al*. (2017) in the U.S established that majority (52.4% out of 52.9%) of family caregivers who were either employed on part-time or full time basis experienced interference with their employment while about 60% of FCGs who were not employed and 40% of those employed experienced strain related to caregiving. Caregiving also contribute to loss of job among family caregivers. This is supported by a study conducted by Vahidi *et al*. (2016) in Iran which established that 49.4% of FCGs abandoned their job to take care of the patient while 13.3% of FCGs got fired from their job due to constant absenteeism. In addition, Arian *et al*. (2017) revealed that meeting transportation costs during patient clinic attendance was also a factor which contributed to financial strain among FCGs. Further, National Alliance for Caregiving (2016) in the U.S found out that 25% of FCGs experienced intense financial strain and according to Lund *et al*. (2014) 6% of FCGs had to seek financial counseling.

Another study by Nortey *et al*. (2017) in Ghana established that about 87% of FCGs experienced heightened financial strain due to caregiving and about 62% of the FCGs reported that their finances had got worse as a result of caregiving.

Further, another study by Kent *et al.* (2016) based on review of current evidence posited that FCGs lack financial incentives like health insurance, billing, and other funding which could cushion them against financial strain. Similarly, another study conducted in Morocco by Lkhoyaali *et al.* (2015) established that majority of patients (87.3%) did not have any health insurance and 62.7% of families did not have any source of a monthly income which meant that healthcare services were financed through out-of-pocket leading to impoverization of families. Further, this study also established that 56% of FCGs had to secure bank loans and sold properties to finance healthcare for their patients while 54% got terminated from employment due to caregiving. In addition, Kenya National Bureau of Statistics (2014) established that majority of Kenyans lacked health insurance with 79% of men and 82% of women lacking any form of health insurance.

Family caregivers are also psycho-socially strained. This is supported by a study conducted by Sercekus *et al.* (2014) which established that FCGs were affected psychologically and socially during caregiving. In addition, Arian *et al*. (2017) in Iran established that FCGs get psychologically upset but keep concealing their emotional devastation which becomes worse due to disrupted social life, family role conflict and disturbed sleep-cycle. Another study by Mthembu *et al*. (2016) in South Africa established that family caregivers had no time to rest, had to abandon their social life and terminated their employment due to caregiving.

Further, a study conducted by Lkhoyaali *et al*. (2015) in Morocco also established that 46% of FCGs experienced sleep disorders while 39.3% experienced loss of appetite. Furthermore, a study conducted by Kulkarni *et al*. (2014) in India established that more than half (52.17%) of FCGs that were sampled experienced tiredness/exhaustion, while 45.98% of FCGs lacked sleep, 45.65% of FCGs experienced mental confusion and were not able to focus while about half (50%) of the FCGs failed to adapt to the high strain related to caregiving.

In addition, a research report produced by National Alliance for Caregiving (2016) in the U.S established that caregiving is very challenging which predisposes FCGs to psychological stress. Indeed, caregiving strain can be intense necessating interventions. This is supported by a survey conducted by Lund *et al*. (2014) in Copenhagen which established that limited social time predisposed FCGs to psychological distress with 23% of FCGs seeking psychological counseling as a result of heightened psychological distress.

2.4 Patient related factors associated with role strain among family caregivers of adult patients suffering from cancer

Patient related factors have been identified as sources of role strain; of importance are patient poor functional status and those in need of specialized procudres like stoma care. In support of this; Maguire *et al*. (2016) in Ireland established that the most influential factors in determining the role strain experienced by FCGs were patient related factors like physical functional status (performance status) and patients with stoma. Similarly, a study conducted by Luo *et al*. (2020) in China established that patient’s physical functional status and treatment modality (that is either chemotherapy or chemoradiation) contributed to caregiving strain. Further, a study conducted by Hsu *et al*. (2014) in Canada established that FCGs perception of patient’s physical status (performance status) and caring for a patient who required more help with ADL (Activities of Daily Living) contributed to high role strain among FCGs. In addition, a study conducted by Chindaprasirt *et al*. (2014) in Thailand established that cancer type and frequency of assisting with ADL contributed to increased role strain among FCGs.

Further, Ge and Mordiffi (2017) in their systematic review established that psychological distress, limited social activities, lower physical functional status score, comorbidities involving musculoskeletal disorder, cancer type, solid tumour and a poor perceived health status as some of the patient related factors that contributed to high role strain among family caregivers.

Patient’s physical condition also aggravates caregiving strain. This is supported by a study conducted by Mosher *et al*. (2016) in U.S which established that FCGs felt helpless, frustrated and sad as a result of constantly witnessing patient suffering from various physical symptoms like pain, diarrhoea, weight loss, fatigue and sexual symptoms.

Patient socio-demographic factors have also been shown to influence relationships which lead to strain. This is supported by a study conducted by Litzelman *et al*. (2016) in the US which established that FCGs who cared for a female patient experienced less social strain and relationship quality was better. In addition, a study conducted by Metzelthin *et al*. (2017) on TOPICS-MDS data set established that Sex (male), marital status (married/cohabiting), poor self-perceived health/psychological stress, disability and comorbidities as some of the patient related factors that contributed to high role strain experienced by FCGs who were taking care of patients with cancer. Additionally, a study conducted by Amamou *et al*. (2019) in Tunisia established that sex (a male patient), older age (over 60 years), comorbidities and patient receiving chemotherapy as some of the patient related factors contributing to role strain experienced by FCGs taking care of adult patients with cancer.

2.5 Institutional factors influencing role strain experienced by family caregivers of adult patients suffering from cancer

The least developed and developing countries have inadequate medical resources and dysfunctional healthcare systems to handle the increasing cancer burden (Shah *et al*., 2019). Indeed, a study conducted by Stefan (2015) in relation to cancer care resources in Africa established that there were only 102 cancer treatment centres in Africa which are inadequate to cover the increasing cancer burden in Africa. The brunt of dysfunctional healthcare systems is borne by the patients and their Family caregivers (FCGs). Comparably, Petrovic and Gaggioli (2020) posited that FCGs offer a valuable support in filling the gap between meeting the patient needs and what can be offered by the healthcare institutions. Furthermore, a systematic review of literature conducted by Ullgren *et al*. (2018) established that some of the major roles performed by FCGs included disease symptom management, monitoring treatment side effects, psychosocial support, practical tasks of caregiving, patient care coordination and decision making. Family caregivers also help their patients in navigating the complex healthcare systems (Lilleheie *et al*., 2020).

Cancer caregiving is a taxing role which often contributes to role strain among FCGs. Yet, it is often overlooked by healthcare personnel (Kong & Guan, 2019). A review of current evidence by Kent at al. (2016) established that supporting FCGs of patients with cancer is well acknowledged by healthcare workers but most health care systems lack a standardized mechanism of incorporating FCGs in the unit of care and supporting them in caregiving role. Indeed, a qualitative study conducted in Norway by Lilleheie *et al*. (2020) revealed that FCGS felt that their needs are ignored by healthcare workers who only focus on patients, yet provision of the services is supposed to be holistic. Moreover, healthcare personnel have a crucial role of identifying and mitigating caregiving challenges faced by FCGs (Taleghani *et al*., 2021).

Family caregivers require information and emotional support to enhance their caregiving but rarely are these being addressed in healthcare settings. Indeed, a survey conducted by Lund *et al*. (2015) in Copenhagen established that 39% of FCGs were not satisfied with information they got from healthcare workers while 31% had to inquire the needed information and 51% of FCGs reported that healthcare workers rarely assessed or supported them in caregiving while 30% of FCGs wished that healthcare workers involved them fully in treatment and care plan of their patients. Another research report by National Alliance for Caregiving (2016) in the U.S established that almost half of family caregivers (43%) required help and information on how to handle physical and psychological stress, while 40% required help in handling end of life decisions and 33% on how to ensure their patient was safe at home. Furthermore, a study conducted by Borges *et al*. (2017) in Brazil established that effective communication among healthcare workers, patients and FCGs is very important in lessening the role strain. Furthermore, a study by Saleh and O'Neill (2018) in Bahrain established that lack of healthcare workers support contributed to the strain that FCGs experienced.

Another study conducted by Maheshwari and Mahal (2016) in India established that there was a high strain among family caregivers and their patients who travelled longer geographical distance to access cancer treatment services. Additionally, a study conducted in Kenya established that patients and their FCGs travel long distances to access cancer care services, also there is no decentralization of comprehensive cancer care services to some counties, in addition to costly cancer diagnosis and treatment services. This study also established that there is poor knowledge about cancer among the general population and healthcare workers as well as poor communication among healthcare workers and the patients (Makau-Barasa *et al.*, 2018).

In Kenya, patients suffering from cancer and their family face treatment delays, high cost of cancer treatment and cover long geographical distances in search of cancer treatment services (Ronniey, 2019; Malloy *et al.*, 2017). This has psychosocial, financial and physical implications on the patients and their family caregivers. Moreover, a study conducted by Hanna *et al.* (2020) revealed that cancer treatment delay is significantly associated with patient mortality.

The least developed and developing countries have few specialized health care personnel and nurses are the most relied up on in reconstitution and administration of chemotherapy as well as care of patients with cancer (WHO, 2017). Another study conducted by Walubita *et al.* (2018) in Zambia established that there are few specialized healthcare workers involved in cancer care, ineffective communication among healthcare workers and family caregivers, inadequate working space and inadequate medical supplies. Another study by Haileselassie *et al.* (2019) in Ethiopia established that cancer centres have poor infrastructure, lack essential medical equipments, experience chronic shortage of chemotherapy drugs which results in buying of expensive drugs from private chemists. Further, a study conducted by Miseda *et al.* (2017) in Kenya established that there is a huge shortage of specialised healthcare workforce (85% based on norms and national standard guidelines) across the different health cadres in all the counties. Specifically, by then there were no nurse oncology practitioners in all the 47 counties.

There are a number of health system barriers to supporting family caregivers. Indeed, a study in Canada posited that such barriers included lack of proper communication, lack of access to information, lack of knowledge on family caregiver needs, challenges in navigating healthcare system, lack of access to financial resources and lack of policies that address family caregivers integration in healthcare system (Charles *et al.*, 2017). Further, a study conducted in U.S established that there was poor communication between FCGs and healthcare workers, lack of care coordination and challenges in accessing cancer care (Patel *et al.* (2017). Another study conducted by Lafortune *et al.* (2015) on community-based primary health care for older adults in South-western Ontario established that patients and their family caregivers experience difficulties in navigating healthcare system and accessing the services, lengthy wait time before they are attended to, problem in scheduling appointments, and poor integration in the healthcare system. Similarly, another study conducted by Qualls (2016) in U.S established that there was a problem of integrating family and family caregivers into healthcare systems despite their important role in the healthcare/long-term care as well as policy and practice challenges to incorporating FCGs into the healthcare systems. Furthermore, Mosher *et al.* (2016) in the U.S established that FCGs experienced challenges in dealing with practical skills in caregiving which included balancing their employment, household responsibilities, patient personal care, clinic appointments, uncertain future and regularly updating other family members on patient's health status.

Despite the evidence that interventions can mitigate the role strain experienced by family caregivers, a meta-analysis conducted by Northouse *et al.* (2012) established that such interventions are not implemented in clinical practice, there is also no framework in place to guide implementation of support programmes and most cancer treatment centers do not offer comprehensive family caregiver support programs. Indeed, WHO (2016) has posited that there is need for psychosocial care to address the psychological, emotional, social and financial well-being of patients and family members. However, there is a problem of integrating FCGs in the unit of care and healthcare systems do not share vital information with FCGs nor support them in caregiving which makes them feel unprepared in their caregiving role.

2.6 Summary

Currently cancer care and treatment services have largely become outpatient-based than inpatient-based services, hence assessment and mitigation of the strain that FCGs experience is very crucial. Empowering FCGs in caregiving is in line with the ambitious plan of universal health coverage as part of community empowerment. FCGs are an important pillar in matters relating to long term/chronic care at home. Caring for patients with chronic ailments is a very daunting task especially if FCGs have not been empowered with knowledge and skills in caregiving and as a result family caregivers experience role strain.

Role strain is multifaceted which encompasses psychological strain, social strain, physical strain and financial strain. It also adversely affects general health of FCGs. There are factors that contribute to role strain which includes socio-economic and psychological factors, patient related and institutional factors. High strain can affect the quality of care that FCGs offer to patients, thus compromising the patient’s health.

Family caregivers are a vulnerable and at risk population which has remained neglected by the healthcare system. Healthcare workers specialized in cancer care undergo training in order to handle complexities related to cancer care, yet FCGs who offer variety of care to patients with cancer, enter into provision of this care without any practical skills training and without healthcare system supporting them. FCGs face the challenge in silence and experience strain as they multi-task and prioritize the patient needs. There is a gap in integrating FCGs in the therapeutic unit of care by healthcare systems which should be addressed in order to effectively support FCGs and lessen the role strain that they experience.

Healthcare workers especially nurses spend substantial time interacting with patients and their FCGs, hence are in better position to assess the strain experienced by FCGs as well as supporting them in dealing with challenges relating to practical aspects of caregiving or referring them to appropriate services. Family caregivers should be supplied with information in regard to the potential strain and its impact on their general health as well as ways of lessening the strain. It is necessary to enhance effective coping skills among FCGs and also intervene to alter ineffective coping skills.

Every individual has a right to highest attainable health care as enshrined in our constitution and it is hoped that the universal health coverage initiative will address the health inequalities especially subsidizing or making cancer treatment and care free or affordable in Kenya as well as enactment of policies to guide supportive care for FCGs involved in cancer caregiving.

2.7 Research gaps

Most of the studies conducted on FCGs are quantitative and largely have been conducted in western countries; hence there is paucity of data relating to FCGs of adult patients with cancer in Africa. There is also need for a mixed method studies. The researcher enriched the information by employing the qualitative methods at data collection level by use of focus group discussions among family caregivers and key informant interviews among healthcare workers who are experts in cancer care.

In Kenya, a literature gap exists regarding the role strain experienced by FCGs who offer care to adult patients suffering from cancer, hence this research provides a foundation for role strain assessment and its predictor factors, this being a first step to inform in the development of strategies to address role strain and enhance caregiving among FCGs of adult patients suffering from cancer in a Kenyan context.

CHAPTER THREE

METHODOLOGY

3.1 Study design

This study utilized analytical cross-sectional design to assess the role strain and its associated predictor factors among family caregivers of adult patients suffering from cancer at Kenyatta National Hospital cancer treatment clinic. Analytical cross-sectional study design is a type of observational study where data is collected at a single point in time from the study participants. It also seeks to measure the relationship or association between the dependent and independent variables though no causal effects can be inferred (Kesmodel, 2018). This study was a QUAN → qual design utilizing both quantitative and qualitative approaches, where its primary component was quantitative being supplemented by qualitative aspects (Schoonenboom & Johnson, 2017).

3.2 Study area

The study was carried out at Kenyatta National Hospital (KNH). KNH was established in 1901 and is the largest Teaching and Referral Hospital in East and Central Africa and the main national referral hospital in Kenya with a bed capacity of 1800 offering services to over 2000 patients daily. It is located in Nairobi County which is also the capital city of Kenya, Upper Hill area, 3 kilometers from Nairobi central business district along Hospital road off Ngong' road. The hospital serves as a research, teaching and main referral center in Kenya. It is also the teaching hospital for University of Nairobi and Kenya Medical Training College.

KNH receives referrals from across the whole country and is the largest government hospital that offers comprehensive cancer treatment and care services which include the main cancer treatment modalities (surgery, chemotherapy, radiotherapy) and follow up care. KNH was an ideal site for this study since it receives patients with cancer from across the country that have to cover long geographical distances among other strains in order to access the comprehensive cancer treatment and care services which are only available in very few health care facilities in Kenya.

The study was conducted at KNH cancer treatment outpatient clinic located at GFC ward. The clinic is open for services on all the week days except public holidays and weekends. The clinic attends to adult patients with cancer who are booked on weekly basis for chemotherapy, radiotherapy as well as newly diagnosed cancer patient for treatment preparation. Every week there are patients booked for treatment preparation; routine treatment and post treatment follow up. Approximately 1000 patients are booked per week for the various services (cancer treatment centre health information department statistics, 2018). Almost every patient is accompanied by a family caregiver to the clinic. The clinic is manned by nursing staff and oncologists among other healthcare workers.

3.3 Study population

Study population comprised of family caregivers and their corresponding adult patients with cancer attending KNH cancer outpatient treatment clinic at GFC and who met the inclusion criteria. Also the study population comprised of the healthcare workers who were permanent employees of KNH currently working at cancer treatment centre; these included seven nursing officers who were experts in oncology and palliative care as well as three medical social workers who were targeted for key informant interviews.

Based on the cancer treatment centre health information department statistics, the annual data for the year 2017/2018 (july 2017-june 2018 period) indicated that 8673 patients were offered chemotherapy, this data was inclusive of patients who were on treatment combination of chemotherapy plus radiotherapy. For the same period, the annual data for the year 2018/2019 indicated that 9098 patients received chemotherapy or a combination of chemotherapy and radiotherapy, under this category of patients there was an increase of approximately 4.9% from the latter year. From this data of year 2018/2019, it indicated that on average 758 patients received chemotherapy or chemo-radiation every month. Almost every patient is accompanied to the clinic by a family caregiver; hence the estimated study population was approximately 758 respondents, since the study was undertaken in one month.

3.4 Sample size determination

The sample size was determined using Cochran formula (1963); $n=z^{2}dq/d^{2}$

where:

n=the desired sample size (if the target population is greater than 10,000)

z=the standard normal distribution at 95% confidence level (=1.96)

P=the expected population correlation coefficient (population effect size), in this case 50% (large effect size) was used to determine the sample size.

q=1-p

d=degree of freedom or the level of precision, set at 0.05.

Substituting these figures in the above formula:

$$N = \frac{(1.96x1.96)\ x\ 0.5(1-0.5)}{(0.05x0.05)}$$

= approximately 384 family caregivers.

Since the target population was less than 10,000, the sample size was adjusted using the Finite Population Correlation Factor formula below:

$$nf = \frac{n}{1 + (n/N)}$$

Where;

nf= the desired sample size after Finite Population Correction Factor is applied,

n= the desired sample size (384) from the above calculation, (when the population > 10,000),

N= the estimate of the study population (758 patients attended per month) which corresponded to approximately 758 family caregivers,

Hence, the desired sample size for family caregivers was,

$$nf = \frac{384}{1 + 384/758}$$

=384/1+ 0.506

=384/1.506

=255 family caregivers.

Regarding focus group discussion, three focus group discussions were conducted from the initial five focus group discussions that were intended to be conducted while six key informant interviews were conducted against a total of eight interviews that were planned. Each focus group discussion comprised of eight family caregivers who were purposefully selected. According to Palinkas *et al.* (2015) purposeful sampling is important in qualitative data collection where it is utilized in selection of participants rich in information concerning the phenomenon under study. No further focus group discussions were conducted after 3rd focus group discussion and 6th key informant interview since theoretical saturation was achived. Theoretical or data saturation provides a fundamental direction in sample size determination in qualitative research (Guest *et al.*, 2006) and according to Malterud *et al.* (2016) based on information power, saturation can be achieved quickly if the recruited participants holds rich information pertaining to the phenomenon under study, hence few participants are needed for the study. Further, Hennink *et al.* (2019) observed that 60% of codes emerged within the first focus group discussion while 90% of codes emerged at 4th focus group discussion. However, it is quite impossible to totally reach meaning saturation with qualitative data.

3.5 Sampling and recruitment of participants

3.5.1 Sampling method

The study adopted systematic sampling method with the patient booking register forming the sampling frame.

3.5.2 Sampling interval

Every N^{th} patient in the booking register was sampled and together with the family caregiver accompanying the patient to the clinic were recruited in the sample (N as the sampling Interval).

$$Sampling\ interval\ (N)\ = \frac{Population\ size\ (758)}{Sample\ size\ (255)} = 2.97 = 3$$

3.5.3 Recruitment process

The first patient and corresponding FCG (as identified by patient) were picked randomly from the booking register; this was based on the sampling interval (N^{th}=3) and involved picking a random number between the 1st and 3rd patients booked for clinic that week. Thereafter, every 3rd patient in the booking register together with the FCG accompanying patient to the clinic were recruited in the sample until when a sample size of 255 family caregivers and their corresponding patients was attained. If the booked patient did not turn up or was not accompanied by a family caregiver, or did not consent to participate in the study, the researcher sampled the next N^{th} patient and the corresponding FCG based on the sampling frame (booking register). All the nursing officers who were trained experts in oncology care and medical social workers working at KNH Cancer Treatment Centre were also included in the sample as key informants.

The booking register formed the sampling frame and only the patient and corresponding FCG as well as the expert healthcare workers who consented to participate in the study were recruited. The unit of sampling for this study was FCGs.

Each of the recruited study participants based on the inclusion and exclusion criteria were supplied with the requisite information regarding the study/study procedures by the researcher/research assistant. The researcher translated the participant information form from English to Kiswahili (the local national language) for ease of understanding.

3.6 Inclusion criteria

Participants who were aged over 18 years, currently receiving chemotherapy or a combination of chemotherapy and radiotherapy were included in the study. FCGs who have been providing care to the patient for at least two weeks and above were also included in the study. If more than one family caregiver was present, then the order of preference was; the one who has provided care the longest, closest relative and one who has been residing near the patient. Regarding healthcare workers, all specialized oncology/palliative care nursing officers and medical social workers who were permanent employees of Kenyatta national hospital and were working at KNH cancer treatment centre were selected.

3.7 Exclusion criteria

Family caregivers who had co-morbidities, family caregivers who were being paid for care rendered. Family caregivers and patients who were completely illiterate; those who could not comprehend Kiswahili or English language, If either the patient or the family caregiver did not consent, then none of them was recruited, family caregivers who were trained healthcare professionals as well as nursing officers who were not trained experts in oncology and palliative care.

3.8 Data collection tools

Collection of data involved use of a structured questionnaire, modified caregiver strain index (MCSI) tool, ECOG-PS scale of Performance Status, key informant interview schedule, and focused group discussion topical guide.

3.8.1 Structured questionnaire

Researcher developed a structured questionnaire which was administered among the family caregivers. This questionnaire was composed of two parts. Part I of the questionnaire gathered information on socio-demographic characteristics of the family caregiver and the corresponding patient while Part II gathered data on predictors of role strain among family caregivers of patients with cancer (patient related factors, family caregiver related factors (psychological related factors and financial related factors) and Institutional related factors. Each of these factors were assessed using a 5 item likert scale where the respondents were requested to rate each item statement on a 5 point scale from strongly disagree=1, disagree=2, somewhat agree=3, agree=4 and strongly agree=5. However, the first two scores (1 and 2) were an indicator that the respondents were totally not in support of the statement or did not perceive any strain. The scores of 3, 4 and 5 were taken as indicators that the respondents perceived the strain, though at different levels.

For data analysis purposes the scores of 1 and 2 were computed together under disagree which meant that the respondents did not perceive any strain while a score of 3 meant that the respondents slightly perceived the strain. Scores of 4 and 5 were computed together under agree which meant that the respondents totally perceived the strain.

The questionnaire was translated to Kiswahili for ease of understanding. It was self-administered under the guidance of researcher or research assistants. Each questionnaire was evaluated for completeness after administering it. This tool is in appendix 6.

3.8.2 The Modified Caregiver Strain Index (MCSI)

The Modified Caregiver Strain Index (MCSI) tool (Thornton & Travis, 2003) was adopted with permission for use in assessing the level of family caregiver role strain. It is a tool which is composed of 13 questions aimed at measuring strain due to care provision. The tool is used to assess strain among individuals of any age who are taking care of an older adult. The major domains of this tool includes psychological, social, financial, physical and personal. The tool is scored by awarding 2 points for each "yes" and 1 point for each "sometimes" response. The sum score of the items ranges from 0 to 26. The lowest score is zero (no strain) and highest score is 26 (high strain). High scores reflect high level of caregiver strain.

For data analysis purposes the scores for regular and sometimes were computed together which meant that the family caregivers (FCGs) experienced strain though at different degrees. Further, the level of role strain was categorized as mild strain (0-8), moderate strain (9-17) and severe strain (18-26). Similar categorization of strain has been adopted by Dhandapani *et al*. (2015). The MCSI measures the extent to which FCGs perceive caregiving as contributing to substantial strain on their psychological, social, physical and economic well-being.

The items in this tool were translated to Kiswahili for ease of understanding. This is a screening tool for strain among the family caregivers of adult patients. It was administered by the researcher or research assistants among the study respondents. Each of the tool items was evaluated for completeness immediately after interviewing the respondent. This tool is in appendix 7.

3.8.3 Eastern Cooperative Oncology Group (ECOG-PS) scale for performance status

Performance status is an estimate of patient's functional capability to execute certain activities of daily living (ADLs) without being helped by significant others. This was estimated by ECOG-PS scale for performance status (Oken, 1982). This is a free tool available for use by the healthcare workers in clinical practice and oncology research. The ECOG-PS scale of performance status was developed in 1960 by

Eastern Cooperative Oncology Group to be used by health care workers in clinical practice and oncology research. The ECOG-PS scale is a six point scale which range from grade 5 (dead) to 0 (fully active).

For this study and based on the operational definition of functional status; ECOG-PS was categorized where a scale of less than 3 reflected good patient functional status while a scale of more than 3 reflected poor patient functional status. The items in this scale were translated to Kiswahili for ease of understanding. The scale was scored by the researcher or research assistant on the patient corresponding to each of the family caregiver who has been interviewed. This tool is in appendix 8.

3.8.4 Focus group discussion guide

The researcher developed a focus group discussion topic guide which majored on caregiving challenges or issues that could be contributing to the role strain among FCGs of adult patients suffering from cancer. The topic guide was also translated to Kiswahili for ease of understanding. This tool is in appendix 9. Focus group discussion sessions were done in English which was a consensus reached among the participants. Focus group discussions are a robust mechanism for data collection and are used to triangulate the data (Luke & Goodrich, 2019). Compared to one-on-one interview, FGD is a facilitated interactive group discussion among study participants and is useful in obtaining information regarding views, experiences and social phenomena (Flynn *et al*., 2018).

3.8.5 Key informant interview schedule

The investigator developed a key informant interview schedule for interviewing all the nursing officers who were specialized in oncology nursing and palliative care as well as the medical social workers working at KNH CTC. The key informant interview guide majored on; Role strain and institutional challenges in relation to the role strain experieenced by family caregivers among patient suffering from cancer. This tool is in appendix 10.

3.9 Pretesting

The study tools were pretested at KNH adult oncology ward (GFD). The researcher purposefully selected about 30 patients (10% of the study sample size) admitted at GFD (Adult oncology ward) who were visited by their family caregivers, then administered them data collection tools. Pretesting helped in ensuring proper wording, checking for any omissions and clarity of study tools as well as estimation of time to be utilized in the administration of the study tools. Pretesting data was also used in determining reliability (internal consistency) of the structured questionnaire.

3.10 Validity and reliability of data collection tools

Validity refers to the degree to which a tool measures what it is intended to measure (Bolarinwa, 2015). Validity results help researchers in establishing to what degree the obtained measurements correspond to the established theories and constructs under the study. On the other hand, reliability refers to the degree to which a tool consistently measures an attribute under the study and ability to produce similar results following consecutive measurements. Reliability results help researchers in establishing to what degree the tool can reproduce consistent results if measurements are repeated under similar conditions and pretesting data can be utilized in testing reliability of data collection tools (Bolarinwa, 2015).

The modified caregiver strain index (MCSI) tool has been validated in a wide range of studies to measure the level of caregiver strain. The established internal reliability coefficient for MCSI tool by Thornton and Travis (2003) was found to be slightly higher (=.90) compared to the coefficient reported for the original CSI in 1983 (=.86) and a test-retest reliability coefficient of .88 (Thornton & Travis, 2003).

Conill *et al*. (1990) in their study to evaluate validity and reliability of ECOG when scored independently by physicians and patients, established that Kendall’s correlation for ECOG was 0.75 when scored by physicians while it was 0.59 when scored by patients.

The researcher established validity of the structured questionnaire through face validity and ensured proper wording, readability, checked for any omissions, clarity and comprehensiveness concerning the data collection tools. The researcher also established content validity of the data tools through expert reviews with research supervisors, peers and biostatician who also reviewed the data tools for clarity, readability and comprehensiveness. Literature review also guided in questionnaire construction.

The researcher established reliability of the structured questionnaire by determining the instruments internal consistency using pretest data where the cronbach's alpha was calculated for each of the scales in the questionnaire. Cronbach's alpha coefficient of 0.60 to 0.70 is considered reliable while that of 0.80 and above is highly reliable (Ursachi *et al.*, 2015). In this regard, the five items constituting the scale on patient current status related factors had a corresponding cronbach's alpha coefficient of 0.71 while the five items constituting the scale on pscho-social strain related factors had a corresponding cronbachs's alpha coefficient of 0.75. Similarly, the 5 items constituting the scale on financial strain related factors had a corresponding cronbach's alpha coefficient of 0.75 while the 16 items constituting the scale on institutional related factors had a corresponding cronbach's alpha coefficient of 0.80.

3.11 Data collection procedures

The researcher first recruited two research assistants among the Bachelor of Science nursing interns to assist in the data collection. The researcher organised one day training for the recruited research assistants on data collection procedures.

Data collection period was between the months of February and March 2020. Quantitative data was collected over one month (February 2020) and qualitative data (focus group discussions and key informant interviews were conducted from 2nd to 12th of March 2020). The researcher reviewed booking register to identify patients who were scheduled to attend clinic that week and for generation of random numbers. During clinic attendance, the researcher then privately created rapport with the sampled patient and the respective FCG as well as to determine their eligibility for inclusion in the study. Patient and their FCG were excluded from the study if they did not meet the inclusion criteria. The researcher provided information about the study purpose and the data collection process to the patient and the respective family caregiver who passed the inclusion criteria. The sampled patient and respective family caregiver who did not consent were excluded from the study.

The participants who had a problem in reading or writing, the researcher or the research assistants assisted by reading to them the data tools in their preferred language (either English or Kiswahili) and correctly filling the data tools as per the participant’s responses.

The structured questionnaire and the MCSI tool were administered by the researcher and research assistants to gather data on the role strain among FCGs who met the inclusion criteria and consented to take part in the study. The researcher and research assistants also scored ECOG-PS scale for each of the patient corresponding to the FCG who has been interviewed. The researcher and the research assistants also conducted focus group discussions among the FCGs. Only FCGs who were not involved in the quantitative aspect of this research (those that were not administered the structured questionnaire and MCSI tool) were targeted for focus group discussions, this was ensured by targeting a different week (based on the booking register) that does not correspond to when those already administered the structured questionnaire will be attending the clinic. Three focus group discussions were conducted and each comprised of eight family caregivers who were purposefully selected and then were supplied with information regarding study purpose and data collection process as well as informed consent was obtained in order to participate in the study, after which an audio-recorded focus group discussion was conducted. Initially, the researcher conducted three focus group discussions and further discussions ceased after data saturation levels were reached. The researcher acted as the facilitator while one research assistant took notes and the other audio-recorded the conversation. Each FGD session on average lasted for 40 minutes.

After completing focus group discussion sessions, the researcher then targeted all nursing officers who are trained experts in oncology and palliative care as well as medical social workers who work at KNH Cancer Treatment Centre (CTC) for key informant interviews. The researcher informed them about the study purpose and data collection process as well as obtained informed consent to take part in the study. The researcher administered key informant interview schedules among the healthcare professionals to collect data on institutional factors contributing to the role strain experienced by the family caregivers of adult patients with cancer. Only healthcare professional who were present and consented to be interviewed at the time of data collection were administered the key informant interview schedule. These included two nursing officers specialized in oncology nursing (masters level), two nursing officers specialized in palliative care and two medical social workers.

3.11.1 Data management, Quality control and analysis

The Investigator reviewed each data collection tool at the end of each session to ensure completeness and clarity. The Investigator kept the collected data safely. The data was put in a lockable secure place as well as ensured maximum confidentiality of the gathered data. The respondents were given information about the study and only the respondents who met the inclusion criteria and consent to participate in the study were interviewed. Researcher translated the questionnaires to Kiswahili for ease of understanding among the respondents who could not prefer English language.

Quantitative data generated from structured questionnaire, MCSI tool and ECOG-PS scale for performance status were analyzed by deriving descriptive statistics and percentages. Also inferential statistics were computed to derive the relationship between the independent and dependent variables through ordinal logistic regression analysis; with confidence interval set at 95% (p-value < 0.05 was considered significant). Data was presented by use of tables and charts. Statistical Package for the Social Sciences (SPSS) software version 25 was utilized in data analysis.

Regarding the analysis of qualitative data gathered from key informant interviews and focus group discussions, the researcher utilized thematic analysis steps which involved familiarization, transcription of data, organizing the data, generation of codes and categories which were then linked to the emerging themes and finally, a report was generated depicting the phenomenon of interest (Braun & Clarke, 2006;

Lester *et al*., 2020). Data was transcribed manually where the researcher read each transcript and made a content summary before re-reading each meaning unit (phrase, sentence or paragraph), then generated codes and categories which were then linked to the emerging themes. Researcher also compared the notes that were taken during FGD sessions with content summary generated after transcription of data and there were no differences noted. Finally, a comprehensive report was produced based on the phenomenon of interest as experienced by the study participants. To ensure credibility of the process, researcher engaged a social scientist who also coded each transcript independently and then comparison was done. A consensus was reached after it was evident that there were no major differences between the themes generated.

3.12 Ethical considerations

The researcher obtained an introduction letter from J.K.U.A.T school of nursing to apply to Kenyatta National Hospital and University of Nairobi Ethics and Review Committee (KNH/UON ERC), the body which approved this study. Clearance to conduct the study was also obtained from the head of department Cancer Treatment Centre (CTC). The researcher also obtained a research permit from the National Commission for Science, Technology and Innovation (NACOSTI).

Consent was sought from the participants based on Declaration of Helsinki Statement of ethical principles for medical research involving human subjects. This involved explaining what the study was all about, voluntary participation, potential risks and benefits, ability to withdrawal from the study at any time without any victimization, confidential and privacy assurance and commitment. Study participants were offered an opportunity to ask any questions and have their concerns addressed. They were also informed that the study did not involve any invasive procedures. The researcher/research assistants obtained informed consent from the study participant who had made the decision to participate in the study and the participants signed the consent form or had their thumb print appended on the form before data collection which signified that the individual participant had freely volunteered to participate in the study having made an informed decision.

Confidentiality was maintained by ensuring that the data tools were assigned a unique code or serial number instead of official names of the participants. This was important to ensure the study participants remained anonymous. Computer was secured with a password for data security. Access to the data was only limited to the researcher only. Any forms or lists that linked study participants to the unique code/serial number or any other identity information were filed for safe keeping by the researcher in a lockable cabinet and were accessible to the researcher only.

The researcher ensured privacy by ensuring that during data collection, the study participants filled the data tools in a secure, comfortable and private area free of any intrusion. The researcher liased with the In-charge of KNH oncology outpatient clinic (GFC) and was availed a secure private area during data collection as well as during interviews and focus group discussions. The researcher briefed the research assistants on the level of confidentiality expected and strictly observed confidentiality and privacy during data collection. The researcher ensured strict adherence to the study procedures as well as trained the research assistants on the study procedures.

The researcher further minimized potential risks through providing adequate information regarding the study to participants, offering counselling, sharing of health messages and referral for further support and management. To exemplify this, the researcher had a referral protocol in place (refer to Appendix 15) to handle study participants who on assessment using the M.C.S.I tool were experiencing severe (18-26) role strain. The researcher also had in place a protocol on how to handle potential psychological distress (refer to Appendix 14) that some participants could experience during data collection process. Participants were also informed of their right to withdraw from the study or terminate their participation if they felt uncomfortable or experienced uncontrollable emotional distress.

3.14 Study results dissemination plan

Study results will be disseminated at scientific and professional conferences, academic forums, hard and soft copies will be availed to JKUAT library for reference. The study results will also be published in peer reviewed journals.

CHAPTER FOUR

RESULTS

4.1 Introduction

This chapter presents the result and analysis of study findings. The response rate for this study was 100% (n=255) for family caregivers where each corresponded to a respective patient. The researcher also conducted three focused group discussions involving a total of 24 family caregivers as well as key informant interviews involving 2 nursing officers specialized in oncology nursing, 2 nursing officers specialized in palliative care and 2 medical social workers.

4.2 Demographic characteristics of the respondents

Data on demographic characteristics of the respondents was collected from the family caregivers and their patients. This involved the family caregiver's socio-demographic characteristics and the associated caregiving characteristics while for the patients it involved their socio-demographic characteristics and the associated disease characteristics.

4.2.1 Family caregiver Socio-demographic and caregiving related characteristics

The socio-demographic characteristics of the family caregivers that were assessed during the study included sex, age, level of education, marital status, employment status and monthly income while caregiving related characteristics included residence of the family caregiver in relation to the patient, relationship with the patient, duration of caregiving to the patient, hours of care provision per day and membership to a social support group as illustrated in table 4.1. The results revealed that majority (57.6%, n=147) were females while most (83.1%, n=212) of the respondents were middle aged (36-60 years). The study results also showed that 41.6% (n=106) of the respondents had attained secondary level of education and the majority (80.8%, n=206) of the respondents were married. Further, the study revealed that over half (57.3%, n=146) of the respondents were unemployed and majority (85.9%, n=219) of the respondents were under low income category which comprised of a monthly income of less than 20,000 Kenya shillings (Ksh).

Regarding caregiving related characteristics as illustrated in table 4.1, the results revealed that majority (91.0%, n=232) of the respondents resided with the patient within the same homestead and most (36.9%, n=94) of the respondents cared for a spouse. The study also revealed that majority (67.1%, n=171) of the respondents have been caring for the patient for a period of less than 1 year while most (74.5%, n=190) of the respondents provided care for a period of less than 5 hours per day. Further, the study established that majority (91.8%, n=234) of respondents were not members to any social support group specifically for family caregivers taking care of adult patients suffering from cancer.

Table 4.1: Family caregiver socio-demographic and caregiving related characteristics

Variable	Category	Frequency (n)	Percent (%)
Family caregiver socio-demographic characteristics			
Sex	Male	108	42.4
	Female	147	57.6
	Total	255	100.0
Age	18-35 years (Young Adult)	31	12.2
	36-60 years (Middle Aged)	212	83.1
	Over 61 years (Elderly)	12	4.7
	Total	255	100.0
Education	Primary	110	43.1
	Secondary	106	41.6
	Tertiary/College	39	15.3
	Total	255	100.0
Marital status	Married	206	80.8
	Not married (Single, Separated, Widowed)	49	19.2
	Total	255	100.0

Employment status	Unemployed	146	57.3
	Employed (Full time, Part time, Self-employed)	109	42.8
	Total	255	100.0
Monthly income	Low Income (<20,000Ksh)	219	85.9
	Moderate Income (>20,001-50,000Ksh)	32	12.5
	High Income (>50,001Ksh)	4	1.6
	Total	255	100.0
Caregiving related characteristics			
Caregiver resides with patient (co-residency)	No	23	9.0
	Yes	232	91.0
	Total	255	100.0
Relationship with patient	Parent/In-law parent	87	34.1
	Spouse/Partner	94	36.9
	Son/Daughter	10	3.9
	Friend/Neighbour	9	3.5
	Brother/Sister	55	21.6
	Total	255	100.0
Duration of caregiving to patient	>2 week - 1 year	171	67.1
	>1 year - 3 years	80	31.4
	>3 years	4	1.6
	Total	255	100.0
Hours of care provision per day	<5 hours	190	74.5
	>5 hours	65	25.5
	Total	255	100.0
Membership to a social support group	Yes	21	8.2
	No	234	91.8
	Total	255	100.0

4.2.2 Socio-demographic characteristics of the patients

The socio-demographic characteristics of the patients that were assessed during the study included sex, age, NHIF membership and the patient’s county of residence as shown in table 4.2. The results showed that majority (63.9%, n=163) of the patients were females and most (69.8%, n=178) were aged between 36 to 60 years. The study also revealed that majority (97.3%, n=248) of patients were enrolled with National Hospital Insurance Fund (NHIF). In addition to NHIF only 1.2% (n=3) had a private medical insurance and majority (74.5%, n=190) of the patients were from other counties other than Nairobi county.

Table 4.2: Patient socio-demographic characteristics

Variable	Category	Frequency (n)	Percent(%)
Sex	Male	92	36.1
	Female	163	63.9
	Total	**255**	**100.0**
Age	18-35 years (Young Adult)	5	2.0
	36-60 years (Middle Aged)	178	69.8
	Over 61 years (Elderly)	72	28.2
	Total	**255**	**100.0**
Patient has NHIF	Yes	248	97.3
	No	7	2.7
	Total	**255**	**100.0**
Patient has Private medical insurance	Yes	3	1.2
	No	252	98.8
	Total	**255**	**100.0**
County of residence	Nairobi	65	25.5
	Other county	190	74.5
	Total	**255**	**100**

4.2.3 Patient’s disease characteristics

The patient’s disease characteristics that were assessed during the study included cancer type, stage of cancer at diagnosis, treatment modality, chronic condition co-morbidity and physical functional status based on ECOG scale as shown in table 4.3. The study revealed that majority (33.7%, n=86) of the patients had breast cancer, followed by 21.6% (n=55) of patients who had cervical cancer and over half (53.4%, n=136) of patients had early stage cancer (cancer stage I and stage II) at diagnosis. The study also established that majority of patients (60.4%, n=154) were on chemotherapy alone while 27.5% (n=70) had a chronic medical condition in addition to cancer. Regarding physical functional status based on ECOG scale; majority

(75.7%, n=193) of patients were in good physical functional status (ECOG grades < 2).

Table 4.3: Patients' disease characteristics

Variable	Category	Frequency (n)	Percent (%)
Cancer type	Breast	86	33.7
	Prostate	34	13.3
	Cervical	55	21.6
	Colo-rectal	13	5.1
	Gastric	13	5.1
	Esophageal	18	7.1
	Nasopharyngeal	14	5.5
	Ovarian	6	2.4
	Lung	5	2.0
	Laryngeal	8	3.1
	Other types of cancer	3	1.2
	Total	**255**	**100.0**
Stage of cancer at diagnosis	Early stage cancer (Stage I & Stage II)	136	53.4
	Late stage cancer (Stage III & Stage IV)	119	46.6
	Total	**255**	**100.0**
Treatment modality	Chemotherapy only	154	60.4
	Chemotherapy and Radiotherapy	101	39.6
	Total	255	100.0
Chronic medical condition in addition to cancer	Yes	70	27.5
	No	185	72.5
	Total	**255**	**100**
ECOG performance status	Good functional status (ECOG grades <2)	193	75.7
	Poor functional status (ECOG grades >3)	62	24.3
	Total	**255**	**100.0**

4.2.4 Socio-demographic characteristics of family caregivers during focus group discussion

As illustrated in table 4.4 all FCGs had attained secondary level of education, both sexes were equally represented and their average age was 43 years.

Table 4.4: Socio-demographic characteristics of family caregivers during focus group discussion

Variable	**Category**	**Frequency (n)**	**Percentage (%)**
Sex	Male	12	50.0
	Female	12	50.0
	Total	**24**	**100.0**
Education level	Secondary	14	58.3
	Tertiary	10	41.7
	Total	**24**	**100.0**
Employment status	Employed	10	41.7
	Unemployed	14	58.3
	Total	**24**	**100.0**
Duration of caregiving	Less than 6 months	11	45.8
	Over 6 months to 1 year	13	54.2
	Total	**24**	**100.0**
Age	Mean	43 years	
	Mode	36 years	

4.2.5 Socio-demographic characteristics of key informants

As illustrated in table 4.5; majority (n=4, 66.7%) of key informants were females, their average age was 43.8 years while average years of working experience at KNH was 7.5 years.

Table 4.5: Socio-demographic characteristics of key informants

Variable	Category	Frequency (n)	Percentage (%)
Gender of Key Informants	Male	2	33.3
	Female	4	66.7
	Total	**6**	**100**
Education level of Key Informant	Master of Science	3	50.0
	Degree	1	16.7
	Higher diploma	2	33.3
	Total	**6**	**100**
Average Age of Key Informant	Mean	43.8 years	
Average Years of working experience at KNH	Mean	7.5 years	

4.3 Level of role strain among the family caregivers of adult patients suffering from cancer

4.3.1 Results on the responses to the Modified Caregiver Strain Index (MCSI Tool)

The results on the responses to the modified caregiver strain index(MCSI Tool) as displayed in table 4.6 revealed that all (100%, n=255) the FCGs experienced financial strain as a result of caregiving. The results also revealed that 80% (n=204) of FCGs had other demands apart from caregiving. Likewise, 78.8% (n=201) of FCGs reported that they made changes in personal plans to accommodate caregiving and majority (72.2%, n=184) of FCGs had made family related adjustments while also an equal percentage (72.2%, n=184) had made work related adjustments. Further, the results revealed that 70.6% (n=180) of FCGs perceived caregiving as confining while 68.2% (n=174) reported that caregiving had inconvenienced them. In general, most (65.5%, n=167) of the FCGs were overwhelmed by caregiving.

Table 4.6: Responses to Modified Caregiver Strain Index

	Responses					
	Regular		Sometimes		No	
Variables	**F**	**%**	**F**	**%**	**F**	**%**
My sleep is disturbed	4	1.6	140	54.9	111	43.5
Caregiving is inconvenient	9	3.5	165	64.7	81	31.8
Caregiving is a physical strain	5	2.0	117	45.9	133	52.2
Caregiving is confining	22	8.6	158	62.0	75	29.4
There have been family adjustment	33	12.9	151	59.3	71	27.8
There have been changes in personal plan	77	30.2	124	48.6	54	21.2
There have been other demands on my time	148	58.0	56	22.0	51	20.0
There have been emotional adjustments	1	0.4	102	40.0	152	59.6
Some behaviour is upsetting	2	0.8	22	8.6	231	90.6
It is upsetting to find the person I care for has changed so much from his/her former self	5	2.0	142	55.7	108	42.4
There have been work adjustments	86	33.7	98	38.5	71	27.8
Caregiving is a financial strain	232	91.0	23	9.0	0	0.0
I feel completely overwhelmed	14	5.5	153	60.0	88	34.5

4.3.2 Summary on response to MCSI tool: Categorization of role strain among FCGs adult patients suffering from cancer

The responses to Modified Caregiver Strain Index tool (MCSI) were summarized and categorized as illustrated in figure 4.1. The results revealed that the family caregivers who had mild, moderate and severe role strain were 25.9%, 44.3% and 29.8% respectively.

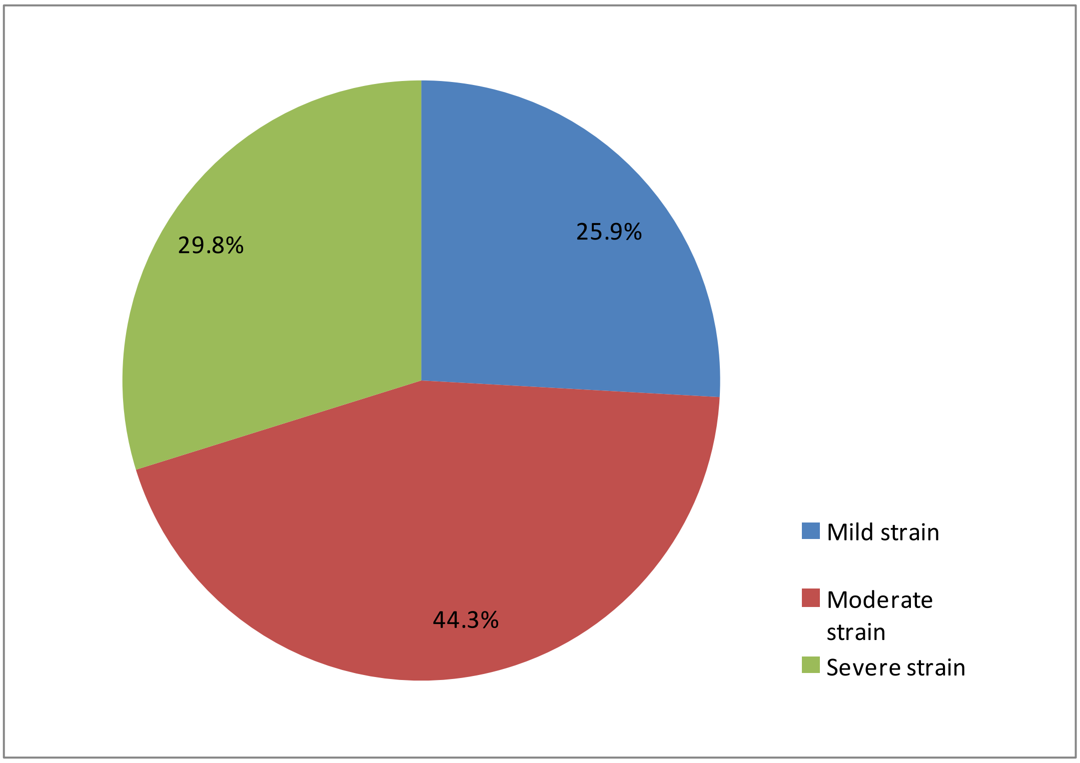

Figure 4.1: Level of family caregivers role strain

4.4 Family caregiver related factors associated with the role strain experienced by the family caregivers of adult patients suffering from cancer

Family caregiver related factors assessed during the study included family caregiver socio-demographic, caregiving related characteristics, family caregiver related psycho-social and financial factors. Further, in examining the hypothesis that “There is no relationship between the family caregiver related factors and the role strain experienced by the family caregivers of adult patients suffering from cancer at KNH cancer treatment clinic” ordinal logistic regression was utilized since the dependent variable (Role strain) had three categories that were ordered as measured using the Modified Caregiver Strain Index (MCSI). The results were presented as follows.

4.4.1 Family caregiver related psycho-social factors contributing to role strain experienced by family caregivers of adult patients suffering from cancer

Family caregiver related psycho-social factors assessed during the study included strain related to social isolation, lack of social support, anxiety and being fatigued, disturbed sleep cycle and psychological upset as shown in table 4.7. The results revealed that majority (80.8%, n=206) of FCGs totally perceived (those who agreed) social isolation as a strain while 74.1% (n=189) of FCGs totally perceived lack of social support as a strain. The study also revealed that over three quarter (77.3%, n=197) of FCGs were psychologically upset while 80.0% (n=204) of FCGs totally perceived strain related to anxiety and fatigue due to caregiving. Further, the study revealed that about two fifth (40.8%, n=104) of FCGs totally perceived disturbed sleep cycle as a strain while 32.5% (n=83) slightly perceived the strain (those who somewhat agreed) related to disturbed sleep cycle.

Table 4.7: Responses on family caregiver related psycho-social factors influencing role strain among family caregivers of adult patients suffering from cancer

	Responses					
	Disagree		Somewhat agree		Agree	
Variable	**F**	**%**	**F**	**%**	**F**	**%**
I have become socially isolated from my family, friends and social events which strain me (Social Isolation).	21.0	8.2	28	11.0	206	80.8
I experience sleep disturbance or lack of sleep due to caregiving which strain me (Disturbed Sleep Cycle).	68.0	26.7	83	32.5	104	40.8
In the last two weeks, I have felt psychologically upset or experienced some stress which strains me (Psychological Distress).	37.0	14.5	21	8.2	197	77.3
I no longer get social support from my family/relatives which strains me (Lack of Social Support).	32.0	12.5	34	13.3	189	74.1
I experience anxiety and get fatigued which strains me (Anxiety and Fatigue).	15.0	5.9	36	14.1	204	80.0

Disagree (Strongly disagree + Disagree)= Did not perceive any strain
Somewhat agree= Slightly perceived the strain
Agree (Strongly agree + Agree)= Totally perceived the strain

4.4.2 Qualitative data analysis on psycho-social factors contributing to role strain experienced by family caregivers of adult patients suffering from cancer

The following themes emerged after thematic analysis of the qualitative data that was collected during focus group discussions.

Theme 1: Social isolation

During focus group discussions, social isolation was a major concern among the participants who indicated that there was no time for social activities as most of their time was utilized taking care of the patient. Others also felt socially isolated by their social groups and friends as supported by the following quotes from some of the participants:

> "*Cancer treatment consumes a lot of time such that I have little time to attend my social group meetings*" (**Family caregiver (FCG).2, (Focus group discussion (FGD).1**.))

> "*We can not have a social life with other people, majority of people isolate us*" (**FCG.11, FGD.2**).

> "*I hardly have any time to visit friends and other family members; my life revolves around my patient*" (**FCG.22, FGD.3**).

However, there are other participants who also indicated that they enjoyed cordial social relations as supported by the following quote:

> *"Women chamas (merry-go-round) where I am a member have been very understanding and supportive"* (**FCG.1, FGD.1**).

Theme 2: Lack of social support

During focus group discussions, lack of social support was also a major concern among the participants who indicated that they experienced lack of social support from their families including friends and neighbors. Others experienced job challenges or job loss related to unsupportive employers as supported by the following quotes from some of the participants:

> "*My neighbours used to assist me in taking care of my children when I bring my patient to the clinic, but of late they feel it is a big bother, even neighbours have gotten tired with me*" (FCG.5, FGD.1).

> "*Caring for my sick sister has brought some misunderstanding between me and my husband; he feels that I have brought a big burden to his family*" (FCG.21, FGD.3).

> "*I have to accompany my patient every time she attends the clinic, on her own she can not make it, the employer has told me to choose between the job and my sick wife*" (FCG.3, FGD.1).

> "*I no longer go to work; I stay with the patient at home all the time*" (FCG.17, FGD.3).

However, there are other participants who felt socially supported as indicated by the following quote from one of the participants:

> "*Friends and family have fully supported me*" (FCG.14, FGD.6).

Theme 3: Psychologically distressed

Psychological distress was also a major concern among the participants during focus group discussions where they indicated that they were psychological upset due to caregiving as supported by the following quotes from some of the participants:

> "*I get psychologically upset when I see how my daughter has been afflicted by cancer*" (FCG.6, FGD.1).

> "*Right now I am stressed, my children are very young, I have called back home and been informed that they have not been prepared any meals*" (FCG.14, FGD.2).

> "*My Patient feeds and vomits everything, this is stressing me and I do not know what type of food to give her*" (FCG.20, FGD.3).

Theme 4: Sleep disturbance

During focus group discussions, participants reported that caregiving had deprived them sleep as supported by the following quotes from some of the participants:

> "My *patient is usually very weak for the first two weeks after receiving chemotherapy, I hardly sleep because I have to constantly check on my patient*" (FCG.10, FGD.2).
>
> "*The week that my patient is scheduled for treatment, we hardly sleep that whole week. We also have to wake up at 2.00am at night in order to arrive early at the clinic*" (FCG.24, FGD.3).

Theme 5: Anxiety and fatigue

During focus group discussions it was also revealed that participants experienced anxiety and fatigue due to caregiving as supported by the following quotes from some of the participants:

> "*I am worried if my patient will make it,…a number of things we do not understand, we are usually in the dark*" (FCG.7, FGD.1).
>
> *"…sometimes we have to go to town (*Nairobi city*) to buy the prescribed drugs that are not available at the hospital, we go searching from one chemist to another, this is tiresome, waste of time and expensive"* (FCG.22, FGD.3).

4.4.3 Association between family caregiver related psycho-social factors and role strain experienced by the family caregivers of adult patients suffering from cancer

To determine the relationship between the family caregiver related psycho-social factors and role strain, the researcher examined the influence of family caregiver psycho-social factors on the role strain experienced by the family caregivers (FCGs). First bivariate ordinal logistic regression for each of the predictor variables was performed and the results revealed that perceived strain related to social isolation, lack of social support, anxiety and being fatigued, disturbed sleep cycle and psychological upset significantly influenced the role strain experienced by the family caregivers of adult patients suffering from cancer. Further, the researcher performed multivariate ordinal logistic regression for all the predictor variables that were significant after bivariate ordinal logistic regression as shown in table 4.8.

The multivariate ordinal logistic regression results revealed that social isolation significantly influenced the role strain experienced by the FCGs. In this regard, the FCGs who did not perceive any strain (those who disagreed) related to social isolation were 80% less likely to experience severe role strain compared to those who totally perceived the strain (those who were in agreement) (OR=0.20, 95% CI 0.075-0.541, p=0.001). Likewise, disturbed sleep cycle related to caregiving significantly influenced the role strain experienced by the FCGs. In this case, the FCGs who did not perceive any strain (those who disagreed) related to disturbed sleep cycle were 70% less likely to experience severe role strain compared to those who totally perceived the strain (those who agreed) (OR=0.30, 95% CI 0.141-0.641, p=0.002) while those who slightly perceived the strain (those who somewhat agreed) were 46% less likely to experience severe role strain compared to those who totally perceived the strain (OR=0.54, 95% CI 0.299-0.982, p=0.044).

Further, the study also revealed that lack of social support significantly influenced the role strain experienced by the family caregivers. In this case, FCGs who did not perceive any strain related to lack of social support from family and friends were 87% less likely to experience severe role strain than those who totally perceived the strain (OR=0.13, 95% CI 0.051-0.305, p=0.001), equally those who slightly perceived the strain (those who somewhat agreed) were 85% less likely to experience severe role strain compared to those who totally perceived the strain (OR=0.15, 95% CI 0.061-0.391, p=0.001).

Among the family caregiver related psycho-social factors, this study did not establish any significant relationship between psychological stress (OR=0.94, 95% CI 0.375-2.380, p=0.905) and anxiety-fatigue (OR=1.30, 95% CI 0.375-4.166, p=0.717) related to caregiving with the role strain experienced by family caregivers of adult patients suffering from cancer at KNH cancer treatment outpatient clinic.

Table 4.8: Association between family caregiver related psycho-social factors and family caregiver role strain among adult patients suffering from cancer

	Beta Estimate	**Sig.**	**Crude Odds Ratio**	**Beta estimate**	**Sig**	**Adjusted O.R**	**95% C.I**	
Variable							**Lower**	**Upper**
Level of Role Strain (MCSI); (1=Mild strain, 2= Moderate strain, 3= Severe strain (Ref)								
Bivariate Ordinal Logistic Regression				Multivariate Ordinal Logistic Regression				
I have become socially isolated from the family, friends and social events which strains me (Social Isolation)								
Disagree	-1.264	**0.004**	0.30	-1.606	**0.001**	0.20	0.075	0.541
Somewhat agree	-0.801	**0.035**	0.45	0.541	0.222	1.72	0.722	4.084
Agree (Ref)								
I experience sleep disturbance related to caregiving which strains me (Disturbed Sleep Cycle)								
Disagree	-1.633	**0.001**	0.20	-1.201	**0.002**	0.30	0.141	0.641
Somewhat agree	-0.243	0.380	0.78	-0.612	**0.044**	0.54	0.299	0.982
Agree (Ref)								
In the last two weeks I have felt Psychologically Upset which Strain me (Psychological stress)								
Disagree	-1.366	**0.001**	0.30	-0.057	0.905	0.94	0.375	2.380
Somewhat agree	-0.467	0.277	0.63	0.543	0.308	1.72	0.606	4.894
Agree (Ref)								
I no longer get social support from the family/friends and this strains me (Lack of social support)								
Disagree	-1.226	**0.001**	0.30	-2.077	**0.001**	0.13	0.051	0.305
Somewhat agree	-0.799	**0.023**	0.45	-1.868	**0.001**	0.15	0.061	0.391
Agree (Ref)								
Anxiety and Fatigue related to Caregiving Strains me								
Disagree	-1.120	**0.028**	0.33	0.222	0.717	1.30	0.375	4.166
Somewhat agree	-0.654	**0.054**	0.52	0.108	0.803	1.10	0.477	2.606
Agree (Ref)								

Disagree= Did not perceive any strain
Somewhat agree= Slightly perceived the strain
Agree= Totally perceived the strain

4.4.4 Family caregiver related financial factors contributing to role strain experienced by family caregivers of adult patients suffering from cancer

Family caregiver related financial factors assessed during the study included strain related to accommodation costs, paying for laboratory and radiological investigations, buying chemotherapy drugs, and the general financial strain as shown in table 4.9.

The results as shown in table 4.9 revealed that 45.5% (n=116) of FCGs totally perceived (those who agreed) transportation costs as a strain while about 46.3% (n=118) of FCGs totally perceived accommodation costs as a strain. It was also established that over three fifth (65.1%, n=166) of FCGs perceived drug costs as a strain while almost a quarter (24.7%, n=63) of FCGs slightly perceived the strain (those who somehow agreed) related to drug costs. Further, the study revealed that majority (72.9%, n=186) of FCGs totally perceived strain related to supporting patient financially in general.

Table 4.9: Responses on family caregiver related financial factors influencing role strain among family caregivers of adult patients suffering from cancer

	Responses					
	Disagree		**Somewhat agree**		**Agree**	
Variable	**F**	**%**	**F**	**%**	**F**	**%**
Paying for transportation during my patient clinic attendance strains me (Transportation Costs).	89.0	34.9	50	19.6	116	45.5
Paying for accommodation during my patient clinic attendance strains me (Accommodation Costs).	95.0	37.3	42	16.4	118	46.3
Buying chemotherapy drugs for my patient strains me (Drug Costs).	26.0	10.2	63	24.7	166	65.1
Paying for laboratory and radiological investigations ordered for my patient strains me (Investigation Costs).	14.0	5.5	69	27.1	172	67.4
Supporting my patient financially has made my financial status worse (General Financial Strain).	8.0	3.2	61	23.9	186	72.9

Disagree (Strongly disagree + Disagree)= Did not perceive any strain
Somewhat agree= Slightly perceived the strain
Agree (Strongly agree + Agree)= Totally perceived the strain

4.4.5 Qualitative data analysis on financial factors contributing to role strain experienced by family caregivers of adult patients suffering from cancer

The following themes emerged after thematic analysis of the qualitative data that was collected during focus group discussions.

Theme 1: Costly transportation

During focus group discussions, costs attributed to transport during patient clinic attendance was a major concern among the participants as supported by the following quotes from some of the participants:

> "*I lack fare and other times fare is increased such that I can not afford*" (**Family caregiver (FCG).1, (Focus group discussion (FGD.1**).

> "*Using public transport is a big challenge, since my patient is weak I have to hire a private vehicle every time she is scheduled for clinic attendance, it is costly*" (**FCG.20, FGD.3**).

Theme 2: Costly accomodation services

Costs related to accommodation services during patient clinic attendance was also a major concern during focus group discussions as supported by the following quotes from some of the participants:

> "*Here (*Nairobi*) is not my home, I have to rent a place to stay during my patient clinic attendance and treatment. This is very costly"* (**FCG.5, FGD.1**).

> "*At the moment, during my patient clinic attendance, we can not afford accommodation services; we usually spend the night at the casualty department till patient gets the services*" (**FCG.13, FGD.2**).

Theme 3: Costly chemotherapy drugs

During focus group discussions, participants indicated that not only buying of chemotherapy drugs common but also they were expensive as supported by the following quotes from some of the participants:

> "*Buying cancer drugs is expensive" (***FCG.4, FGD.1***).*

> *"...sometimes you are ordered to go and buy a drug prescribed for the patient, thinking it will cost you only two hundred Kenya shillings, instead, it costs you sixteen thousand Kenya shillings" (***FCG.19, FGD.3***).*

Further, during focus group discussions, participants revealed that they were financially strained due to supporting their patient financially as supported by the following quote from one of the participant:

> *"Financial hardship is a big problem….., this disease requires a lot of money"* (**FCG.21, FGD.3**).

4.4.6 Association between family caregiver related financial factors and role strain experienced by the family caregivers of adult patients suffering from cancer

To determine the relationship between the family caregiver related financial factors and the role strain, the researcher examined the influence of family caregiver related financial factors on the role strain experienced by the family caregivers. First bivariate ordinal logistic regression for each of the predictor variables was performed and the results revealed that perceived strain related to transportation costs, accommodation costs, and the general financial strain significantly influenced the role strain experienced by the family caregivers of adult patients suffering from cancer while costs related to drugs and investigations were not significant. Further, the researcher performed multivariate ordinal logistic regression for all the predictor variables that were significant after bivariate ordinal logistic regression as shown in table 4.10.

The multivariate ordinal logistic regression results established that FCGs who did not perceive any strain (those who disagreed) related to transportation costs were 68% less likely to experience severe role strain compared to those who totally perceived the strain (those who agreed) (OR=0.32, 95% CI 0.121-0.816, p=0.017). This study did not establish any significant relationship between the accommodation costs (OR=1.45, 95% CI 0.618-3.380, p=0.397) and general financial strain (OR=2.30, 95% CI 0.547-9.412, p=0.259) with the role strain experienced by the family caregivers of adult patients suffering from cancer.

Table 4.10: Association between family caregiver related financial factors and the family caregiver role strain among adult patients suffering from cancer

							95% C.I	
Variable	**Beta Estimate**	**Sig.**	**Crude Odds Ratio**	**Beta Estimate**	**Sig.**	**Adjusted O.R**	**Lower**	**Upper**
Level of Role Strain (MCSI); (1=Mild strain, 2= Moderate strain, 3= Severe strain (Ref)								
Bivariate Ordinal Logistic Regression				Multivariate Ordinal Logistic Regression				
Paying for transportation during patient clinic attendance strains me (Transportation Costs)								
Disagree	-0.845	**0.002**	0.43	-1.155	**0.017**	0.32	0.121	0.820
Somewhat agree	-0.568	0.074	0.57	-0.621	0.194	0.54	0.211	1.372
Agree (Ref)								
Paying for accommodation during patient clinic attendance strains me (Accommodation Costs)								
Disagree	-0.500	**0.053**	0.61	0.368	0.397	1.45	0.618	3.380
Somewhat agree	0.353	0.292	0.70	0.059	0.906	1.10	0.398	2.826
Agree (Ref)								
Buying chemotherapy drugs for the patient strains me (Drug Costs)								
Disagree	-0.170	0.665	0.84					
Somewhat agree	0.148	0.592	1.20					
Agree (Ref)								
Paying for laboratory and radiological investigations ordered for the patient strains me (Investigation Costs)								
Disagree	0.067	0.897	1.20					
Somewhat agree	0.016	0.953	1.02					
Agree (Ref)								
Supporting the patient financially has made my financial status worse (General Financial Strain)								
Disagree	0.265	0.695	1.30	0.819	0.259	2.30	0.547	9.412
Somewhat agree	-0.638	**0.021**	0.53	-0.166	0.624	0.85	0.436	1.645
Agree (Ref)								

Disagree= Did not perceive any strain
Somewhat agree= Slightly perceived the strain
Agree= Totally perceived the strain

4.4.7 Association between family caregiver socio-demographic/caregiving characteristics and the role strain experienced by the family caregivers of adult patients suffering from cancer

To determine the relationship between the family caregiver socio-demographic characteristics/associated caregiving characteristics and the role strain, the researcher examined the influence of the following family caregiver socio-demographic characteristics (sex, age, education level, marital status, employment status and monthly income in Kenya shillings) and the caregiving related characteristics (family caregiver co-residency with the patient, family caregiver relationship with the patient, duration of caregiving, hours of caregiving per day and membership to a social support group) on the role strain experienced by the family caregivers.

First bivariate ordinal logistic regression for each of the predictor variables was performed and results revealed that family caregiver age, education level, marital status, employment status, monthly income, co-residency with patient, relationship with patient and hours of caregiving per day significantly influenced the role strain experienced by the family caregivers of adult patients suffering from cancer while sex of the respondent, duration of caregiving and respondent’s membership to a social support group were not significant. Further, the researcher performed multivariate ordinal logistic regression for all the predictor variables that were significant after bivariate ordinal logistic regression as shown in Table 4.11.

The multivariate ordinal logistic regression results established that marital status significantly influenced the role strain experienced by the family caregivers. In this regard, the family caregivers who were married were 51% less likely to experience severe role strain as compared to those who were not married (OR=0.49, 95% CI 0.252-0.960, p=0.038). Likewise, employment status significantly influenced the role strain experienced by the family caregivers. In this case, the respondents who were unemployed were over three times likely to experience severe role strain compared to their counterparts (OR=3.29, 95% CI 1.833-5.894, p=0.001). The period in hours per day spent caring for the patient also significantly influenced the role strain experienced by the family caregivers. In this respect, family caregivers providing care for less than 5 hours per day were 60% less likely to experience severe role strain than those who provided care for more than 5 hours per day (OR 0.40, 95% CI 0.227-0.715, p=0.002).

Among the family caregiver socio-demographic and the associated caregiving characteristics, this study did not establish any significant relationship between the respondent’s age (OR 0.64, 95% CI 0.151-2.670, p=0.536), level of education (OR 1.80, 95% CI 0.821-3.827, p=0.145), monthly income (OR 1.12, 95% CI 0.295-4.246, p=0.869), co-residency with the patient (OR 0.60, 95% CI 0.217-1.659, p=0.325) and the relationship with the patient (OR 0.83, 95% CI 0.421-1.647, p=0.598) with the role strain experienced by family caregivers of adult patients suffering from cancer at KNH cancer treatment outpatient clinic.

Table 4.11: Association between family caregiver socio-demographic/caregiving characteristics and role strain experienced by family caregivers of adult patients suffering from cancer

							95% CI	
Variable	**Beta Estimate**	**Sig.**	**Crude O.R**	**Beta Estimate**	**Sig.**	**Adjusted O.R**	**Lower**	**Upper**
Bivariate Ordinal Logistic Regression				Multivariate Ordinal Logistic Regression				
Level of Role Strain (MCSI); (1=Mild strain, 2= Moderate strain, 3= Severe strain (Ref)								
Sex								
Male (Female;Ref)	0.032	0.893	1.03					
Age								
18-35 years (Young adult)	-1.729	**0.010**	0.18	-0.453	0.536	0.64	0.151	2.670
36-60 years (Middle aged)	-1.218	**0.038**	0.30	-0.188	0.765	0.83	0.242	2.840
Over 61 years (Elderly)Ref)								
Education level								
Primary	0.970	**0.006**	2.60	0.573	0.145	1.80	0.821	3.827
Secondary	0.111	0.751	1.12	-0.123	0.749	0.90	0.416	1.879
Tertiary (Ref)								
Marital status								
Not married	-0.775	**0.010**	0.46	-0.710	**0.038**	0.49	0.252	0.960
Married (Single, Seperated, Widowed)Ref)								
Employment status								
Unemployed	1.415	**0.001**	4.12	1.190	**0.001**	3.29	1.833	5.894
Employed (Full time, Part time, Self-employed)Ref)								
Monthly Income level								
Low Income (<20,000Ksh)	1.345	**0.024**	3.83	0.112	0.869	1.12	0.295	4.246
Moderate Income(>20,000 - 50,000Ksh)	0.222	0.749	1.25	0.116	0.877	1.12	0.257	4.903
High Income(>50,000Ksh)Ref)								
FCG co-residency with the patient								
No (Yes; Ref)	-0.845	**0.041**	0.43	-0.510	0.325	0.60	0.217	1.659
Family caregiver relationship with the patient (Who the patient is to the FCG)								
Parent/Parent In-law	0.356	0.270	1.43	-0.183	0.598	0.83	0.421	1.647
Spouse/Partner	0.880	**0.006**	2.41	0.087	0.818	1.10	0.520	2.289
Son/Daughter	-0.283	0.661	0.80	-0.942	0.167	0.40	0.102	1.484
Friend/Neighbour	-0.658	0.338	0.52	-0.455	0.587	0.63	0.123	3.267
Brother/Sister (Ref)								
Duration of caregiving								
2weeks to 1 year	-0.806	0.398	0.50					
>1 year to 3 years	-0.247	0.798	0.80					
>3 years (Ref)								
Hours of caregiving per day								
< 5hours (>5hours;Ref)	-1.021	**0.001**	0.40	-0.909	**0.002**	0.40	0.227	0.715
Membership to a social support group for FCG of adult patient with cancer								
Yes	-0.487	0.252	0.61					
No (Ref)								

4.5 Patient related factors associated with the role strain experienced by the family caregivers of adult patients suffering from cancer

Patient related factors assessed during the study included patient demographic/disease related characteristics and patient current status related factors which were assessed using a 5 item likerts scale. Further, in examining the hypothesis that “There is no relationship between the patient related factors and the role strain experienced by the family caregivers of adult patients suffering from cancer at KNH cancer treatment clinic” ordinal logistic regression was utilized since the dependent variable (Role strain) had three categories that were ordered as measured using the Modified Caregiver Strain Index (MCSI). The results were presented as follows.

4.5.1 Patient current status related factors contributing to role strain experienced by family caregivers of adult patients suffering from cancer

Patient current status related factors assessed during the study included strain related to patient’s current physical functional status, chronic condition co-morbidity, cancer stage and interpersonal relations as shown in table 4.12.

The results as shown in table 4.12 revealed that almost half (47.1%, n=120) of FCGs slightly perceived strain (those who somewhat agreed) related to the current physical functional status of the patient while over half (52.9%, n=135) of FCGs did not perceive any strain (those who disagreed) related to caring for a patient who had other chronic condition(s) apart from cancer. The study also established that over half (52.5%, n=134) of FCGs totally perceived the strain related to patient’s current treatment modality while over three fifth (62.4%, n=159) of FCGs totally perceived strain related to the patient’s current cancer stage. Further, the study revealed that over half (52.5%, n=134) of FCGs did not perceive any strain related to the current interpersonal relations with the patient.

Table 4.12: Responses on patient current status related factors influencing role strain among family caregivers of adult patients suffering from cancer

	Responses					
	Disagree		Somewhat agree		Agree	
Variable	F	%	F	%	F	%
The current physical functional status of the patient strains me (Physical Functional Status).	92	36.1	120	47.1	43	16.9
The patient suffers from other disease conditions which also strain me (Chronic condition co-morbidities).	135	52.9	51	20.0	69	27.1
The patient current treatment modality strains me (Treatment Modality).	63	24.7	58	22.7	134	52.5
The patient current cancer stage strains me (Cancer Stage).	42	16.5	54	21.2	159	62.4
My current interpersonal relations with the patient strains me (Interpersonal Relations).	134	52.5	41	16.1	80	31.4

Disagree (Strongly disagree + Disagree)= Did not perceive any strain
Somewhat agree= Slightly perceived the strain
Agree (Strongly agree + Agree)= Totally perceived the strain

4.5.2 Qualitative data analysis on patient current status related factors contributing to role strain experienced by family caregivers of adult patients suffering from cancer

The following themes emerged after thematic analysis of the qualitative data that was collected during focus group discussions where participants were asked how their patient argumented the support they provided or what made caring for the patient a hard task.

Theme 1: Altered physical functional status

During focus group discussions, participants indicated that patient general body weakness due to cancer treatment was a major concern among participants as supported by the following quotes:

> "*Currently my patient is weak after starting treatment, undertakes no work, only stays at home*" (**Family caregiver (FCG).1, (Focus group discussion (FGD).1**.
>
> "*Chemotherapy has made her weak, now I cook and wash her clothes*" (**FCG.3, FGD.1**).
>
> "*The first week after chemotherapy session, my patient can not do anything*" (**FCG.12, FGD.2**).
>
> "*After chemotherapy session, the patient is often very weak and I closely stay with the patient for over a week and can not leave her alone*" (**FCG.24, FGD.3**).

On the contrary, there are other participants who indicated that their patients enjoyed a good physical functional status which eased role strain associated with caregiving as supported by the following quotes;

> "*My patient is full of strength and still goes to work and attends well to her basic chores*" (**FCG.13, FGD.2**).
>
> "*My patient is physically fit which makes things abit easy*" (**FCG.23, FGD.3**).

Theme 2: Poor interpersonal relations

Poor interpersonal relations with patients was also a concern identified by participants during the focus group discussions as supported by the following quotes:

> "*My patient wants to be kept company all the time, any time he is left alone he becomes furious with me and everybody else around, caring for him is difficult*" (**FCG.5, FGD.1**).
>
> "*…it is a bit difficult dealing with my sick elder brother since he views me as a junior, I think if he is counseled that can make things easier for me*" (**FCG.9, FGD.2**).
>
> "*My patient sometimes has tempers and handling her is hard*" (**FCG.12, FGD.2**).

On the contrary, there are other participants who indicated that their patients had a positive view of the situation which contributed to warm relations between them and their patients as supported by the following quotes;

> "*My patient is in good spirit, she encourages us like a family to stay strong and when we see her strong, we also stay strong*" (**FCG.8, FGD.1**).
>
> "*My patient is supportive, good hearted and encourages me not to give up on her*" (**FCG.15, FGD.2**).

Theme 3: Caregiving challenges at home

During focus group discussions participants voiced a major concern relating to caregiving challenges that they were experiencing at home as supported by the following quotes:

> "*I wish healthcare workers can advise on how I can support my patient nutrition wise and foods that can boost his blood levels*" (**FCG.7, FGD 1**).
>
> "*My patient is in pain all the time, doesn't feed well, only takes porridge and juice, so far I am confused*" (**FCG.10, FGD 2**).
>
> "*My patient is always emotional and wants to be kept company all the time…..I find it hard"* (**FCG.12, FGD 2**)

> "*After chemotherapy session my patient is unable to eat and vomits a lot. I do not understand what the patient can eat and won't vomit"* (**FCG.14, FGD 2**).
>
> "*After chemotherapy session my patient is often very weak, does not feed and diarrhoea is a problem*" (**FCG.16, FGD 3**).
>
> "*My patient has problem in feeding and I do not know how to support the patient in terms of nutrition*" (**FCG.18, FGD 3**).
>
> "*My patient after chemotherapy is very weak and requires to be assisted with all activities; usually I have no time and energy for other roles as a married woman"* (**FCG.24, FGD 3**)

4.5.3 Association between patient current status related factors and role strain experienced by the family caregivers of adult patients suffering from cancer

To determine the relationship between patient current status related factors and the role strain, the researcher examined the influence of patient current status related factors on the role strain experienced by the family caregivers. First bivariate ordinal logistic regression for each of the predictor variables was performed and the results revealed that perceived strain related to patient's current physical functional status of the patient, chronic condition co-morbidity, treatment modality, patient cancer stage and interpersonal relations significantly influenced the role strain experienced by the family caregivers of adult patients suffering from cancer. Further, the researcher performed multivariate ordinal logistic regression for all the predictor variables that were significant after bivariate ordinal logistic regression as shown in Table 4.13.

The multivariate ordinal logistic regression results established that patient's current functional status significantly influenced the role strain experienced by the family caregivers. In this case, FCGs who did not perceive any strain (those who disagreed) related to patient's current physical functional status were 83% less likely to experience severe role strain compared to those who totally perceived the strain (those who agreed) (OR=0.17, 95% CI 0.072-0.408, p=0.001) while those who slightly perceived the strain (those who somewhat agreed) were 62% less likely to experience severe role strain compared to those who totally perceived the strain (OR=0.38, 95% CI 0.176-0.826, p=0.015).

Further, the study also established that patient's current treatment modality significantly influenced the role strain experienced by the family caregivers. In this respect, FCGs who did not perceive any strain (those who disagreed) related to patient's current treatment modality were 79% less likely to experience severe role strain compared to those who totally perceived the strain (those who agreed) (OR=0.21, 95% CI 0.107-0.425, p=0.001). Likewise, the results also revealed that patient's current stage significantly influenced the role strain experienced by the family caregivers. In regard to this, FCGs who slightly perceived strain (those who somewhat agreed) related to patient's current cancer stage were 61% less likely to experience severe role strain compared to those who totally perceived the strain (OR=0.39, 95% CI 0.200-0.777, p=0.007). Similarly, the results established that the current interpersonal relations with the patient significantly influenced the role strain experienced by the family caregivers. In this respect, FCGs who did not perceive any strain (those who disagreed) related to current interpersonal relations with the patient were 70% less likely to experience severe role strain compared to those who totally perceived the strain (OR=0.30, 95% CI 0.153-0.569, p=0.001).

Among the patient related factors, this study did not establish any significant relationship between the patient's chronic condition co-morbidity (OR 1.20, 95% CI 0.632-2.284, p=0.576) with the role strain experienced by the family caregivers of adult patients suffering from cancer at KNH cancer treatment outpatient clinic.

Table 4.13: Association between patient current status related factors and the family caregiver role strain among adult patients suffering from cancer

			Crude	Beta estimate	Sig.	Adjusted	95% C.I	
Variable	**Beta Estimate**	**Sig.**	**Odds Ratio**			**O.R**	**Lower**	**Upper**
Level of Role Strain (MCSI); (1=Mild strain, 2= Moderate strain, 3= Severe strain (Ref)								
Bivariate Ordinal Logistic Regression				Multivariate Ordinal Logistic Regression				
Patient’s current Physical Functional Status strains me (Physical functional status)								
Disagree	-2.690	**0.001**	0.07	-1.767	**0.001**	0.17	0.072	0.408
Somewhat agree	-1.207	**0.001**	0.30	-0.964	**0.015**	0.38	0.176	0.826
Agree (Ref)								
Patient suffers from other Chronic Condition(s) which strain me (Co-morbidity)								
Disagree	-0.547	**0.052**	0.59	0.184	0.576	1.20	0.632	2.284
Somewhat agree	-1.933	**0.001**	0.15	-0.711	0.092	0.49	0.215	1.124
Agree (Ref)								
Patient’s current Treatment Modality Strains me (Treatment modality)								
Disagree	-2.303	**0.001**	0.10	-1.547	**0.001**	0.21	0.107	0.425
Somewhat agree	-1.724	**0.000**	0.20	-0.645	0.078	0.53	0.256	1.075
Agree (Ref)								
Patient’s current Cancer Stage Strains me (Cancer stage)								
Disagree	-0.914	**0.006**	0.40	-0.717	**0.058**	0.49	0.232	1.026
Somewhat agree	-1.173	**0.001**	0.31	-0.929	**0.007**	0.39	0.200	0.777
Agree (Ref)								
My current Interpersonal Relations with the Patient Strains me (Interpersonal relations)								
Disagree	-1.877	**0.001**	0.20	-1.219	**0.001**	0.30	0.153	0.569
Somewhat agree	-0.665	**0.070**	0.51	-0.574	0.157	0.56	0.254	1.247
Agree (Ref)								

Disagree= Did not perceive any strain
Somewhat agree= Slightly perceived the strain
Agree= Totally perceived the strain

4.5.4 Association between patient demographic/disease related characteristics and the role strain experienced by the family caregivers of adult patients suffering from cancer

To determine the relationship between the patient demographic characteristics/disease related characteristics and the role strain, the researcher examined the influence of the following patient demographic and disease related characteristics (sex of the patient, patient age, patient County of residence, stage of cancer at diagnosis and functional status based on ECOG scale) on the role strain experienced by the family caregivers.

First bivariate ordinal logistic regression for each of the predictor variables was performed and results revealed that patient's county of residence, stage of cancer at diagnosis and functional status based on ECOG scale significantly influenced the role strain experienced by the family caregivers of adult patients with cancer while sex of the patient and age were not significant. Further, the researcher performed multivariate ordinal logistic regression for all the predictor variables that were significant after bivariate ordinal logistic regression as shown in Table 4.14.

The multivariate ordinal logistic regression results established that patient's county of residence significantly influenced the role strain experienced by the family caregivers. In this regard, family caregivers who were caring for patients residing within Nairobi county were 46% less likely to experience severe role strain than those who cared for patients residing in other counties (OR=0.54, 95% CI 0.314-0.937, p=0.028). Equally, stage of cancer significantly influenced the role strain experienced by family caregivers. In this case, family caregivers who were caring for patients with early cancer stage (stage I and II) at diagnosis were 44% less likely to experience severe role strain than those who cared for patients with late cancer stage (stage III and IV) at diagnosis (OR=0.56, 95% CI 0.347-0.911, p=0.019). The study also revealed that patient's functional status as assessed by ECOG scale significantly influenced the role strain experienced by the family caregivers. In this regard, family caregivers who were caring for patients with good functional status (ECOG grades below 2) were 67% less likely to experience severe role strain than those who cared for patients with poor functional status (ECOG grades above 3) at diagnosis (OR=0.33, 95% CI 0.184-0.590, p=0.001).

Among the patient demographic characteristics, this study did not establish any significant relationship between the patient's sex (OR 1.54, 95% CI -0.044-0.912, p=0.075) and age (OR 2.50, 95% CI -0.861-2.664, p=0.316) with the role strain experienced by the family caregivers of adult patients suffering from cancer at KNH cancer treatment outpatient clinic.

Table 4.14: Association between patient socio-demographic/disease related characteristics and role strain experienced by family caregivers of adult patients suffering from cancer

					Sig.	**Adjusted O.R**	**95% C.I**	
Variable	**Beta Estimate**	**Sig.**	**Crude O.R**	**Beta Estimate**			**Lower**	**Upper**
Level of Role Strain (MCSI); (1=Mild strain, 2= Moderate strain, 3= Severe strain (Ref)								
Bivariate Ordinal Logistic Regression				Multivariate Ordinal Logistic Regression				
Sex								
Male (Female; Ref)	0.434	0.075	1.54					
Age								
18-35 years (Young Adult)	0.901	0.316	2.50					
36-60 years (Middle Aged)	-0.272	0.295	0.80					
Over 61 years (Elderly; Ref)								
Patient county of residence								
Nairobi	-0.865	**0.002**	0.42	-0.612	**0.028**	0.54	0.314	0.937
Other County (Ref)								
Cancer stage								
Early Cancer Stage (Stage I & II)	-0.824	**0.001**	0.44	-0.575	**0.019**	0.56	0.347	0.911
Late Cancer Stage (III & IV; Ref)								
Functional status based on ECOG scale								
Good Functional Status (ECOG Grades <2)	-1.345	**0.001**	0.30	-1.110	**0.001**	0.33	0.184	0.590
Poor Functional Status (ECOG Grades >3; Ref)								

4.6 Institutional related factors associated with role strain experienced by family caregivers of adult patients suffering from cancer

Among the institutional related factors assessed during the study included strain related to physical navigation of healthcare system, unreasonable turnaround time, non-involvement in the plan of care, knowledge on treatment side effect management, shortage of chemotherapy drugs, inefficient radiotherapy services, Limited guidance on caregiving roles, caregiving challenges at home, geographical disparity and cost of cancer treatment as illustrated in table 4.15. The results revealed that majority (93.7%, n=239) of respondents totally perceived strain related to cost of cancer treatment services offered at the hospital while 80.4% (n=205) of the respondents totally perceived strain related to buying drugs not available at the hospital. Another institutional factor assessed was strain related to inefficient radiotherapy services. In this respect, almost three quarter (73.7%, n=188) of the respondents did not perceive any strain related to inefficient radiotherapy services while 64.3% (n=164) of the respondents totally perceived physical strain when getting around cancer treatment centre at Kenyatta National hospital.

Strain related to lack of guidance on caregiving roles by the healthcare workers was also another institutional factor assessed. In this case, majority (70.6%, n=180) of the respondents slightly perceived strain related to limited guidance on caregiving roles. Further, the study established that over three quarter (76.9%, n=196) of respondents totally perceived strain related to caregiving challenges at home when caring for the patient. In relation to strain related to cancer information deficit, majority (72.5%, n=185) of respondents totally perceived strain related to limited information on cancer as a disease, its treatment and progression which hampered their caregiving while over half (57.6%, n=147) of respondents slightly perceived strain related to understanding what treatment side effects to monitor and their management at home.

The study also assessed strain related to traversing long geographical distance in search of cancer treatment services where over two third (69.5%, n=177) of respondents totally perceived strain related to traversing long distance in search of cancer treatment services for their patients while over two thirds (67.1%, n=171) of respondents slightly perceived strain related to getting their patient assessed by a specialized healthcare professional like oncologist and over three fifth (62.0%, n=158) of respondents did not perceive any strain when caring for the patient due to non-involvement in treatment decisions and care plan by the healthcare professionals.

Table 4.15: Responses on the institution related factors influencing role strain among family caregivers of adult patients suffering from cancer

Variables	Responses					
	Disagree		Somewhat agree		Agree	
	F	%	F	%	F	%
It strains me physically to get around Cancer Treatment Centre. (Physical strain navigating the system).	24	9.4	67	26.3	164	64.3
It strains to wait long before being attended to. (Unreasonable Turnaround time).	66	25.9	73	28.6	116	45.5
Non-involvement in treatment decisions by healthcare professionals strains me. (Non-involvement in the unit of care).	158	62.0	81	31.8	16	6.2
It strains to schedule timely clinic appointments. (Timely Clinic appointments).	167	65.5	62	24.3	26	10.2
I strain in understanding communication by health care professionals. (Health personnel Communication skills).	142	55.6	100	39.2	13	5.2
I strain in understanding what treatment side effects to monitor at home. (Knowledge on treatment side effect management).	13	5.1	147	57.6	95	37.3
I lack information on cancer as a disease, treatment and its progression which strains me in caring for this patient. (Cancer information deficit).	8	3.2	62	24.3	185	72.5
Shortage of cancer drugs at this hospital strains me and the patient in buying the drugs. (Shortage of cancer drugs).	20	7.8	30	11.8	205	80.4
Inefficient radiotherapy services strains me and the patient. (Efficiency of radiotherapy services).	188	73.7	42	16.5	25	9.8
Lack of assessment of my general health and capacity in caring for patient by healthcare workers strains me (Family caregiver health assessment).	15	5.9	192	75.3	48	18.8
I experience strain due to limited guidance on caregiving roles by healthcare workers. (Guidance on caregiving roles).	18	7.1	180	70.6	57	22.3
I experience some caregiving challenges or concerns at home which strain me. (Caregiving challenges at home).	24	9.4	35	13.7	196	76.9
I experience strain due to lack of a home visit by a nurse or doctor to enhance my skills in caregiving. (Home visit services).	26	10.2	191	74.9	38	14.9
I experience strain due to travelling long distance in search for cancer treatment services. (Geographical distance).	44	17.2	34	13.3	177	69.5
I experience strain in getting my patient assessed by a specialized healthcare professional like Oncologist. (Ease of assessing specialized health personnel services).	27	10.5	171	67.1	57	22.4
Cost of cancer treatment services offered at this hospital strains me and the patient. (Treatment cost).	1	0.4	15	5.9	239	93.7

Disagree (Strongly disagree + Disagree)= Did not perceive any strain
Somewhat agree= Slightly perceived the strain
Agree (Strongly agree + Agree)= Totally perceived the strain

4.6.1 Qualitative data analysis on institutional related factors contributing to role strain experienced by family caregivers of adult patients suffering from cancer

The following themes emerged after thematic analysis of the qualitative data that was collected during focus group discussions and key informant interviews.

Theme1: Physical strain

During focus group discussions participants voiced that physical strain was a major concern when getting around the hospital together with their patients as supported by the following quotes:

> "*Here at KNH (*Kenyatta National Hospital*) I strain with my patient moving from one point of service to another since service points at CTC (Cancer Treatment Centre) are not in one place*" (**Family Caregiver** (**FCG).3, Focus Group Discussion** (**FGD 1**)).
>
> "*You are at radiotherapy department, then you are ordered to go at Linac and check if the patient's file is there, you strain with your patient to Linac which is very far, only to go there and get turned back again to radiotherapy department*" (**FCG.14, FGD 2**).
>
> "*The distance from Linac to CTC is very far and straining*" (**FCG.20, FGD 3**).

Further, during key informant interviews the respondents indicated that indeed patients and their family givers experienced physical strain when assessing cancer treatment services at Kenyatta National Hospital (KNH) as supported by the following quotes:

> "*Our services are not under one roof, navigating the system to get the services is a strain itself to patients and their family caregivers. Our system navigation programme has solved the directional need but physical strain has remained*" (**Key Informant (KI).1**).
>
> "*Our CTC service points are quite scattered and KNH is large, for one to find their way from one service point to another is really stressful, though system*

> *navigation programme has assisted, there is still a lot of walking to be done from one service point to another*" (**KI.2**).

> "*Patients and their family caregivers make a lot movement; to and fro across the scattered cancer service points*" (**KI.6**).

Theme 2: Costly cancer treatment services

During focus group discussions high cost of cancer treatment services emerged as a major concern among participants as supported by the following quotes:

> "*There are problems with finances, sometimes NHIF pays for treatment, other times NHIF credit has been exhausted*" (**FCG.2, FGD 1**).

> "*The biggest problem is financing the cost of cancer treatment, it is too expensive. Cancer treatment should be made affordable or free like tuberculosis and HIV treatment*" (**FCG.14. FGD 2**).

> "*Cancer treatment is costly*" (**FCG.20. FGD 3**).

Indeed, during the key informant interviews it emerged that cancer treatment services are unaffordable, hence a huge financial strain on patients and their family caregivers, sometimes to the point of discontinuing treatment as supported by the following quotes:

> "*Affordability of cancer treatment and care is a major strain because cancer treatment and care is expensive, the investigations that are required for this patient to start treatment are very expensive and the clientele we get here at KNH are usually from low and middle income levels*" (**KI.2**).

> "*For patients and their family caregivers who are to buy drugs privately, it is expensive and others discontinue treatment waiting for the drug to be stocked again at KNH for them to continue with treatment…patients who have exhausted their NHIF, default treatment and wait untill NHIF matures again for them to continue with treatment*" (**KI.3**).

> "*Financial resources are limited and most of the patients who come to us have got some economic issues considering that cancer treatment is costly and is a process that takes quite some time…though there are some instances we offer financial assistance guided by need assessment*" (**KI.5**).

Theme 3: Drug shortage

During focus group discussions drug stock outs at the hospital emerged as a major concern among the participants as supported by the following quotes:

> "*Buying cancer drugs is expensive and some drugs are not available here (KNH)*" (**FCG.5, FGD 1**).

> "*Another day, my patient was in great pain and the prescribed pain killer was not available here at KNH, we had to buy it from a private pharmacy*" (**FCG.8, FGD 1**).

> "*Sometimes the patient is prescribed chemotherapy drugs and some are not available and you are required to buy them, yet you were not prepared psychologically that these drugs are not available so that when bringing patient to the clinic you come prepared to buy them*" (**FCG.15, FGD 2**).

In addition, during key informant interviews respondents were also in agreement that there were some instances that drug stock outs were experienced at the hospital as supported by the following quotes:

> "*We have drug stock outs, either some drugs in a treatment regimen are out of stock, this really strains the patients and their family caregivers especially when they are using NHIF and the drug covered for is not available…sometimes there are stock outs of laboratory reagents, yet laboratory results are required to make some treatment decisions*" (**KI.1**).

> "*Sometimes we have drug stock outs…it's a challenge when we have drug stock outs or some investigations not being done due laboratory reagents stock out, yet patients and their family caregivers come here from far expecting the services*" (**KI.2**).

> "*…at least nowadays most of the drugs that are commonly used are available, but sometimes we get stock outs*" (**KI.3**).

> "*Most of the cases we encounter is that a patient got prescribed some drugs of which NHIF could not cover; they have no cash and also the drugs are not available within KNH, so the patient has to buy the drugs which is expensive*" (**KI.5**).

Theme 4: Inefficient radiotherapy services

During focus group discussions participants voiced concerns over radiotherapy machines breakdown which affected cancer services turnaround time as supported by the following quotes:

> "*Currently branchytherapy services at KNH are not available; it is expensive to access these services at the very few private health facilities where they are available*" (**FCG.3, FGD 1**).

> "*Here at KNH, sometimes radiotherapy machines stalls the whole day and this is where the whole country comes for these services, and you are left wondering where are you supposed to take your patient*" (**FCG.11, FGD 2**).

In addition, during the key informant interviews it emerged that there was a mismatch between the available radiotherapy machines and the increased work load, also there were some instances that radiotherapy machines stalled down as supported by the following quotes:

> "*Currently we have only three radiotherapy machines which have been here for many years serving patients from the entire country…there are also some instances where radiotherapy machines break down and turnaround time for the services is prolonged, hence causing treatment delays*" (**KI.1**).

> "*There are a times radiotherapy machines breaks down which causes treatment delays*" (**KI.4**).

> "*Sometimes radiotherapy machines breaks down which causes treatment delay considering KNH is the only public hospital offering radiotherapy*

> *services across the country…most patients discontinue treatment until the stalled down radiotherapy machines are fixed*" (**KI.5**).
>
> "*Sometimes radiotherapy machines breaks down…there are also long queues because we have fewer machines verses the many patients requiring the services, hence they wait a little bit longer*" (**KI.6**).

Theme 5: Geographical disparity

During focus group discussions participants also expressed concerns over the long geographical distance they traversed in search of cancer treatment services for their patients as supported by the following quotes:

> "*I brought my patient from far away (*Lamu County*) for services here in Nairobi, this is not fair…at the peripheries citizens are suffering due to lack of cancer services at the counties*" (**FCG.3, FGD 1**).
>
> "*We were referred from Homabay county after my patient was operated to remove a swelling and complications ensued; by the time we came here it was too late*" (**FCG.11, FGD 2**).
>
> "*Coming all the way from Kakamega county to here (*KNH*) just for chemotherapy only, yet my patient is not in a good condition*" (**FCG.15, FGD 2**).

In addition, during the key informant interviews the respondents were in agreement that the family caregivers and their patients traversed long geographical distances to access cancer treatment services owing to the fact that there are no comprehensive cancer treatment services in their geographical regions. It also emerged that the patients and their family caregivers coming from other counties for cancer treatment services in Nairobi faced a huge problem of accommodation since there are no accommodation facilities within KNH as supported by the following quotes:

> "*Cancer treatment services are not available in all the regions across the country making patients and their family caregivers to travel far and wide in*

> *search of these services hence they strain because they can not access these services in their geographical regions*" (**KI.1**).

> "*Our major challenge is that the kind of services our patients require are not available in their counties…I wish the counties could do more of cancer care, then even the family caregivers and their patients would have shorter distances to travel to access the services*" (**KI.2**).

> "*Accommodation is a big issue, there are patients who are coming daily and from far…so they are not able to go back home, they opt to spend at casualty department for those days*" (**KI.3**).

> "*No accommodation facilities for patients and their family caregivers despite the fact that majority are coming from far, a lot is spent on accommodation costs which makes a number of patients not to comply with clinic attendance*" (**KI.6**).

Theme 6: Communication challenges

Communication problems with healthcare workers were also a major concern identified by participants during focus group discussions as supported by the following quotes:

> "*Not all healthcare workers are good, there are those who are rude and this gets me stressed*" (**FCG.1, FGD 1**).

> "*Majority of healthcare workers are very good but there are a few who shout at patients till we all get confused*" (**FCG.6, FGD 1**).

> "*Majority are good, but there are a few who are not…when healthcare workers are rude to patients, this may increase patient's depression and all together stop attending the clinic*" (**FCG.14, FGD 2**).

> "*You go to a doctor X who blames you for bringing the patient for treatment when it is too late, there is even a certain healthcare personnel who instructed that my sick mother should first draft a will*" (**FCG.21, FGD 3**).

Indeed, during key informant interviews communication challenges were also identified as a concern as supported by the following quotes:

> "*There are communication challenges with patients who have cancer that has compromised communication especially those with cancer of esophagus and larynx who have been put tracheostomy and it becomes hard for them to communicate, especially when we do not have somebody around who is specialized in sign language*" (**KI.1**).

> "*Sometimes there is language barrier when communicating with patients and their family caregivers*" (**KI.2**).

> "*…we encounter sometimes language barrier but we utilize our staffs who are conversant with the language of the patient or that of family caregiver*" (**KI.4**).

Theme 7: Treatment process challenges

Treatment process challenges during focus group discussions emerged as a concern among participants as supported by the following quotes:

> "*…treatment process is long and cancer progresses while the patient is still waiting to start treatment…I brought my patient in stage II, then cancer progressed to stage III while waiting a decision to start her on chemotherapy*" (**FCG.16, FGD 3**).

> "*Another day I brought my sick father to the clinic and was just told that he was going to be molded a head hat which I did not understand and wondered if it was like that of a motorbike helmet…a number of things we do not understand, we are usually in the dark, even you can not explain to another person what sought of treatment your patient is getting*" (**FCG.7, FGD 1**).

> "*I wish I am in a position to know all what is being done to my patient and all that is required every time during treatment*" (**FCG.18, FGD 3**).

However, during key informant interviews it was established that patients and their family caregivers are empowered with reading materials to enhance their understanding about cancer and its treatment though these reading materials are not available in the local dialects as supported by the following quote:

> "*During the first patient encounter, patients and their family caregivers are empowered with reading materials…while not all the patients and family caregivers are able to read and understand about cancer and it's treatment…still the literature materials available have not been transrated to local dialects to enhance understanding among the patients and their family caregivers*" (**KI.1**).

Theme 8: Payment system invoice challenges

Payment system invoice challenges during focus group discussions emerged as a concern among participants. Specifically, NHIF (National Hospital Insurance Fund) was singled out as a major challenge especially in generating timely invoices which in turn affected turnaround time for services delivery as supported by the following quotes from some of the participants:

> "*I come here and wait for many hours before my patient gets treated… my patient is still waiting for NHIF to approve so that he can continue with his chemotherapy session, there is a system problem in generating the invoices*" (**FCG.1, FGD 1**).

> "*There is poor NHIF system network, like today since we came here, nothing has been processed, last week I applied for a radiological scan for the patient*

> *as ordered and up to date it has not been processed, yet it is required for patient to continue with treatment*" (**FCG.11, FGD 2**).
>
> "*…sometimes the system fails when paying for treatment, there is a time my patient had chemotherapy session deferred since the invoice was not processed in good time*" (**FCG.23, FGD 3**).

Theme 9: Lack of integration in the unit of care

During key informant interviews, lack of FCGs integration in the plan of care and guidance in caregiving by healthcare workers emerged as a concern. Specifically, respondents voiced that there was no policy in place to guide integration of family caregivers in the unit of care at Kenyatta National Hospital as supported by the following quotes:

> "*…since there isn't a policy in place, we are not able to do as much and as a such there is a lot of ground to be covered when it comes to the family caregivers…we have not involved the family caregivers to know what strain they go through or where they need help*" (**KI.2**).
>
> "*We do not have social support groups for family caregivers but we have support groups for patients…No skills training for family caregivers or home visits to address their needs when caring for their patients*" (**KI.3**).
>
> "*We engage the family caregivers but there is no policy in place for integrating them formally in the unit of care*" (**KI.4**).

4.6.2 Association between institution related factors and role strain experienced by the family caregivers of adult patients suffering from cancer

To determine the relationship between the institutional related factors and the role strain, the researcher examined the influence of institution related factors on the role strain experienced by the family caregivers. First bivariate ordinal logistic regression for each of the predictor variables was performed and the results revealed that perceived strain related to physical strain when navigating the system, shortage of cancer drugs, inefficient radiotherapy services, caregiving challenges and traversing long geographical distance in search of cancer treatment services significantly influenced the role strain experienced by the family caregivers of adult patients with cancer while unreasonable turnaround time, non-involvement in the unit of care, timely clinic appointment, communication with healthcare workers, monitoring treatment side effects at home, limited information on cancer as a disease, lack of general health assessment and caregiving capacity by healthcare workers, guidance on caregiving roles, enhancing caregiving skills through home visits by healthcare workers, ease of accessing specialized healthcare personnel and treatment costs were not significant.

Further, the researcher performed multivariate ordinal logistic regression for all the predictor variables that were significant after bivariate ordinal logistic regression as shown in table 4.16. The multivariate ordinal logistic regression study results established that physical strain when navigating the system significantly influenced the role strain experienced by the family caregivers. In this regard, the FCGs who did not perceive any strain (those who disagreed) related to physical strain when navigating the system were 61% less likely to experience severe strain (OR=0.39, 95% CI 0.168-0.928, p=0.033) compared to those who totally perceived the strain (those who agreed). The results also established that strain related to shortage of cancer drugs at the hospital significantly influenced the role strain experienced by the family caregivers. In this regard, the FCGs who did not perceive any strain (those who disagreed) related to shortage of cancer drugs at the hospital were 70% less likely to experience severe strain (OR=0.30, 95% CI 0.108-0.711, p=0.005) compared to those who totally perceived the strain (those who agreed).

Further, the results revealed that the strain related to inefficient radiotherapy services due to breakdown of radiotherapy machines or lack of radiotherapy services significantly influenced the role strain experienced by the family caregivers. In this case, the FCGs who did not perceive any strain related to inefficient radiotherapy services were 61% less likely to experience severe strain (OR=0.39, 95% CI 0.171-

0.902, p=0.028) while those who slightly perceived the strain were 68% less likely to experience severe role strain (OR=0.32, 95% CI 0.119-0.838, p=0.021) compared to those who totally perceived the strain. Strain related to caregiving challenges at home also significantly influenced the role strain experienced by the family caregivers. In this respect, FCGs who did not perceive any strain related to caregiving challenges at home were 60% less likely to experience severe strain (OR=0.40, 95% CI 0.174-0.926, p=0.032) compared to those who totally perceived the strain.

In addition, the results also revealed that the strain related to traversing long geographical distance in search of cancer treatment services significantly influenced the role strain experienced by the family caregivers. In this case, the FCGs who slightly perceived strain related to traversing long geographical distance were 62% less likely to experience severe role strain (OR=0.38, 95% CI 0.183-0.775, p=0.008) compared to those who totally perceived the strain.

Table 4.16: Association between Institution related factors and the family caregiver role strain among adult patients suffering from cancer

Variable		**Beta Estimate**	**Sig.**	**Crude Odds Ratio**	**Beta Estimate**	**Sig.**	**Adjusted O.R**	**95% C.I**	
								Lower	**Upper**
Level of Role Strain (MCSI); (1=Mild strain, 2= Moderate strain, 3= Severe strain (Ref)									
Bivariate Ordinal Logistic Regression					Multivariate Ordinal Logistic Regression				
It strains me and my patient to get around Cancer Treatment Centre. (Physical strain)									
Disagree		-1.050	**0.012**	0.35	-0.929	**0.033**	0.39	0.168	0.928
*S.A	(Agree (Ref)	-0.178	0.509	0.84	-0.055	0.844	0.95	0.547	1.637
It strains to wait long before being attended to. (Unreasonable Turnaround time)									
Disagree		-0.086	0.765	0.92					
*S.A	(Agree (Ref)	0.122	0.661	1.13					
Non-involvement in treatment decisions by healthcare professionals strains me.(Non-involvement in unit of care)									
Disagree		-0.008	0.987	1.00					
*S.A	(Agree (Ref)	-0.101	0.843	0.90					
It strains to schedule timely clinic appointments. (Timely Clinic appointments)									
Disagree		0.794	0.071	2.2 0					
*S.A	(Agree (Ref)	-0.059	0.898	0.94					
I strain in understanding communication by healthcare professionals. (Communication with healthcare workers)									
Disagree		0.700	0.198	2.01					
*S.A	(Agree (Ref)	0.699	0.206	2.01					
I strain in understanding what treatment side effects to monitor at home. (Monitoring treatment side-effects)									
Disagree		-0.161	0.769	0.90					
*S.A	(Agree (Ref)	-0.094	0.702	0.91					
I lack information on cancer as a disease, treatment and its progression which strains me in caring for this patient									
Disagree		-0.706	0.297	0.50					
*S.A	(Agree (Ref)	-0.271	0.321	0.80					

Shortage of Cancer drugs at this hospital strains me and the patient in buying the drugs (Drug shortage)								
Disagree	-1.400	**0.002**	0.25	-1.282	**0.008**	0.30	0.108	0.711
*S.A (Agree (Ref)	0.073	0.840	1.10	0.050	0.894	1.10	0.504	2.192
Breakdown of radiotherapy machines and lack of radiotherapy services Strains me and the patient (Inefficient Radiotherapy Services)								
Disagree	-1.085	**0.009**	0.34	-0.935	**0.028**	0.39	0.171	0.902
*S.A (Agree (Ref)	-1.226	**0.012**	0.30	-1.151	**0.021**	0.32	0.119	0.838
Lack of assessment of my general health and capacity in caring for patient by healthcare workers strains me								
Disagree	-0.037	0.946	1.00					
*S.A (Agree (Ref)	0.472	0.118	1.60					
I experience strain due to lack of healthcare workers guidance on caregiving roles (Guidance on caregiving roles)								
Disagree	-0.448	0.377	0.64					
*S.A (Agree (Ref)	0.444	0.118	1.60					
I experience Caregiving Challenges at Home which strain me (Caregiving challenges)								
Disagree	-0.796	**0.051**	0.45	-0.914	**0.032**	0.40	0.174	0.926
*S.A (Agree (Ref)	-0.109	0.750	0.90	-0.261	0.458	0.80	0.387	1.536
I experience strain due to lack of a home visit by a nurse or doctor to enhance my skills in caregiving								
Disagree	-0.746	0.117	0.50					
*S.A (Agree (Ref)	-0.280	0.399	0.81					
I experience strain due to travelling long distance in search for cancer treatment services for my patient.(Long geographical distance)								
Disagree	-0.705	**0.026**	0.50	-0.626	**0.058**	0.53	0.280	1.021
*S.A (Agree (Ref)	-1.030	**0.004**	0.41	-0.976	**0.008**	0.38	0.183	0.775
I experience strain in getting my patient assessed by a specialized healthcare professional like Oncologist								
Disagree	-0.465	0.286	0.63					
*S.A (Agree (Ref)	0.090	0.751	1.10					
Cost of cancer treatment services offered at this hospital strains me and the patient. (Cancer treatment cost)								
Disagree	-0.084	0.964	0.92					
*S.A (Agree (Ref)	0.215	0.664	1.24					

Disagree= Did not perceive any strain; *S.A (Somewhat agree)= Slightly perceived the strain;
Agree= Totally perceived the strain

CHAPTER FIVE

DISCUSSION, CONCLUSSION AND RECOMMENDATION

5.1 Introduction

The study results have been discussed based on the study objectives. Comparison of the study results with other study findings has also been made. In addition, conclusion and recommendations have been highlighted based on the study results.

5.2 Level of role strain experienced by family caregivers of adult patients suffering from cancer at KNH cancer treatment clinic

This current study findings revealed that all family caregivers experienced some level of role strain where mild strain (n=66; 25.9%) and severe strain (n=76; 29.8%) were experienced in almost equal proportions while over two fifth (n=113; 44.3%) of the respondents experienced moderate strain as assessed using the MCSI tool.

These findings are consistent with another study conducted by Yakubu and Schutte (2018) in South Africa which established that family caregivers experienced moderate to high strain due to caregiving. Another study conducted by Nortey *et al*. (2017) in Ghana established that 78% of FCGs experienced a high level of caregiver strain. However, a study conducted by Dhandapani *et al*. (2015) in India established that majority (64%) of family caregivers experienced mild role strain and only 5% had severe role strain. This could be attributed to many roles that FCGs take up in caring for adult patients with cancer and often offer such care with very little preparation and support or none, thus are vulnerable to role strain. Likewise, it is likely that there are many factors such as family caregiver related factors, patient related factors and institutional factors that could be influencing the role strain experienced by FCGs due to caregiving. Indeed, it was observed by a study conducted by Nipp *et al*. (2016) in the U.S that FCGs assist patients with personal care, finances, transportation, emotional support and symptom management; often FCGs offer such care to patients with very little preparation and support, thus are vulnerable to role strain.

5.3 Family caregiver related factors contributing to the role strain experienced by family caregivers of adult patients suffering from cancer at KNH cancer treatment clinic

This study has established that there are a number of family caregiver related factors contributing to the role strain that FCGs experience when caring for adult patients suffering from cancer. FCGs are psycho-socially and financially strained. There are also family caregiver social-demographic characteristics influencing the role strain. These family caregiver related factors have been discussed as follows.

5.3.1 Socio-demographic/caregiving related characteristics contributing to the role strain experienced by the FCGs of adult patients suffering from cancer at KNH cancer treatment clinic

This current study has established that marital status, employment status and period of hours spent caring for the patient is statistically associated with the role strain experienced by the FCGs of adult patients suffering from cancer. In this regard, this study findings have revealed that being married (OR=0.49, 95% CI 0.252-0.960, p=0.038) was associated with less likelihood of experiencing severe strain while being unemployed (OR=3.29, 95% CI 1.833-5.894, p=0.001) was associated with more likelihood of experiencing severe strain. These study findings are consistent with another study which revealed that being single contributed to high caregiving strain (Ge & Mordiffi, 2017). Similarly, another study in the U.S established that being unemployed contributed to increased strain (Longacre *et al.*, 2017). However, there are other studies (Ge & Mordiffi, 2017); Hsu *et al.*, 2014) which have established that being employed also contributed to high caregiving strain. The findings of this current study could likely be because family caregivers who are married have access to stronger and wider social support systems. Likewise, those that are employed are financially empowered and also have access to extra social support systems at work place.

This study also established that provision of care for less than 5 hours per day (OR 0.40, 95% CI 0.227-0.715, p=0.002) was associated with less likelihood of expereincing severe strain compared to FCGs who provided care for more than 5 hours per day. This study finding is in tandem with other studies (Metzelthin *et al*., 2017; Zubaidi *et al*., 2020) which have established that more caregiving hours are associated with high caregiving strain but another study by Semere *et al*. (2021) in US established that there was no association. This study finding could be attributed to role-conflict with other responsibilities and lack of extra time for social and economic ventures which could cushion against role strain.

5.3.2 Family caregiver psycho-social related factors contributing to the role strain experienced by the family caregivers of adult patients suffering from cancer at KNH cancer treatment clinic

Quantitatively, this study has established that perception of strain related to social isolation, disturbed sleep cycle and lack of social support was statistically associated with the role strain experienced by the FCGs of adult patients suffering from cancer. In this regard, this study established that not perceiving social isolation as a strain (OR=0.20, 95% CI 0.075-0.541, p=0.001) was less associated with severe strain. Qualitatively, this study based on focus group discussions that were conducted revealed that respondents felt socially isolated while taking care of their patients; they had no or little time for social activities and also felt socially isolated by friends and social groups. This study finding is consistent with another study conducted in Denmark which established that limited social time with friends and family contributed to high psychological distress (Lund *et al*., 2014). Similarly, another study conducted by Arian *et al*. (2017) in Iran established that FCGs experienced disrupted social life and family-role conflict which greatly predisposed them to psychological distress.

In addition, another study conducted by Mthembu *et al*. (2016) in South Africa established that family caregivers had no time to rest and abandoned their social life in order to optimally take care of the patient. This study finding is likely because being socially isolated can lead to being disconnected from the social support systems which could cushion against the role strain.

This study also revealed that FCGs who did not perceive disturbed sleep cycle as a strain (OR=0.30, 95% CI 0.141-0.641, p=0.002) or slightly perceived the strain

(OR=0.54, 95% CI 0.299-0.982, p=0.044) were less associated with severe strain. Qualitatively, this study also based on focus group discussions revealed that respondents experienced sleep disturbance while taking care of their patients. This finding is supported by another study conducted in Jordan which established that caregiving strain was associated with poor quality of sleep among FCGs of adult patients with cancer (Al-Daken &Ahmad, 2018). There are other studies which have revealed that caregiving contributes to poor quality of sleep among FCGs of adult patients suffering from cancer (Lkhoyaali *et al*., (2015); Kulkarni *et al*., (2014)). This study finding is likely since majority of patients with cancer receive chemotherapy and radiotherapy as an outpatient service and afterwards return back home where FCGs continue monitoring the patient around the clock thus have little time to rest and as a result their sleep cycle is altered.

This current study also revealed that not perceiving lack of social support as a strain (OR=0.13, 95% CI 0.051-0.305, p=0.001) or slightly perceiving the strain (OR=0.15, 95% CI 0.061-0.391, p=0.001) was less associated with severe strain. In addition, during focus group discussions; respondents were in agreement that they lacked social support from significant others. They also experienced job challenges or job loss related to unsupportive employers.

This study finding is in line with another study in Nigeria which established that social support (b=-0.137, p=0.001) significantly influenced caregiving strain (Gabriel *et al*., 2019). Similarly, another study in India established that low perceived social support was associated with high caregiving strain (Maheshwari & Kaur, 2016). This study finding is likely since social support provides extra avenues for assistance and social support networks which could cushion against role strain.

5.3.3 Financial related factors contributing to the role strain experienced by the family caregivers of adult patients suffering from cancer at KNH cancer treatment clinic

In both qualitative and quantitative data, this current study established that transportation costs contribute immensely to the financial strain that FCGs experience. Quantitatively, this study established that there is a significant statistical association between transportation costs related to patient clinic attendance and the role strain experienced by family caregivers. In this case, lack of perception of transportation costs as a strain (OR=0.32, 95% CI 0.121-0.816, p=0.017) was associated with less severe strain. In Addition, based on focus group discussions; transportation costs during patient clinic attendance emerged as a major concern among the respondents. The other issues that emerged which financially strained respondents included accommodation costs incurred during patient clinic attendance and costs related to buying of chemotherapy drugs.

This finding is consistent with another study in Iran which established that FCGs experienced financial strain related to transportation costs (Arian *et al*., 2017). Another study in Ghana established that about 87% of FCGs experienced increased financial strain related to caregiving while 62% of FCGs reported that their finances had gotten worse (Nortey *et al*., 2017). This study finding is likely because FCGs and their patients face increased transportation costs as they transverse wide geographical distance in search of cancer treatment services which are not available in their regions.

5.4 Patient related factors contributing to the role strain experienced by family caregivers of adult patients suffering from cancer at KNH cancer treatment clinic

This current study has established that there is a significant statistical association between patient's county of residence and the role strain experienced by the family caregivers. In this regard, caring for a patient residing within Nairobi County was associated with less severe strain compared to taking care of a patient residing in other counties (OR=0.54, 95% CI 0.314-0.937, p=0.028). This finding is likely because many FCGs and their patients travel from other counties to Nairobi County which is the only county in the entire country offering comprehensive cancer treatment services; hence family caregivers and their patients face a number of challenges including costly transportation and accommodation costs which heighten caregiving strain. This is in line with a study conducted by Makau-Barasa *et al*. (2018) in Kenya which established that there is lack of decentralization of comprehensive cancer care services to the counties thus patients and their FCGs traverse long geographical distances in order to access these services.

This current study also established that there is a significant statistical association between the stage of cancer as a patient characteristic and the role strain experienced by the family caregivers. In this case, caring for patients with early cancer stage (stage I and II) at diagnosis was less associated with severe strain compared to caring for patients with late cancer stage (stage III and IV) at diagnosis (OR=0.56, 95% CI 0.347-0.911, p=0.019). Likewise, slightly perceiving patient's current cancer stage as a strain (OR=0.39, 95% CI 0.200-0.777, p=0.007) was also statistically associated with less severe strain compared to those who totally perceived the strain. These study findings could probably be explained that patients with late cancer stage (stage III and IV) are likely to have deteriorated health due to advanced disease, are also likely to require more assistance with activities of daily living especially if cancer has altered their functional status. Family caregivers caring for such patients are prone to increased caregiving strain. These findings are consistent with a study conducted by Priya *et al*. (2021) in India which established that late cancer stage was associated with higher caregiving strain. On the contrary, a study by Borges *et al*. (2017) in Brazil found out that stage of cancer was not associated with caregiving strain.

This current study also established that there is a significant statistical association between the patient's functional status as assessed by ECOG-PS scale and the role strain experienced by the family caregivers. In this regard, caring for a patient with good functional status (ECOG-PS grades below 2) was associated with less severe strain compared to caring for a patient with poor functional status (ECOG grades above 3) (OR=0.33, 95% CI 0.184-0.590, p=0.001). Similarly, not perceiving patient's current physical functional status as a strain strain (OR=0.17, 95% CI 0.072-0.408, p=0.001) or slightly perceiving the strain (OR=0.38, 95% CI 0.176-0.826, p=0.015) was associated with less severe strain compared to those who totally perceived the strain. In addition, based on focus group discussions; it emerged that altered patient physical functional status was a factor that contributed to role strain experienced by FCGs during caregiving. This finding is likely because patients with compromised physical functional status are likely to require more assistance with ADLs and more hours of caregiving; as a result FCGs caring for such patients are prone to increased role strain. This finding is in line with a study conducted by Wood *et al*. (2019) in France, Germany and Italy which established that poor patient functional status as assessed by ECOG-PS was associated with higher caregiving strain.

This current study also established that there is a significant statistical association between perceived strain related to interpersonal relations and the role strain experienced by the FCGs. In this case, not perceiving any strain related to the current interpersonal relations with the patient was associated with less severe strain (OR=0.30, 95% CI 0.153-0.569, p=0.001) compared to those who totally perceived the strain. In addition, during focus group discussions; it emerged that there were poor interpersonal relations between FCGs and their patients.

This finding is likely because strained or poor interpersonal relation with the patient exerts extra psychological strain on the family caregivers. Patients are likely also not to comply with FCGs instructions thereby making caregiving a difficult role. This study finding is supported by a study conducted by Halpern *et al*. (2017) in the United states of America which established that assisting with non-medical roles was associated with high psychological strain and worse interpersonal relations with patients while assisting with medical care roles significantly contributed to psychological/emotional strain. Similarly, a study conducted by Streid *et al*. (2014) in Sub-Saharan Africa established that FCGs with healthy family caregiver-patient relationships experience daily rewarding relations and interactions which further reduce the emotional strain among them.

Further, the results also revealed a significant statistical association between the strain related to patient treatment modality and the role strain experienced by the family caregivers. In this respect, not perceiving any strain related to patient's current treatment modality was associated with less severe strain (OR=0.21, 95% CI 0.107-0.425, p=0.001) compared to those who totally perceived patient's current treatment modality as a strain. This finding is likely because chemotherapy and radiotherapy services are offered as out-patient services at Kenyatta National hospital. These services are also not readily available across the country and cancer treatment is usually very expensive and as such family caregivers face many challenges in ensuring their patients access these services. This finding is in line with a study conducted by Amamou *et al*. (2019) in Tunisia which established that FCGs taking care of a patient receiving chemotherapy were prone to increased caregiving strain. Similarly, a study conducted by Sercekus *et al*. (2014) in Turkey established that FCGs are affected psychologically, socially and physiologically during caregiving and treatment process.

5.5 Institutional factors contributing to the role strain experienced by family caregivers of adult patients with cancer at KNH cancer treatment clinic

This current study established that not perceiving physical navigation of the hospital as a strain was statistically associated with less likelihood of severe strain among family caregivers (OR=0.39, 95% CI 0.168-0.928, p=0.033). Further, qualitatively it emerged that FCGs together with their patients experienced physical strain when navigating KNH cancer treatment centre. Explanation for this finding is that cancer treatment services at KNH are not all under one roof; as a result FCGs and their patients have to enormously walk to different designated points of cancer care services which are wide apart, hence they experience physical strain.

This finding is in line with a survey conducted by National Alliance for Caregiving (2016) in U.S which established that 21% of family caregivers to patient with cancer reported high levels of physical strain as a result of providing care while 23% reported moderate physical strain. Another study conducted by Kulkarni *et al*. (2014) in India also established that 52.17% of FCGs experienced tiredness/exhaustion related to caregiving.

This current study also established that not perceiving shortage of cancer drugs at the hospital as a strain was statistically associated with less likelihood of severe strain among family caregivers (OR=0.30, 95% CI 0.108-0.711, p=0.005). In addition, based on qualitative data it emerged that shortage of drugs was common which resulted to FCGs buying drugs for their patients. Explanation for this finding is that buying cancer drugs is expensive and this exerts extra financial strain on the patient and their FCGs. This also contributes to treatment delays and heightened psychological and physical strain among patients and their family caregivers. In support of this finding is a study conducted by Haileselassie *et al*. (2019) in Ethiopia which established that cancer treatment centres experience chronic shortage of chemotherapy drugs and as a result buying of these expensive drugs from private chemists is common. Moreover, a scoping review conducted by Coumoundouros *et al*. (2019) revealed that FCGs incur a great deal of out of pocket costs related to drugs, special diets and transport costs.

This current study also established that not perceiving inefficient radiotherapy services at the hospital as a strain (OR=0.39, 95% CI 0.171-0.902, p=0.028) or slightly perceiving the strain (OR=0.32, 95% CI 0.119-0.838, p=0.021) was statistically associated with less likelihood of severe strain among family caregivers. Further, qualitatively; it emerged that there were instances radiotherapy machines broke down which affected turnaround time for services delivery. Explanation for this finding is that inefficient radiotherapy services results in treatment delays which exert financial, psychological and physical strain on the patients and their family caregivers. Also, comprehensive radiotherapy services are only available at KNH. This finding is in line with another study conducted by Anakwenze *et al*. (2017) in Nigeria which established that 80% of patients could not access radiotherapy treatment without financial support and that 91.3% of patient who had completed radiotherapy treatment experienced treatment delays or treatment was cancelled due to either radiotherapy machines breakdown, electricity outage or prolonged waiting time.

Further, the study established that not perceiving caregiving challenges at home as a strain was statistically associated with less likelihood of severe strain among family caregivers (OR=0.40, 95% CI 0.174-0.926, p=0.032). Further, during focus group discussions it emerged that FCGs experienced caregiving challenges at home which they wished if healthcare workers could guide on how to tackle them. This study finding is likely because FCGs may strain with some aspects of caregiving since they are not offered any caregiving skills by healthcare professionals. This finding is consistent with a study conducted by Saleh and O’Neill (2018) in Bahrain which established that lack of a healthcare professional support contributed to the strain that FCGs experienced. Indeed, a study conducted by Mosher *et al*. (2016) in the U.S established that FCGs experienced challenges in dealing with practical skills of caregiving. Further, a study conducted by Amamou *et al*. (2019) in Tunisia established that lack of health care professional services at home contributed to the strain experienced by FCGs.

In addition, the current study has also established that slightly perceiving traversing long geographical distance in search for cancer treatment services for the patient as a strain was statistically associated with less likelihood of severe strain among family caregivers (OR=0.38, 95% CI 0.183-0.775, p=0.008). Further, qualitatively; it also emerged that FCGs were strained due to traversing long geographical distance together with their patients in search of cancer treatment services. Explanation for this finding is that patient and their family caregivers travel from far across the country to access the comprehensive cancer treatment services at Kenyatta National hospital since these services are not available in their regions; hence patients and their FCGs face a myriad of challenges in accessing theses services. This finding is supported by a study conducted by Maheshwari and Mahal (2016) in India which established that there was a high strain among family caregivers and their patients who travelled longer geographical distance to access cancer treatment services. In addition, a study conducted by Makau-Barasa *et al*. (2018) in Kenya established that there is lack of decentralization of comprehensive cancer care services to the counties.

5.6 Conclusion

i. Every family caregiver experienced role strain. Both mild and severe role strain were experienced in equal proportions.
ii. Family caregiver socio-demographic characteristics that were associated with severe role strain included marital status (not married), employment status (being not employed) and hours of caregiving per day (more than five hours per day).

iii. Family caregiver psycho-social and financial factors that were associated with severe role strain included perceived strain related to social isolation, perceived strain related to disturbed sleep cycle, perceived strain related to lack of social support and perceived strain related to transport costs.

iv. Patient related factors that were associated with severe role strain included patient’s county of residence (residing in other counties other than Nairobi county), stage of cancer (late cancer stage; III & IV) and perceived strain related to patient’s current cancer stage, patient functional status (poor patient functional status based on ECOG-PS scale; Grades above 3) and perceived strain related to patient’s current physical functional status, perceived strain related to patient’s current treatment modality and perceived strain related current interpersonal relations with family caregiver.

v. Institution related factors that were associated with severe role strain included perceived physical strain related to system navigation, perceived strain related to shortage of chemotherapy drugs at the hospital, perceived strain related to ineffective radiotherapy services, perceived strain related to caregiving challenges at home and perceived strain related to traversing long geographical distance in search of cancer treatment services.

5.7 Recommendations

Based on the findings of this study, the following recommendations have been made;

1. Health care practitioners should assess all family caregivers of adult cancer patients for role strain and ensure appropriate referrals for psychological counselling, social and financial support.
2. Health care practitioners should educate and support family caregivers and their patients on the following as well as champion for development of a FCG education program or literature rich materials putting the following into consideration;
    i. Family caregiver self-care; Attention to own health care needs.

    ii. Social and spiritual support; Create time for self, enjoy adequate sleep, social support groups and family meetings, spiritual nourishment, effective communication.
    iii. Health financing; Health insurance.
    iv. Nutrition wellness.
    v. Financial self empowerment; Create time and engage in business or activities with potential of cushioning against the financial hardship.
    vi. Caregiving skills training and enhancement of skills; Information on cancer as a disease, treatment and progression, management of drug side effects, wound and stoma care, practical aspects of caregiving, decision making and problem solving skills, navigating health care service delivery system, respite care services.

3. Kenyatta National Hospital to consider putting the following in place;
    i. A policy to guide on the integration of family caregivers in the unit of care to promote good patient outcomes. Also patient-family caregiver education program and family caregiver social support groups should be put in place.
    ii. Setting up of a comprehensive cancer treatment unit with all the associated services under one roof to address the physical strain that patients and their family caregivers endure when navigating the system.
    iii. Ensure adequate supply of chemotherapy drugs and other related supplies.
    iv. Ensure efficient radiotherapy services through timely servicing of machines and acquisition of the state of the art radiotherapy machines to match increased work load.
    v. Ensure free or affordable accommodation facilities within KNH especially for patients who are on chemotherapy and radiotherapy treatment.

4. Policy makers
    i. Setting up of regional or county comprehensive cancer treatment centres to address the geographical disparity and related strain in accessing comprehensive cancer treatment services.
    ii. Making cancer treatment and care services affordable or free to ease the financial burden relating to cost of cancer treatment as part of sustainable development goal 3 on universal health coverage.
    iii. Address the system challenges related to NHIF especially timely generation of invoices to facilitate seamless services for cancer patients.
    iv. Mass health education on cancer to empower communities; importance of seeking early cancer screening, diagnosis and treatment, supportive environments to stem out stigma against patient suffering from cancer and their FCGs so as to ensure healthy lives and promote well-being for all.
    v. Enactment of a policy to guide integration of FCGs in unit of care across all cancer treatment centres.
    vi. Government to consider establishment of centres to offer respite care to patients requiring palliative care.

REFERENCES

Acquati, C., Hibbard, J. H., Miller-Sonet, E., Zhang, A., & Ionescu, E. (2021). Patient activation and treatment decision-making in the context of cancer: examining the contribution of informal caregivers' involvement. *Journal of cancer survivorship : research and practice*, 10.1007/s11764-021-01085-9. Advance online publication. https://doi.org/10.1007/s11764-021-01085-9

Akpan-Idiok, P.A., & Anarado, A.N.(2014).Perceptions of burden of caregiving by informal caregivers of cancer patients attending University of Calabar Teaching Hospital, Calabar, Nigeria.*Pan African Medical Journal*, 18,159. https://doi.org/10.11604/pamj.2014.18.159.2995

Al-Daken, L.I., & Ahmad, M.M.(2018).Predictors of Burden and Quality of Sleep among Family Caregivers of Patients with Cancer.Supportive care:Official journal of the multinational association of supportive care in cancer, 26(11), 3967-3973.https://doi.org/10.1007/500520-018-4287-x

Amamou, B., Fathallah, S., Ammar, D., Mhalla, A., Zaafrane, F., & Gaha, L.(2019).Impact of demographic, clinical and psychological variables of patients and caregivers on the perception of burden among the family caregivers of patients with cancer. *Integr Cancer Sci Therap*, 6. https://doi.org/10.15761/ICST.1000303

Anakwenze, C. P., Ntekim, A., Trock, B., Uwadiae, I. B., & Page, B. R. (2017). Barriers to radiotherapy access at the University College Hospital in Ibadan, Nigeria. Clinical and translational radiation oncology, 5, 1–5. https://doi.org/10.1016/j.ctro.2017.05.003

Arian, M., Younesi, S.J & Khanjani, M.S.(2017).Explaining the Experiences and Consequences of Care Among Family Caregivers of Patients with Cancer in the Terminal Phase: A Qualitative Research. Int J Cancer Manag, 10(10). https://doi.org/10.5812/ijcm.10753

Bolarinwa O. A. (2015). Principles and methods of validity and reliability testing of questionnaires used in social and health science researches. *The Nigerian postgraduate medical journal*, *22*(4), 195–201. https://doi.org/10.4103/1117-1936.173959

Borges, E. L., Franceschini, J., Costa, L. H., Fernandes, A. L., Jamnik, S., & Santoro, I. L. (2017). Family caregiver burden: the burden of caring for lung cancer patients according to the cancer stage and patient quality of life. *Jornal brasileiro de pneumologia : publicacao oficial da Sociedade Brasileira de Pneumologia e Tisilogia*, *43*(1), 18–23. https://doi.org/10.1590/S1806-37562016000000177

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, *3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Carpenito, J.L.(2013).*Handbook of Nursing Diagnosis*.Wolters Kuluwer. https://dl.uswr.ac.ir/bitstream/Hannan/138720/1/9781608311101

Charles, L., Bremault-Phillips, S., Parmar, J., Johnson, M., & Sacrey, L.(2017).Understanding how to support family caregivers of seniors with complex needs.*Canadian geriatrics journal*, *20*(2). https://doi.org/10.5770/cgj.20.252

Chindaprasirt, J., Limpawattana, P., Pakkaratho, P., Wirasorn, K., Sookprasert, A., Kongbunkiat, K., & Kittisak, S.(2014).Burdens among Caregivers of Older Adults with Advanced Cancer and Risk Factors. *Asian Pac J Cancer Prev,* 15(4), 1643-1648. https://doi.org/10.7314/APJCP.2014.15.4.1643

Cochran, W.G.(2013). *Sampling Techniques*. 2nd ed. John Wiley and Sons, Inc.

Conill, C., Verger, E., & Salamero, M. (1990). Performance status assessment in cancer patients. *Cancer*, *65*(8), 1864–1866. https://doi.org/10.1002/1097-0142(19900415)65:8<1864::aid-cncr2820650832>3.0.co;2-u

Coumoundouros, C., Ould Brahim, L., Lambert, S. D., & McCusker, J. (2019). The direct and indirect financial costs of informal cancer care: A scoping review. *Health & social care in the community*, *27*(5), e622–e636. https://doi.org/10.1111/hsc.12808

Dhandapani, M., Gupta, S., Dhandapani, S., Kaur, P., Samra, K., Sharma, K., Dolma, K., Mohanty, M., Singla, N., & Gupta, S. K. (2015). Study of factors determining caregiver burden among primary caregivers of patients with intracranial tumors. *Surgical neurology international*, *6*, 160. https://doi.org/10.4103/2152-7806.167084

Flynn, R., Albrecht, L., & Scott, S. D. (2018). Two Approaches to Focus Group Data Collection for Qualitative Health Research: Maximizing Resources and Data Quality. International Journal of Qualitative Methods. https://doi.org/10.1177/1609406917750781

Gabriel, I.O., Aluko, J.O & Okeme, M.I.(2019).Caregiver Burden Among Informal Caregivers of Women with Breast Cancer. *Biomed J Sci & Tech Res*, *15*(3). https://doi.org/10.26717/BJSTR.2019.15.002704

Ge, L., & Mordiffi, S.Z.(2017).Factors associated with higher caregiver burden among family caregivers of elderly cancer patients.*cancer nursing*, *40*(6), 471. https://doi.org/10.1097/NCC.0000000000000445

Given, C. W. (2019). Family Caregiving for Cancer Patients: the State of the Literature and a Direction for Research to Link the Informal and Formal Care Systems to Improve Quality and Outcomes. *Seminars in oncology nursing*, *35*(4), 389–394. https://doi.org/10.1016/j.soncn.2019.06.014

Gropper, S., Van der Meer, E., Landes, T., Bucher, H.,Stickel, A., & Goerling, U.(2016).Assessing cancer-related distress in cancer patients and caregivers receiving outpatient psycho-oncological counselling. *Support Care Cancer*, *24*, 2351–2357. https://doi.org/10.1007/s00520-015-3042-9

Guest, G., Bunce, A., & Johnson, L. (2006). How Many Interviews Are Enough?: An Experiment with Data Saturation and Variability. *Field Methods*, *18*(1), 59–82. https://doi.org/10.1177/1525822X05279903

Haileselassie, W., Mulugeta, T., Tigeneh, W., Kaba, M., & Labisso, W. L.(2019).The Situation of Cancer Treatment in Ethiopia: Challenges and Opportunities. *Journal of cancer prevention*, *24*(1), 33–42. https://doi.org/10.15430/JCP.2019.24.1.33

Halpern, M. T., Fiero, M. H., & Bell, M. L. (2017). Impact of caregiver activities and social supports on multidimensional caregiver burden: analyses from nationally-representative surveys of cancer patients and their caregivers. *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation*, *26*(6), 1587–1595. https://doi.org/10.1007/s11136-017-1505-9

Hanna, T. P., King, W. D., Thibodeau, S., Jalink, M., Paulin, G. A., Harvey-Jones, E., O'Sullivan, D. E., Booth, C. M., Sullivan, R., & Aggarwal, A. (2020). Mortality due to cancer treatment delay: systematic review and meta-analysis. *BMJ (Clinical research ed.), 371*, m4087. https://doi.org/10.1136/bmj.m4087

Hennink, M. M., Kaiser, B. N., & Weber, M. B. (2019). What Influences Saturation? Estimating Sample Sizes in Focus Group Research. *Qualitative Health Research*, *29*(10), 1483–1496. https://doi.org/10.1177/1049732318821692

Henriksson, A., Carlander, I., & Årestedt, K.(2015).Feelings of rewards among family caregivers during ongoing palliative care. *Palliative & supportive care, 13*(6), 1509–1517. https://doi.org/10.1017/S1478951513000540

Hiremath, P., Mohite, V.R., Naregal, P., Chendake, M., Mulani, A., & More, U.R.(2017).Family burden and stress among caregiver of oral cancer patients at krishna hospital karad. *Innovare Academic Sciences Pvt Ltd*, 10(3), 16010. https://doi.org/10.22159/ajpcr.2017.v10i3.16010

Hsu, T., Loscalzo, M., Ramani, R., Forman, S., Popplewell, L., Clark, K., Katheria, V., Feng, T., Strowbridge, R., Rinehart, R., Smith, D., Matthews, K., Dillehunt, J., & Hurria, A. (2014). Factors associated with high burden in caregivers of older adults with cancer. *Cancer*, *120*(18), 2927–2935. https://doi.org/10.1002/cncr.28765

Hudson, P., Trauer, T., Kelly, B., O'Connor, M., Thomas, K., Zordan, R., & Summers, M. (2015). Reducing the psychological distress of family caregivers of home based palliative care patients: longer term effects from a randomised controlled trial. *Psycho-oncology*, *24*(1), 19–24. https://doi.org/10.1002

Johansen, S., Cvancarova, M., & Ruland, C. (2018). The Effect of Cancer Patients' and Their Family Caregivers' Physical and Emotional Symptoms on Caregiver Burden. *Cancer nursing*, *41*(2), 91–99. https://doi.org/10.1097/NCC.0000000000000493

Kahriman, F,. & Zaybak, A.(2015).Caregiver Burden and Perceived Social Support among Caregivers of Patients with Cancer.*Asian Pac J Cancer Prev,* 16(8), 3313-3317. http://dx.doi.org/10.7314/APJCP.2015.16.8.3313

Karabulutlu, E.Y.(2014).Coping with stress of family caregivers of cancer patients in Turkey. *Asia-Pacifi c Journal of Oncology Nursing*, *1*(1). https://doi.org/10.4103/2347-5625.135822

Kent, E. E., Rowland, J. H., Northouse, L., Litzelman, K., Chou, W. Y., Shelburne, N., Timura, C., O'Mara, A., & Huss, K. (2016). Caring for caregivers and patients: Research and clinical priorities for informal cancer caregiving. *Cancer*, *122*(13), 1987–1995. https://doi.org/10.1002/cncr.29939

Kenya National Bureau of Statistics.(2014).Kenya demographic and health survey. https://dhsprogram.com/pubs/pdf/fr308/fr308.pdf

Kershaw, T., Ellis, K. R., Yoon, H., Schafenacker, A., Katapodi, M., & Northouse, L. (2015). The Interdependence of Advanced Cancer Patients' and Their Family Caregivers' Mental Health, Physical Health, and Self-Efficacy over Time.

Annals of behavioral medicine : a publication of the Society of Behavioral Medicine, *49*(6), 901–911. https://doi.org/10.1007/s12160-015-9743-y

Kesmodel U. S. (2018). Cross-sectional studies - what are they good for?. *Acta obstetricia et gynecologica Scandinavica*, *97*(4), 388–393. https://doi.org/10.1111/aogs.13331

Kong, S., & Guan, N. (2019). Burden in Family Caregivers of Cancer Patients: The Association with Depression, Religiosity and Religious Coping. *Asian Pacific Journal of Cancer Care*, *4*(4), 171-182. https://doi.org/10.31557/apjcc.2019.4.4.171-182

Kulkarni, P., Kulkarni, P., Ghooi, R., Bhatwadekar, M., Thatte, N., & Anavkar, V.(2014). Stress among Care Givers: The Impact of Nursing a Relative with Cancer. *Indian Journal of Palliative* Care, 20(1). https://doi.org/10.4103/0973-1075.125554.

Kusi, G., Boamah Mensah, A.B., Boamah Mensah, K., Dzomeku,V.M., Apiribu, F., Duodu, P.A., Adamu, B., Agbadi, P & Bonsu, K.O.(2020).The experiences of family caregivers living with breast cancer patients in low-and middle-income countries: a systematic review. *Systematic Reviews,* 9, 165. https://doi.org/10.1186/s13643-020-01408-4

Lafortune, C., Huson, K., Santi, S., & Stolee, P.(2015).Community-based primary health care for older adults: a qualitative study of the perceptions of clients, caregivers and health care providers.*BMC Geriatrics*, 15, 57. https://doi.org/10.1186/s12877-015-0052-x

Lester, J. N., Cho, Y., & Lochmiller, C. R. (2020). Learning to Do Qualitative Data Analysis: A Starting Point. *Human Resource Development Review*, *19*(1), 94–106. https://doi.org/10.1177/1534484320903890

Lilleheie, I., Debesay, J., Bye, A., & Bergland, A. (2020). Informal caregivers' views on the quality of healthcare services provided to older patients aged 80 or more in the hospital and 30 days after discharge. BMC geriatrics, 20(1), 97. https://doi.org/10.1186/s12877-020-1488-1

Litzelman, K., Kent, E. E., & Rowland, J. H. (2016). Social factors in informal cancer caregivers: The interrelationships among social stressors, relationship quality, and family functioning in the CanCORS data set. *Cancer*, *122*(2), 278–286. https://doi.org/10.1002/cncr.29741

Lkhoyaali, S., El Haj, M.A., El Omrani, F., Layachi, M., Ismaili, N., Mrabti, H., & Errihani, H.(2015).The burden among family caregivers of elderly cancer patients: prospective study in a Moroccan population. *BMC Res Notes,* 8, 347. https://doi.org/10.1186/s13104-015-1307-5

Longacre, M.L., Valdmanis, V.G., Handorf, E.A., & Fang, C.Y.(2017).Work Impact and Emotional Stress Among Informal Caregivers for Older Adults. *J Gerontol B Psychol Sci Soc Sci*, 72 (3), 522–531. https://doi.org/10.1093/geronb/gbw027

Luke, M., & Goodrich, K. M. (2019). Focus group research: An intentional strategy for applied group research?[Editorial]. *Journal for Specialists in Group Work, 44*(2), 77–81. https://doi.org/10.1080/01933922.2019.1603741

Lund, L., Ross, L., Petersen, M.A., & Groenvold, M.(2014).Cancer caregiving tasks and consequences and their associations with caregiver status and the caregiver’s relationship to the patient:a survey. *BMC Cancer*, 14, 541. http://www.biomedcentral.com/1471-2407/14/541

Luo, J., Zhou, Y., Liu, H., & Hu, J. (2020). Factors related to the burden of family caregivers of elderly patients with spinal Tumours in Northwest China. *BMC neurology*, *20*(1), 69. https://doi.org/10.1186/s12883-020-01652-0

Maguire, R., Hanly, P., Hyland, P., & Sharp, L.(2016).Understanding burden in caregivers of colorectal cancer survivors: what role do patient and caregiver factors play?. *Eur J Cancer Care,* xx: 1–9. https://doi.org/10.1111/ecc.12527

Maheshwari Preksha, S., & Kaur, M. R. (2016). Perceived social support and burden among family caregivers of cancer patients. *Int J Health Sci Res*, *6*(1), 304-314

Makau-Barasa, L. K., Greene, S. B., Othieno-Abinya, N. A., Wheeler, S., Skinner, A., & Bennett, A. V. (2018). Improving Access to Cancer Testing and Treatment in Kenya. *Journal of global oncology*, *4*, 1–8. https://doi.org/10.1200/JGO.2017.010124

Malloy, P., Boit, J., Tarus, A., Marete, J., Ferrell, B., & Ali, Z. (2017). Providing Palliative Care to Patients with Cancer: Addressing the Needs in Kenya. *Asia-Pacific journal of oncology nursing*, *4*(1), 45–49. https://doi.org/10.4103/2347-5625.199073

Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample Size in Qualitative Interview Studies: Guided by Information Power. *Qualitative health research*, *26*(13), 1753–1760. https://doi.org/10.1177/1049732315617444

Mcewen, M., & Willis, E.M.(2019).Theoretical basis for nursing (5th ed.).Philadelphia, PA:Wolters Kluwer

Metzelthin, S. F., Verbakel, E., Veenstra, M. Y., van Exel, J., Ambergen, A. W., & Kempen, G. (2017). Positive and negative outcomes of informal caregiving at home and in institutionalised long-term care: a cross-sectional study. *BMC geriatrics*, *17*(1), 232. https://doi.org/10.1186/s12877-017-0620-3

Miseda, M.H., Were, S.O., Murianki, C.A., Mutuku, M.P., & Mutwiwa, S.N.(2017).The implication of the shortage of health workforce specialist on universal health coverage in Kenya. *Hum Resour Health 15,* 80. https://doi.org/10.1186/s12960-017-0253-9

MOH.(2017).*National cancer control strategy 2017-2022.*Nairobi. https://www.iccp-portal.org/system/files/plans/KENYA%20NATIONAL%20CANCER%20CONTROL%20STRATEGY%202017-2022_1.pdf

Mosher, C.E., Adams, R.N., Helft, P.R., O'Neil, B.H., Shahda, S., Rattray, N.A., & Champion, V.L.(2016).Family caregiving challenges in advanced colorectal cancer:patient and caregiver perspectives.*Support Care Cancer*, *24*(5), 2017–2024. https://doi.org/10.1007/s00520-015-2995-z

Mthembu, T.G., Brown, Z., Cupido, A., Razack, G., & Wassung, D.(2016).Family caregivers' perceptions and experiences regarding caring for older adults with chronic diseases.*South African Journal of Occupational Therapy*, 46(1), 83-88. Doi: http://dx.doi.org/10.17159/2310-3833/2016/v46n1a15

Muliira, J.K., & Kizza, I.B.(2019).The other untold burden of cancer in sub-Saharan Africa: Anxiety and depressive symptoms among family caregivers of adult cancer patients. *International Journal of Africa Nursing Sciences, 11*, 2214-1391. https://doi.org/10.1016/j.ijans.2019.100166.

National Alliance for Caregiving.(2016).*Cancer caregiving in the U.S: An Intense, Episodic, and Challenging Care Experience.*New York. https://www.caregiving.org/wpcontent/uploads/2016/06/CancerCaregivingReport_FINAL_June-17-2016.pdf

Nipp, R. D., El-Jawahri, A., Fishbein, J. N., Gallagher, E. R., Stagl, J. M., Park, E. R., Jackson, V. A., Pirl, W. F., Greer, J. A., & Temel, J. S. (2016). Factors associated with depression and anxiety symptoms in family caregivers of patients with incurable cancer. *Annals of oncology : official journal of the European Society for Medical Oncology*, *27*(8), 1607–1612. https://doi.org/10.1093/annonc/mdw205

Nortey, S.T., Aryeetey, G.C., Aikins, M., Amendah, D., & Nonvignon, J.(2017).Economic burden of family caregiving for elderly population in southern Ghana: the case of a peri-urban district.*International Journal for Equity in Health*,16, 16. https://doi.org/10.1186/s12939-016-0511-9

Northouse, L., Anna-Leila, W., Given, B.,& Mccorkle, R.(2012).Psychosocial Care for Family Caregivers of Patients With Cancer.*American Society of Clinical Oncology*. https://doi.org/10.1200/JCO.2011.39.5798

Oboh, O.E., & Adayonfo, E.O.(2017).Cancer Informal Caregivers' Burden At The University College Hospital, Ibadan, Nigeria.*International Journal of Innovative Research and Advanced Studies (IJIRAS)*, 4(3), 2394-4404.

Oken, M.M., Creech, R.H., Tormey, D.C., Horton, J., Davis, T.E., McFadden, E.T & Carbone, P.P.(1982).Toxicity And Response Criteria Of The Eastern Cooperative Oncology Group. Am J Clin Oncol 5:649-655

Oleribe, O. O., Momoh, J., Uzochukwu, B. S., Mbofana, F., Adebiyi, A., Barbera, T., Williams, R., & Taylor-Robinson, S. D. (2019). Identifying Key Challenges Facing Healthcare Systems In Africa And Potential Solutions. *International journal of general medicine*, *12*, 395–403. https://doi.org/10.2147/IJGM.S223882

O'Neil, D. S., Prigerson, H. G., Mmoledi, K., Sobekwa, M., Ratshikana-Moloko, M., Tsitsi, J. M., Cubasch, H., Wong, M. L., Omoshoro-Jones, J., Sackstein, P. E., Blinderman, C. D., Jacobson, J. S., Joffe, M., Ruff, P., Neugut, A. I., & Blanchard, C. L. (2018). Informal Caregiver Challenges for Advanced Cancer Patients During End-of-Life Care in Johannesburg, South Africa and Distinctions Based on Place of Death. *Journal of pain and symptom management*, *56*(1), 98–106. https://doi.org/10.1016/j.jpainsymman.2018.03.017

Patel, M.I., Periyakoil, S.V., Blayney, D.W., Moore, D., Nevedal, A., Asch, S., & Coker, T.R.(2017).Redesigning cancer care delivery: views from patients and caregivers.*Journal of Oncology Practice*, 13(4). https://doi.org/10.1200/JOP.2016.017327

Petrovic, M., & Gaggioli, A. (2020). Digital Mental Health Tools for Caregivers of Older Adults-A Scoping Review. *Frontiers in public health*, *8*, 128. https://doi.org/10.3389/fpubh.2020.00128

Petrovic, M., & Gaggioli, A. (2020). Digital Mental Health Tools for Caregivers of Older Adults-A Scoping Review. Frontiers in public health, 8, 128. https://doi.org/10.3389/fpubh.2020.00128

Priya, S. S., Shavi, G. R., Sanga, R., Shankar, S., Lalithambigai, G., Rahila, C., & Santhakumari, S. (2021). Assessment of the perceived stress and burden of family caregivers of the head-and-neck cancer patients at a tertiary care cancer center: A cross-sectional study. *Journal of cancer research and therapeutics*, *17*(4), 1039–1046. https://doi.org/10.4103/jcrt.JCRT_309_19

Qualls, S.H.(2016).Caregiving Families Within the Long-Term Services and Support System for Older Adults.*American psychologist*, 71(4), 283–293. https://doi.org/10.1037/a0040252

Rodakowski, J., Rocco, P. B., Ortiz, M., Folb, B., Schulz, R., Morton, S. C., Leathers, S. C., Hu, L., & James, A. E., 3rd (2017). Caregiver Integration During Discharge Planning for Older Adults to Reduce Resource Use: A Metaanalysis. *Journal of the American Geriatrics Society*, *65*(8), 1748–1755. https://doi.org/10.1111/jgs.14873

Ronniey, O.(2019). Reducing Barriers to Cancer Treatment Completion at Kenyatta Hospital Cancer Treatment Center.*Journal of Oncology Navigation & Survivorship*, *10*(11), p453-453. https://www.jons-online.com/issues/2019/november-2019-vol-10-no-11/2614

Rosen, R.D., & Sapra, A.(2022).*TNM Classification*.Treasure Island (FL):StatPearls Publishing. [Updated 2022 Feb 17]. https://www.ncbi.nlm.nih.gov/books/NBK553187/

Roy, C.(2009).*The Roy adaptation model*. 3 edition. Upper Saddle River New Jersey: Pearson Education.

Saleh, F & O’Neill, C.S.(2018).The experiences of caregivers providing home care for terminally ill family members at the end of life: A phenomenological study in Bahrain.*Clinical Nursing Studies*. *6* (3), 57. https://doi.org/10.5430/cns.v6n3p57

Schoonenboom, J., & Johnson, R. B. (2017). How to Construct a Mixed Methods Research Design. *Kolner Zeitschrift fur Soziologie und Sozialpsychologie*, *69*(Suppl 2), 107–131. https://doi.org/10.1007/s11577-017-0454-1

Semere, W., Althouse, A. D., Rosland, A. M., White, D., Arnold, R., Chu, E., Smith, T. J., & Schenker, Y. (2021). Poor patient health is associated with higher caregiver burden for older adults with advanced cancer. *Journal of geriatric oncology*, *12*(5), 771–778. https://doi.org/10.1016/j.jgo.2021.01.002

Sercekus, P., Besen, D. B., Gunusen, N. P., & Edeer, A. D. (2014). Experiences of family caregivers of cancer patients receiving chemotherapy. *Asian Pacific journal of cancer prevention: APJCP*, *15*(12), 5063–5069. https://doi.org/10.7314/apjcp.2014.15.12.5063

Shah, S. C., Kayamba, V., Peek, R. M., Jr, & Heimburger, D. (2019). Cancer Control in Low- and Middle-Income Countries: Is It Time to Consider Screening?. *Journal of global oncology*, *5*, 1–8. https://doi.org/10.1200/JGO.18.00200

Sharma, R., Aashima, Nanda, M., Fronterre, C., Sewagudde, P., Ssentongo, A. E., Yenney, K., Arhin, N. D., Oh, J., Amponsah-Manu, F., & Ssentongo, P. (2022). Mapping Cancer in Africa: A Comprehensive and Comparable Characterization of 34 Cancer Types Using Estimates From GLOBOCAN 2020. *Frontiers in public health*, *10*, 839835. https://doi.org/10.3389/fpubh.2022.839835

Smith, M. C., & Parker, M. E. (2015). Nursing theories and nursing practice (4th ed.). Philadelphia, PA: F.A. Davis

Stefan D. C. (2015). Cancer Care in Africa: An Overview of Resources. Journal of global oncology, 1(1), 30–36. https://doi.org/10.1200/JGO.2015.000406

Streid, J., Harding, R., Agupio, G., Dinat, N., Downing, J., Gwyther, L., Ikin, B., Mashao, T., Mmoledi, K., Moll, A. P., Sebuyira, L. M., Higginson, I. J., & Selman, L. (2014). Stressors and resources of caregivers of patients with incurable progressive illness in sub-Saharan Africa. *Qualitative health research*, *24*(3), 317–328. https://doi.org/10.1177/1049732314523682

Sung, H., Ferlay, J., Siegel, R. L., Laversanne, M., Soerjomataram, I., Jemal, A., & Bray, F. (2021). Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries. *CA: a cancer journal for clinicians*, *71*(3), 209–249. https://doi.org/10.3322/caac.21660

Taleghani, F., Ehsani, M., Farzi, S., Farzi, S., Adibi, P., Moladoost, A., Shahriari, M., & Tabakhan, M. (2021). Challenges to Family Caregivers in Caring for Gastric Cancer Patients from Perspectives of Family Caregivers, Patients, and Healthcare Providers: A Qualitative Study. Indian journal of palliative care, 27(4), 521–529. https://doi.org/10.25259/IJPC_98_21

Thornton, M & Travis, S.S.(2003).Analysis of the reliability of the modified caregiver strain index. *J Gerontol Ser B.* 2003;58(2):S127 - S132. https://doi.org/10.1093/geronb/58.2.s127

Thornton, M., & Travis, S.S. (2003).Analysis of the reliability of the Modified Careg iver Strain Index.*The Journal of Gerontology: Psychological Sciences and Social Sciences*, 58(2), S127–S132

Ullgren, H., Tsitsi, T., Papastavrou, E., & Charalambous, A. (2018). How family caregivers of cancer patients manage symptoms at home: A systematic review. International journal of nursing studies, 85, 68–79. https://doi.org/10.1016/j.ijnurstu.2018.05.004

Ursachi, G., Horodnic, I.A., & Zait, A. (2015). How Reliable Are Measurement Scales? External Factors with Indirect Influence on Reliability Estimators.

Procedia Economics and Finance, 20, 679-686. https://doi.org/10.1016/S2212-5671(15)00123-9

Vahidi, M., Mahdavi, N., Asghari, E., Ebrahimi, H., Eivazi Ziaei, J., Hosseinzadeh, M., Namdar Areshtanab, H., & Kermani, I. A. (2016). Other Side of Breast Cancer: Factors Associated with Caregiver Burden. *Asian nursing research*, *10*(3), 201–206. https://doi.org/10.1016/j.anr.2016.06.002

Van Ryn, M., Sanders, S., Kahn, K., van Houtven, C., Griffin, J. M., Martin, M., Atienza, A. A., Phelan, S., Finstad, D., & Rowland, J. (2011). Objective burden, resources, and other stressors among informal cancer caregivers: a hidden quality issue?. *Psycho-oncology*, *20*(1), 44–52. https://doi.org/10.1002/pon.1703

Walubita, M., Sikateyo, B., & Zulu, J.M.(2018).Challenges for health care providers, parents and patients who face a child hood cancer diagnosis in Zambia. *BMC Health Serv Res, 18,* 314. https://doi.org/10.1186/s12913-018-3127-5

Wambalaba, F. W., Son, B., Wambalaba, A. E., Nyong'o, D., & Nyong'o, A.(2019). Prevalence and Capacity of Cancer Diagnostics and Treatment: A Demand and Supply Survey of Health-Care Facilities in Kenya. *Cancer control: journal of the Moffitt Cancer Center*, *26*(1), 1073274819886930. https://doi.org/10.1177/1073274819886930

Wood, R., Taylor-Stokes, G., Smith, F., & Chaib, C.(2019).The humanistic burden of advanced non-small cell lung cancer (NSCLC) in Europe: a real-world survey linking patient clinical factors to patient and caregiver burden. *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation*, *28*(7), 1849–1861. https://doi.org/10.1007/s11136-019-02152-6

World Health Organization. (2016). Planning and implementing palliative care services: a guide for programme managers. World Health Organization. https://apps.who.int/iris/handle/10665/250584

World Health Organization. *Guide to Cancer Early Diagnosis*. World Health Organization; 2017. https://apps.who.int/iris/handle/10665/254500. License: CC BY - NC - SA 3.0 IGO

Yakubu, Y.A & Schutte, W.(2018).Caregiver attributes and socio-demographic determinants of caregiving burden in selected low-income communities in cape town, South Africa.*Journal of Compassionate Health Care*, 5(3). https://doi.org/10.1186/s40639-018-0046-6

Zubaidi, Z.S.A., Ariffin, F., Oun, C.T.C & Katiman, D.(2020).Caregiver burden among informal caregivers in the largest specialized palliative care unit in Malaysia: a cross sectional study. *BMC Palliat Care*, 19:186. https://doi.org/10.1186/s12904-020-00691-1

APPENDICES

Appendix I: Participant Information and Consent Form

Title of the study: “Factors Contributing to Role Strain among Family Caregivers of Adult Patients suffering from Cancer at Kenyatta National Hospital.”

RESEARCHER	INSTITUTION	CONTACT
Morris M Muriuki	Jomo Kenyatta University of Agriculture and Technology	P.O.BOX 2609-60200, Meru. Tel: 0723 366 099
SUPERVISORS Dr. Bernard Mbithi	Jomo Kenyatta University of Agriculture and Technology	P.O.BOX, 62000-00200, Nairobi. Tel: 0722 321 945
Prof. Sherry Oluchina	Jomo Kenyatta University of Agriculture and Technology	P.O.BOX, 62000-00200, Nairobi. Tel: 0724 668 425

1 Introduction to the study

Dear respondent, I welcome you to participate in this study being conducted by Morris M Muriuki, who is pursuing Master of Science in Nursing (Oncology and Palliative care) at Jomo Kenyatta University of Agriculture and Technology. The study will be carried out at Kenyatta National Hospital Outpatient Cancer Treatment Clinic. The purpose of this consent form is to give you the necessary information to help you decide whether to participate in this study or not. You are free to ask any questions or voice any concerns you may have regarding this study. This consent form has information about the study, the risks and benefits as well as the procedures to be involved. Once you understand what the study is all about, and if you agree to participate, you will be requested to sign or have your thumb print on the consent form. You will also be given a copy to take home.

Your participation in this study is entirely voluntary and you have the right to withdraw from this study at anytime without necessarily giving any reasons. Kindly also note that, withdrawing or refusal to participate in this study will not affect the services you are entitled to in this health facility or elsewhere.

2 Study purpose

Cancer is a chronic condition, characterized by high continuous care demand and much of care is increasingly being offered as an outpatient service. As a result family caregivers have become the backbone of this care, and this demanding and overwhelming role has impacted all aspects of family caregiver’s life leading to role strain. Therefore, the main purpose of this study is to assess the role strain experienced by family caregivers of adult patients with cancer as well as associated predictors of the role strain. Assessing the role strain among family caregivers is important since it can compromise the quality of care that family caregivers offer to patients with cancer, hence putting patients at great risk. Role strain can also adversely affect the general health of family caregivers. This study will involve the family caregivers and their respective patients attending Kenyatta National Hospital Outpatient Cancer Treatment Clinic.

Approximately 255 family caregivers will be recruited to fill the study questionnaires while their corresponding patients will be administered the ECOG scale to assess their functional status. Also a group of family caregivers will be recruited to participate in focus group discussions and key informant interviews will be conducted among the health care workers who are experts in oncology and palliative care. The researcher assisted by the research assistants will administer the questionnaires which will approximately take between 30-40 minutes while each audio-recorded focus group discussion will take approximately 30 minutes.

3 Benefits

There will be no direct benefits to individual participants, apart from having family caregivers assessed for the role strain and will be referred appropriately as per the referral protocol that the researcher has put in place based on the level of the role strain. The researcher will also counsel each of family caregiver and health educate on selected topics at the end of data collection process. Study findings will also provide crucial information to health care workers, health care institutions, and policy makers in designing programmes or strategies to address the role strain and how family caregivers can be integrated in the therapeutic unit of care by the health care system.

4 Risks and discomforts

There are no risks associated with participating in this study. You may skip any questions in the questionnaire that may make you feel uncomfortable. You also have the right to stop participating in the study at any time. During data collection process, recall of your past or present experiences as a family caregiver may make you feel uncomfortable or become emotional and incase it becomes out of control researcher may intervene to calm you down or may necessitate referral for counseling services.

5 Confidentiality

Kindly note that, in this study you will not be required to write your name or any personal details on the questionnaires which may indentify you as an individual in any way. The information you will supply by way of participating in this study will be handled with ultimate confidentiality and anonymous. The researcher will uphold high level of privacy during data collection process.

Concerning audio-recorded materials during group discussions and the interview, after transcribing the data, these materials will be destroyed and the transcripts kept under lock and key. There will be no way of indentifying the individual participants and there shall be no use of any information that will directly indentify you in any presentations or written reports.

6 Procedures

i. Procedure on Structured uestionnaire, Modified Caregiver Strain Index (MCSI) tool.

You as the family caregiver will be requested to read and understand all the questions contained in the questionnaire. You will be asked a series of questions which will require you to remember some experiences in the past. The questionnaire will be composed of different sections to gather information on your socio-demographic data, roles as a family caregiver, and predictors to role strain. Your level of the role strain will also be assessed using the Modified Caregiver Strain Index (MCSI) tool. You will also be guided by the researcher or the researcher assistant in responding to the questions. Filling of the questionnaire and the MCSI tool will take approximately 30 minutes.

ii. Procedure on focus group discussions

You as the family caregiver you have been given this opportunity to participate in this focus group discussion comprising of 6 to 8 members to assess your experience in taking care of this patient. The researcher has developed a topic guide to capture data on challenges or strain that you experience when taking care of this patient. This topic guide will be used during the discussion. The sessions will be audio-recorded and note taking will be done by the researcher and research assistants. Each session will last approximately for 30 minutes.

iii. Procedure on Eastern Cooperative Oncology Group (ECOG) scale for measuring patient’s level of functional status

You as the patient corresponding to the family caregiver whom we have interviewed, the researcher or research assistant will use ECOG scale to assess your physical performance status or your ability to perform self care activities without being helped by others. This will be very brief and will take less than 3 minutes of your time.

iv. Procedure on Key Informant Interview

You as a professional expert in oncology/palliative care or medical social work, you have been chosen to take part in this study based on your expert knowledge and experience in dealing with patients with cancer and their family. The researcher has developed an interview guide which will be used to capture data on healthcare system factors contributing to the role strain experienced by the family caregivers. The session will be audio-recorded and note taking will be done by the researcher and research assistants. Each interview session will last approximately for 30 minutes.

7. Compensation

There shall be no monetary rewards for taking part in this study. Participating in this research is free of charge.

8. Voluntary participation and withdrawal

Kindly note that, your participation in this study is entirely voluntary. In case you change your mind, you have the right to stop participating at any time and you won’t be harmed in any way. You may also skip some questions or stop participating at any time.

9. Sharing of the study results

The results of this study will be shared through academic forums, scientific conferences and will also be published in scientific journals.

10. Contact persons

You will be given a card containing the contact information of the researcher, his supervisors and those of the director ethics (KNH-UON ERC). Should you have any questions or concerns about this study or even about your rights as a participant, kindly feel free to contact them directly using their contact information below.

Researcher: Morris M Muriuki, P.O. BOX, 2609-60200, Meru. Tel: 0723 366 099

Supervisor: Dr Bernard Mbithi, P.O. BOX, 62000-00200, Nairobi. Tel: 0722 321 945

Supervisor: Prof Sherry Oluchina, P.O. BOX, 62000-00200, Nairobi. Tel: 0724 668 425

The Chairperson/Secretary, KNH-UoN ERC. P.O.BOX, 20723-00202, Nairobi. Tel: 2726300-9 Ext. 44102. Email: uonknh_erc@uonbi.ac.ke.

Thank you.

Appendix II: Fomu Ya Maelezo Kuhusu Idhini

Kichwa cha utafiti: “Sababu zenye kuchangia changamoto za majukumu baina ya watunzaji kwenye familia ya wagonjwa wa saratani, ambao ni watu wazima, katika hospitali kuu ya Kenyatta.”

Table 4.17: Responses on family caregiver related financial factors influencing role strain among family caregivers of adult patients suffering from cancer

MTAFITI MKUU	**CHUO**	**MAWASILIANO**
Morris M Muriuki	Chuo Kikuu cha Kilimo na Teknolojia cha Jomo Kenyatta	Sanduku la Posta, 2609-60200, Meru. Nambari ya simu: 0723 366 099
WASIMAMIZI Dkt. Bernard Mbithi	Chuo Kikuu cha Kilimo na Teknolojia cha Jomo Kenyatta	Sanduku la Posta, 62000-00200, Nairobi. Nambari ya simu: 0722 321 945
Prof. Sherry Oluchina	Chuo Kikuu cha Kilimo na Teknolojia cha Jomo Kenyatta	Sanduku la Posta, 62000-00200, Nairobi. Nambari ya simu: 0724 668 425

1. Utangulizi

Mpendwa Mshiriki, nakukaribisha kushiriki katika utafiti huu unaofanywa na Morris M Muriuki, anayeshiriki katika masomo ya Shahada ya Uzamili ya Uuguzi (Matibabu ya Saratani na Huduma Mwenza) katika Chuo Kikuu cha Kilimo na Teknolojia cha Jomo Kenyatta. Utafiti huu utafanywa katika Kituo cha Matibabu ya Saratani cha Wagonjwa Wasiolazwa cha Hospitali Kuu ya Kenyatta. Madhumuni ya fomu hii ya idhini ni kukueleza taarifa muhimu kuhusiana na utafiti huu zitakazokuwezesha kuamua iwapo utashiriki au hautashiriki kwenye utafiti huu. Uko huru kuuliza maswali yoyote au jambo lolote unaloweza kuwa nalo kuhusiana na utafiti huu. Fomu hii ya idhini iko na taarifa kuhusiana na utafiti huu, madhara na manufaa ya kushiriki na pia kuhusu jinsi ya kushiriki. Baada ya kuelewa kikamilifu juu ya madhumuni ya utafiti huu, na ikiwa utakubari kushiriki, basi utaulizwa/utatakiwa kutia sahihi au kuweka chapa ya kidole kwenye fomu ya idhini. Utapewa nakala yako pia uende nayo nyumbani.

Kushiriki kwako katika utafiti huu ni kwa hiari yako na uko na uhuru wa kujiondoa wakati wowote bila kutoa sababu zozote. Tafadhali, kumbuka kuwa, kujiondoa kwako katika utafiti huu au kukataa kushiriki katika utafiti huu hakutaathiri kwa njia yoyote huduma za afya ambazo huwa unapata katika hospitali hii au zinginezo.

2. Lengo la utafiti

Ugonjwa wa saratani, ni baina ya magonjwa sugu, unaohitaji huduma za afya na utunzaji wa hali ya juu huku utunzaji mwingi ukiwa unafanyika kama Huduma ya kutolazwa hospitalini. Hivyo basi, watunzaji katika familia wamekuwa nguzo muhimu katika Huduma/utunzaji wa wagonjwa wa saratani, huku jukumu hili nzito likiwalemea watunzaji katika familia hivyo kupelekea kutatizika kwa utunzaji huu. Hivyo, lengo kuu la utafiti huu ni kutathmini changamoto za majukumu baina ya watunzaji kwenye familia ya wagonjwa wa saratani na pia mambo yanayochangia kutatizika kwa utunzaji huu. Kutathmini kutatizika kwa utunzaji wa wagonjwa wa saratani baina ya watunzaji katika familia ni muhimu maana huenda ikaathiri vibaya ubora wa utunzaji ambao watunzaji hutoa kwa wagonjwa wa saratani, hivyo kuweka maisha yao hatarini. Changamoto za utunzaji zinaweza pia kuathiri vibaya hali ya afya ya watunzaji katika familia. Utafiti huu utahusisha watunzaji katika familia na wagonjwa wao wanaotafuta matibabu katika Kituo cha Matibabu ya Saratani cha Wagonjwa Wasiolazwa cha Hospitali Kuu ya Kenyatta.

Takriban watunzaji 255 watahusishwa katika kujibu dodosa la utafiti huu huku wagonjwa wao wakikaguliwa kupitia kipimo cha ECOG ili kubaini hali yao ya utendaji kazi. Pia, baadhi ya watunzaji watachaguliwa ili kusjiriki katika majadiliano ya vikundi. Mahojiano ya hoja muhimu yatafanywa baina ya wahudumu wa afya ambao ni wataalam kwa mabo ya Matibabu ya Saratani na huduma zinazoambatana na matibabu hayo. Mtafiti mkuu akisaidiwa na watafiti wasaidizi watapeana dodoso ili ziweze kujazwa, zoezi litakalo chukua takriban dakika 30. Nayo majadiliano ya vikundi, yatakayonaswa kwa kanda, yatachukua takriban dakika 30.

3. Faida ya utafiti huu

Hakutakuwa na faida ya moja kwa moja ya kushiriki katika utafiti huu, isipokuwa watunzaji wa wagonjwa wa saratani watatathminiwa kwa changamoto za utunzaji na kulingana na kiwango chao cha kutatizika watakabidhiwa rufaa kuambatana na mpangilio wa rufaa uliowekwa na mtafiti mkuu. Mtafiti mkuu atatoa ushauri wa nasaha kwa watunzaji katika familia na pia kuwaelimisha baada ya kukuzanya taarifa.

Walakini, matokeo ya utafiti huu yatatoa taarifa muhimu kwa wahudumu wa afya, vituo vya afya, na wanaounda sera katika kubuni mipango na mikakati ya jinsi ya kupunguza changamoto za utunzaji wa wagonjwa wa saratani na hasa jinsi ya kuwashirikisha kikamilifu watunzaji katika familia kwenye matibabu ya wagonjwa hawa, ndani ya mfumo wa afya.

4. Madhara na usumbufu

Hakuna madhara yoyote ya kimwili utakayopata kwa kushiriki katika utafiti huu. Kuna uwezekano kuwa baadhi ya maswali utakayoulizwa huenda ikakutia wasiwasi ama ikadhiaki hisia zako. Wakati wa ukuzanyaji tarifa, kumbumbu za mambo ambayo umepitia au unayopitia kwa sasa kama mtunzaji katika familia huenda ikakutia wasiwasi ama ikadhiaki hisia zako na ambapo hii itakuwa zaidi ya vile ungeidhibiti wewe mwenyewe, mtafiti mkuu ataingilia kati na kukutuliza ama kukupokeza rufaa ya ushauri wa nasaha.

5. Usiri

Tafadhali elewa kuwa katika utafiti huu hautahitajiwa kuandika jina lako au kupeana habari yoyote ambayo inaweza kukutambulisha kwa njia yoyote kwenye dodoso.

Kuhusu taarifa zote zitakazonaswa kwenye kanda katika majadiliano ya vikundi na mahojiano ya hoja muhimu, baada ya kuziandika taarifa hizi, basi rekodi za kanda zitaharibiwa na maandishi iliyotengenezwa kutokana na rekodi hizo kuhifadhiwa mahali salama. Hakutakuwa na njia ya kuwatambua washiriki katika utafiti huu na taarifa ambazo zinaweza kukutambulisha hazitatumika katika ripoti za utafiti huu.

6. Taratibu

i. Taratibu za dodoso na chombo cha MCSI

Wewe kama mtunzaji katika familia utahitajika kuyasoma na kuelewa maswali yote yaliyoko kwenye dodoso. Utaulizwa msululu wa maswali kuhusiana na uzoefu wako wa utunzaji kwa kipindi kilichopita. Dodoso hili limegawa katika sehemu tofauti ili kukusanya habari kuhusu taarifa zako za kibinafsi, majukumu yako kama mtunzaji katika familia, na mambo yanayochangia kutatizika kwenye majukumu haya. Kiwango chako cha kutatizika katika majukumu ya utunzaji wa wagonjwa wa saratani kitapimwa kupitia chombo cha MCSI. Mtafiti mkuu au mtafiti msaidizi atakuelekeza katika kuyajibu maswali ya dodoso. Kuyajibu maswali ya dodoso na kupimwa kupitia chombo cha MCSI kutachukua takriban dakika 30 hadi dakika 40.

ii. Taratibu za majadiliano ya vikundi

Wewe kama mtunzaji katika familia umepewa nafasi hii kushiriki katika majadiliano ya vikundi itakayohusisha washiriki kati ya 6 na 8 ili kubaini uzoefu wako wa utunzaji wa wagonjwa wa saratani. Mtafiti mkuu ametengeneza mwongozo wa kuendesha majadiliano haya ili kukusanya taarifa kuhusu changamoto unazopata au kutatizika unakopitia katika utunzaji wako wa mgonjwa huyu na pia kukusanya taarifa kuhusu aina ya usaidizi unaohitaji ili kupunguza changamoto hizi au kutatizika huku. Mwongozo huu utatumika wakati wa majadiliano ya vikundi. Mazungumzo katika vikao hivi yatanaswa kwenye kanda huku pia mtafiti mkuu na watafiti wasaidizi wakiyanakiri. Kila kikao kitachukua muda wa takriban dakika 30.

iii. Taratibu za kipimo cha ECOG

Wewe kama mgonjwa anayetunzwa na mshiriki tuliyemuuliza maswali kwa mujibu wa utafiti huu, mtafiti mkuu au mtafiti msaidizi atatumia kipimo cha ECOG ili kutathmini hali yako ya kimwili na kama unaweza fanya shughuli tofauti za kujitunza mwenyewe bila kusaidiwa na wengine. Zoezi hili litakuwa fupi sana na litachukua chini ya dakika 3.

iv. Taratibu za mahojiano ya hoja muhimu

Wewe kama mtaalaam katika Matibabu ya Saratani na Huduma zinazoambatana na matibabu haya au katika maswala ya matibabu ya kijamii, umechaguliwa kushiriki katika utafiti huu kulingana na ufahamu na ujuzi wako wa kuwahudumia wagonjwa wa saratani na familia zao. Mtafiti mkuu ametayarisha mwongozo wa mahojiano ambao utatumika kukusanya taarifa kuhusu mambo yanayohusiana na mfumo wa afya na ambayo yanachangia changamoto za utanzaji wa wagonjwa hawa na pia mikakati inayoweza kusaidia kupunguza changamoto hizi baina ya watunzaji katika familia. Mahojiano haya yatanaswa kwenye kanda huku pia mtafiti mkuu na watafiti wasaidizi wakiyanakiri. Kila kikao cha mahojiano kitachukua muda kati ya dakika 30 na dakika 40.

7. Fidia

Hakuna malipo yatakayotolewa kwa kushiriki katika utafiti huu. Kushiriki utafiti huu ni bure.

8. Kushiriki na kujiondoa kwenye utafiti huu

Tafadhali, elewa kuwa kushiriki katika utafiti huu ni kwa hiari yako binafsi. Ikiwa utabadilisha kauli na uamue kutoendelea kushiriki, uko huru kusitisha kushiriki wakati wowote na hutaathiriwa vibaya kwa njia yoyote. Unaweza pia ruka au ukose kujibu maswali mengine au usitishe kushiriki kwa wakati wowote.

9. Usambazaji wa matokeo ya utafiti huu

Matokeo ya utafiti huu yatasambazwa au kushirikishwa kupitia vikao vya kitaaluma, mikutano/kongomano za kisayansi na yatachapishwa katika majarida ya kisayansi.

10. Mawasiliano

Utapewa kadi iliyoko na taarifa kuhusu jinsi ya kuwasiliana na mtafiti mkuu, wasimamizi wake na ile ya mkurugenzi wa maadili katika hospitali kuu ya Kenyatta na chuo kikuu cha Nairobi (KNH-UON ERC). Ukiwa utakuwa na maswali yoyote au tuhuma zozote kuhusu utafiti huu au kuhusiana na haki zako kama mshiriki, jisikie huru kuwasiliana nao ukitumia taarifa za mawasiliano zifuatazo;

Mtafiti mkuu: Morris M Muriuki, Sanduku la Posta, 2609-60200, Meru. Nambari ya Simu: 0723 366 099

Msimamizi: Dkt Bernard Mbithi, Sanduku la Posta 62000-00200, Nairobi. Nambari ya Simu: 0722 321 945

Msimamizi: Prof Sherry Oluchina, Sanduku la Posta 62000-00200, Nairobi. Nambari ya Simu: 0724 668 425

Mwenye kiti/Katibu, KNH-UON ERC, Sanduku la Posta 20723-00202, Nairobi. Nambari ya Simu: 2726300-9 Ext. 44102. Barua pepe: uonknh_erc@uonbi.ac.ke.

Ahsanti.

Appendix III: Consent form (Questionnaire and Modified Caregiver Strain Index tool)

I have read and understood the read the information pertaining to this consent or have had the information read to me. I have had all my questions or concerns about this study addressed in a language that I can understand. The risks and benefits have been explained to me. I understand that my participation in this study is voluntary and that I may choose to withdrawal any time. I freely agree to participate in this research study by way of responding the questionnaires.

I understand that all efforts will be made to keep information regarding my personal identity confidential. By signing this consent form I agree to participate in this research study titled “Factors Contributing to Role Strain among Family Caregivers of Adult Patients suffering from Cancer at Kenyatta National Hospital”.

Signature of participant/Thumb print:…………………………. **Date:**………

Researcher/Research assistant statement

I, the undersigned, have fully explained the relevant details of this research study to the participant signed above and believe that the participant has understood and has willingly and freely given his/her consent.

Researcher/Research assistant Name:………………………………**Date:**……….

Signature…………………………………………………….

Appendix IV: Fomu ya Idhini (Dodoso na Chombo cha MCSI)

Nimesoma na nikaelewa taarifa zote kuhusiana na idhini hii ya kushiriki katika utafiti huu au nimepata kusomewa taarifa kuhusiana na idhini hii. Pia maswali yote niliyokuwa nayo au wasiwasi wowote niliokuwa nao kuhusiana na utafiti huu yamewezwa kujibiwa kwa lugha ninayoelewa. Nimepata pia maelezo kuhusu madhara na manufaa ya kushiriki katika utafiti huu. Ninafahamu kuwa nashiriki katika utafiti huu kwa hiari na kuwa niko huru kujiondoa wakati wowote. Ninakubali kushiriki katika utafiti huu kwa njia ya kujibu dodoso hii.

Ninafahamu kuwa juhudi zote zitafanywa/zitachukuliwa kuhakikisha ya kuwa taarifa zinazonitambulisha zimewekwa siri. Kwa kutia sahihi katika fomu hii ya idhini, ninakubali kushiriki katika utafiti huu wenye kichwa “Sababu zenye kuchangia changamoto za majukumu baina ya watunzaji kwenye familia ya wagonjwa wa saratani, ambao ni watu wazima, katika hospitali kuu ya Kenyatta”.

Sahihi ya mshiriki/ Chapa ya kidole:…………………………. **Tarehe:**…………

Kauli ya mtafiti mkuu/mtafiti msaidizi /

Mimi, niliye tia sahihi hapa chini, nimemwelezea kwa kina habari zote muhimu kuhusiana na utafiti huu mshiriki aliye tia sahihi yake hapo juu na naamini ya kuwa ameelewa na kuwa amekubali kushiriki katika utafiti huu kwa hiari yake mwenyewe.

Jina la mtafiti mkuu/mtafiti msaidizi /:…………………………… **Tarehe:**……………

Sahihi……………………………………………………..

Appendix V: Consent form (Focus group discussion)

I have read and understood the read the information pertaining to this consent or have had the information read to me. I have had all my questions or concerns about this study addressed in a language that I can understand. The risks and benefits have been explained to me. I understand that my participation in this study is voluntary and that I may choose to withdrawal at any time. I freely agree to participate in audio-recorded focus group discussions.

I understand that all efforts will be made to keep information regarding my personal identity confidential. By signing this consent form I agree to participate in this research study titled “Factors Contributing to Role Strain among Family Caregivers of Adult Patients suffering from Cancer at Kenyatta National Hospital”.

Signature of participant/Thumb print:……………………….**Date:**……………..

Researcher/Research assistant statement

I, the undersigned, have fully explained the relevant details of this research study to the participant signed above and believe that the participant has understood and has willingly and freely given his/her consent.

Researcher/Research assistant Name:……………………………**Date:**………

Signature…………………………………………………….

Appendix VI: Fomu ya Idhini (Majadiliano ya Vikundi)

Nimesoma na nikaelewa taarifa zote kuhusiana na idhini hii ya kushiriki katika utafiti huu au nimepata kusomewa taarifa kuhusiana na idhini hii. Pia maswali yote niliyokuwa nayo au wasiwasi wowote niliokuwa nao kuhusiana na utafiti huu yamewezwa kujibiwa kwa lugha ninayoelewa. Nimepata pia maelezo kuhusu madhara na manufaa ya kushiriki katika utafiti huu. Ninafahamu kuwa nashiriki katika utafiti huu kwa hiari na kuwa niko huru kujiondoa wakati wowote. Ninakubali kushiriki katika majadiliano ya vikundi yatakayonaswa kwenye kanda.

Ninafahamu kuwa juhudi zote zitafanywa/zitachukuliwa kuhakikisha ya kuwa taarifa zinazonitambulisha zimewekwa siri. Kwa kutia sahihi katika fomu hii ya idhini, ninakubali kushiriki katika utafiti huu wenye kichwa “Sababu zenye kuchangia changamoto za majukumu baina ya watunzaji kwenye familia ya wagonjwa wa saratani, ambao ni watu wazima, katika hospitali kuu ya Kenyatta”.

Sahihi ya mshiriki/ Chapa ya kidole:………………………….**Tarehe:**…………

Kauli ya mtafiti mkuu/mtafiti msaidizi

Mimi, niliye tia sahihi hapa chini, nimemwelezea kwa kina habari zote muhimu kuhusiana na utafiti huu mshiriki aliye tia sahihi yake hapo juu na naamini ya kuwa ameelewa na kuwa amekubali kushiriki katika utafiti huu kwa hiari yake mwenyewe.

Jina la mtafiti mkuu/mtafiti msaidizi:……………………………**Tarehe:**……

Sahihi…………………………………………………..

Appendix VII: Consent form (ECOG Scale)

I have read and understood the information pertaining to this consent or have had the information read to me. I have had all my questions or concerns about this study addressed in a language that I can understand. The risks and benefits have been explained to me. I understand that my participation in this study is voluntary and that I may choose to withdrawal any time. I freely agree to have my functional status assessed using the ECOG scale.

I understand that all efforts will be made to keep information regarding my personal identity confidential. By signing this consent form I agree to participate in this research study titled “Factors Contributing to Role Strain among Family Caregivers of Adult Patients suffering from Cancer at Kenyatta National Hospital”.

Signature of participant/Thumb print:…………………………. **Date:**…………

Researcher/Research assistant statement

I, the undersigned, have fully explained the relevant details of this research study to the participant signed above and believe that the participant has understood and has willingly and freely given his/her consent.

Researcher/Research assistant Name:…………………………………**Date:**……

Signature…………………………………………………..

Appendix VIII: Fomu ya Idhini (ECOG Scale)

Nimesoma na nikaelewa taarifa zote kuhusiana na idhini hii ya kushiriki katika utafiti huu au nimepata kusomewa taarifa kuhusiana na idhini hii. Pia maswali yote niliyokuwa nayo au wasiwasi wowote niliokuwa nao kuhusiana na utafiti huu yamewezwa kujibiwa kwa lugha ninayoelewa. Nimepata pia maelezo kuhusu madhara na manufaa ya kushiriki katika utafiti huu. Ninafahamu kuwa nashiriki katika utafiti huu kwa hiari na kuwa niko huru kujiondoa wakati wowote. Ninakubali kwa hiari yangu ya utendaji kazi ikaguliwe kupitia kipimo cha ECOG.

Ninafahamu kuwa juhudi zote zitafanywa/zitachukuliwa kuhakikisha ya kuwa taarifa zinazonitambulisha zimewekwa siri. Kwa kutia sahihi katika fomu hii ya idhini, ninakubali kushiriki katika utafiti huu wenye kichwa “Sababu zenye kuchangia changamoto za majukumu baina ya watunzaji kwenye familia ya wagonjwa wa saratani, ambao ni watu wazima, katika hospitali kuu ya Kenyatta”.

Sahihi ya mshiriki/ Chapa ya kidole:…………………………**Tarehe:**…………

Kauli ya mtafiti mkuu/mtafiti msaidizi

Mimi, niliye tia sahihi hapa chini, nimemwelezea kwa kina habari zote muhimu kuhusiana na utafiti huu mshiriki aliye tia sahihi yake hapo juu na naamini ya kuwa ameelewa na kuwa amekubali kushiriki katika utafiti huu kwa hiari yake mwenyewe.

Jina la mtafiti mkuu/mtafiti msaidizi:………………………………**Tarehe:**……

Sahihi…………………………………………………..

Appendix IX: Consent form (Key Informant Interview)

I have read and understood the read the information pertaining to this consent or have had the information read to me. I have had all my questions or concerns about this study addressed in a language that I can understand. The risks and benefits have been explained to me. I understand that my participation in this study is voluntary and that I may choose to withdrawal any time. I freely agree to participate in audio-recorded key informant interviews.

I understand that all efforts will be made to keep information regarding my personal identity confidential. By signing this consent form I agree to participate in this research study titled "Factors contributing to Role Strain among Family Caregivers of Adult Patients suffering from Cancer at Kenyatta National Hospital".

Signature of participant/Thumb print:…………………………**Date:**……………

Researcher/Research assistant statement

I, the undersigned, have fully explained the relevant details of this research study to the participant signed above and believe that the participant has understood and has willingly and freely given his/her consent.

Researcher/Research assistant Name:…………………………………**Date:**……

Signature…………………………………………………..

Appendix X: Consent form (Audio recording)

I have read and understood the information pertaining to this consent or have had the information read to me. I have had all my questions or concerns about this study addressed in a language that I can understand. The risks and benefits have been explained to me. I understand that my participation in this study is voluntary and that I may choose to withdrawal at any time. I freely agree to be audio-recorded by the researcher during focus group discussions or interview.

I understand that all efforts will be made to keep information regarding my personal identity confidential. By signing this consent form I agree to participate in this research study titled “Factors contributing to Role Strain among Family Caregivers of Adult Patients suffering from Cancer at Kenyatta National Hospital”.

Signature of participant/Thumb print:…………………………….**Date:**……………

Researcher/Research assistant statement

I, the undersigned, have fully explained the relevant details of this research study to the participant signed above and believe that the participant has understood and has willingly and freely given his/her consent.

Researcher/Research assistant Name:……………………………**Date:**………

Signature…………………………………………………….

Appendix XI: Fomu ya Idhini (Kunakili sauti)

Nimesoma na nikaelewa taarifa zote kuhusiana na idhini hii ya kushiriki katika utafiti huu au nimepata kusomewa taarifa kuhusiana na idhini hii. Pia maswali yote niliyokuwa nayo au wasiwasi wowote niliokuwa nao kuhusiana na utafiti huu yameweza kujibiwa kwa lugha ninayoelewa. Nimepata pia maelezo kuhusu madhara na manufaa ya kushiriki katika utafiti huu. Ninafahamu kuwa nashiriki katika utafiti huu kwa hiari yangu na kuwa niko huru kujiondoa wakati wowote. Ninakubali kwa hiari sauti yangu kunaswa kwenye kanda na mtafiti mkuu ninaposhiriki katika majadiliano ya vikundi au mahojiano ya moja kwa moja.

Ninafahamu kuwa juhudi zote zitafanywa au zitachukuliwa kuhakikisha ya kuwa taarifa zinazonitambulisha zitawekwa siri. Kwa kutia sahihi katika fomu hii ya idhini, ninakubali kushiriki katika utafiti huu wenye kichwa “Sababu zenye kuchangia changamoto za majukumu baina ya watunzaji kwenye familia ya wagonjwa wa saratani, ambao ni watu wazima, katika hospitali kuu ya Kenyatta”.

Sahihi ya mshiriki/ Chapa ya kidole:…………………………**Tarehe:**…………

Kauli ya mtafiti mkuu/mtafiti masaidizi

Mimi, niliye tia sahihi hapa chini, nimemwelezea kwa kina habari zote muhimu kuhusiana na utafiti huu mshiriki aliye tia sahihi yake hapo juu na naamini ya kuwa ameelewa na kuwa amekubali kushiriki katika utafiti huu kwa hiari yake mwenyewe.

Jina la mtafiti mkuu/mtafiti masaidizi:……………………………..**Tarehe:**……

Sahihi…………………………………………………..

Appendix XII: Consent form (Referral)

I have read and understood the information pertaining to this consent or have had the information read to me. I have had all my questions or concerns about this study addressed in a language that I can understand. The risks and benefits have been explained to me. I understand that my participation in this study is voluntary and that I may choose to withdrawal at any time.

By signing this consent form and having been a participant in this research study titled "Factors contributing to Role Strain among Family Caregivers of Adult Patients suffering from Cancer at Kenyatta National Hospital", I authorize researcher to refer me for further services for the good of my health and have freely shared my phone number to facilitate follow-up by the researcher. I commit to meet the costs of such services.

Signature of participant/Thumb print:…………………………….**Date:**……………

Researcher/Research assistant statement

I, the undersigned, have fully explained the relevant details of this research study to the participant signed above and believe that the participant has understood and has willingly and freely given his/her consent.

Researcher/Research assistant Name:………………………………**Date:**………

Signature…………………………………………………….

Appendix XIII: Fomu ya Idhini (Rufaa)

Nimesoma na nikaelewa taarifa zote kuhusiana na idhini hii ya kushiriki katika utafiti huu au nimepata kusomewa taarifa kuhusiana na idhini hii. Pia maswali yote niliyokuwa nayo au wasiwasi wowote niliokuwa nao kuhusiana na utafiti huu yameweza kujibiwa kwa lugha ninayoelewa. Nimepata pia maelezo kuhusu madhara na manufaa ya kushiriki katika utafiti huu. Ninafahamu kuwa nashiriki katika utafiti huu kwa hiari yangu na kuwa niko huru kujiondoa wakati wowote.

Kwa kutia sahihi katika fomu hii ya idhini, nakama mshiriki katika utafiti huu wenye kichwa “Sababu zenye kuchangia changamoto za majukumu baina ya watunzaji kwenye familia ya wagonjwa wa saratani, ambao ni watu wazima, katika hospitali kuu ya Kenyatta”, nimeidhinisha mtafiti mkuu kunikabithi rufaa ya kuhudhuria huduma zaidi kwa ajiri ya afya yangu na kwa hiari yangu nimepeana nambari yangu ya simu hili kurahisisha kufuatiliwa kwa ukaribu na mtafiti mkuu. Pia nitajitolea kugharamia hizo huduma.

Sahihi ya mshiriki/ Chapa ya kidole:………………………….**Tarehe:**…………

Kauli ya mtafiti mkuu/mtafiti masaidizi

Mimi, niliye tia sahihi hapa chini, nimemwelezea kwa kina habari zote muhimu kuhusiana na utafiti huu mshiriki aliye tia sahihi yake hapo juu na naamini ya kuwa ameelewa na kuwa amekubali kushiriki katika utafiti huu kwa hiari yake mwenyewe.

Jina la mtafiti mkuu/mtafiti masaidizi:……………………………..**Tarehe:**……

Sahihi……………………………………………………..

Appendix XIV: Structured questionnaire for family caregiver

S.NO……../……../…......Date……………………

Dear Respondent, you are much welcome and your responses are valued.

Study Title: "Factors contributing to Role Strain among Family Cargivers of Adult Patients suffering from Cancer at Kenyatta National Hospital"

Instructions:

Kindly note that your name or any personal details will not be written anywhere on this questionnaire

Put a tick in the space provided [ ] next to the right response

There is also a space provided to write your responses as applicable

PART I: FAMILY CAREGIVER SOCIO-DEMOGRAPHIC CHARACTERISTICS

1. What is your gender?
   1. Male [ ] 2. Female [ ]
2. Age in years? Tick which appropriate
   1. 18-35 years (Young adult) [ ]
   2. 36-60 years (Middle aged) [ ]
   3. Over 61 years (Elderly) [ ]
3. Education status?
   1. No formal education [ ] 2. Primary [ ] 3. Secondary [ ] 4. Tertiary/college[ ]
4. Marital status?
   1. Married [ ] 2. Not Married (Single, separated, Widowed) [ ]
5. Employment status?
   1. Employed Formally (Full time, Part time, Self-employed) [ ]
   2. Unemployed [ ]

6. Monthly income in Kenya shillings?
   1. Less than 20,000Ksh (Low income) [ ]
   2. Above 20,000Ksh-50,000Ksh (Moderate income) [ ]
   3. Above 50,000Ksh (High income) [ ]
7. (a). Do you reside with the patient in the same home stead or locality?
   1. Yes [ ]   2. No [ ]
   (b). What is the patient's area of residence?
   1. Nairobi County: ……………………………………………………………………
   2. Other County: …………………………………..………………………………
8. Relationship to the patient?
   1. Parent/In-law parent [ ]   2. Spouse/partner [ ]   3. Son/Daughter [ ]
   4. Friend/Neighbour [ ]   5. Brother/Sister [ ]
   6. Others; Specify; …………………………………………………………
9. Duration of care-giving to patient?
   1. Above 2 weeks-1 year [ ]
   2. Above 1 year-3 years [ ]
   3. Above 3 years [ ]
10. Estimated hours of care provision per day?
   1. Less than 5 hours [ ]
   2. Above 5 hours [ ]

Part II: Family caregiver roles

11. The following are the roles you have been providing or currently providing to your patient. Kindly rate the following statements in a scale of 1 to 5 (where 1= Strongly disagree, 2= Disagree, 3= Somewhat agree, 4= Agree, 5= Strongly disagree) in regard to the strain you experience when providing this care.

	Kindly tick the most that applies to you	Strongly disagree 1	Disagree 2	Somewhat agree 3	Agree 4	Strongly agree 5
1	I am strained by handling transportation issues like organizing and paying for transport					
2	I am strained by handling and supporting my patient financially					
3	I am strained by providing household chores like meals preparation, feeding, shopping and house keeping					
4	I am strained by handling patient medication like measuring and giving drugs, reminding to take drugs, buying drugs					
5	I am strained by keeping watch over treatment side effects at home.					
6	Caring for this patient has strained my other family responsibilities.					

Part III: Predictors of role strain

a. Patient related factors

12. Patient’s sex?
    1. Male [ ]　　　　2. Female [ ]
13. Patient’s age?
    1. 18-35 years (Young adult) [ ]
    2. 36-60 years (Middle aged) [ ]
    3. Over 61 years (Elderly) [ ]
14. Patient medical history

13a. Type of cancer……………………...

13b. Stage of cancer at diagnosis;…………Current stage (if available);……

13c. Treatment modality undertaken; Tick all that apply.

1. Chemotherapy [ ]
2. Radiotherapy [ ]

15. What type of health insurance does the patient have? Tick all that apply.

1. NHIF [ ]   2. Private medical insurance [ ]   3. None [ ]

16. (a) Apart from cancer, does your patient have any other chronic medical condition?   Yes [ ]   No [ ]

(b) If yes to 16 (a); Tick all that apply.

1. Hypertension [ ]   2. Diabetes [ ]   3. HIV/AIDS [ ]

4. Kidney disease [ ]   5. Musculoskeletal disorder [ ]

6. Others; Specify…………………………………………………………

17. Kindly rate the following statements by in a scale of 1 to 5 (where 1= Strongly disagree, 2= Disagree, 3= Somewhat agree, 4= Agree, 5= Strongly disagree) in regard to the strain you experience based on your patient's current situation as listed below.

	Kindly tick the most that applies to you.	Strongly disagree 1	Disagree 2	Somewhat agree 3	Agree 4	Strongly agree 5
1	The current physical functional status of my patient strains me.					
2	My patient suffers from other disease conditions which also strain me.					
3	The current patient treatment modality strains me.					
4	The current patient's cancer stage strains me.					
5	My current					

	interpersonal relations with my patient strains me.					

b. PSYCHOSOCIAL FACTORS

18. Do you belong to any social support group specifically for patients with cancer and their family caregivers?
    1. Yes [ ]   2. No [ ]

19. Based on your experience as a family caregiver, kindly rate the following statements in a scale of 1 to 5 (where 1= Strongly disagree, 2= Disagree, 3= Somewhat agree, 4= Agree, 5= Strongly disagree) in regard to what you experience when caring for your patient.

	Kindly tick the most that applies to you.	Strongly disagree	Disagree	Somewhat agree	Agree	Strongly agree
1	I have become socially isolated from my family, friends and social events which strain me.					
2	I experience sleep disturbance or lack sleep due to caregiving which strain me					
3	In the last two weeks, I have felt psychologically upset or experienced some stress which strains me.					
4	I no longer get social support from the family, relatives and this strains me.					
5	I experience anxiety and get fatigued which strains me.					

c. ECONOMIC FACTORS

20. Kindly rate the following statements in a scale of 1 to 5 (where 1= Strongly disagree, 2= Disagree, 3= Somewhat agree, 4= Agree, 5= Strongly disagree) in regard to the financial strain you experience as a family caregiver?

Kindly tick the most that applies to you		Strongly disagree 1	Disagree 2	Somewhat agree 3	Agree 4	Strongly agree 5
1	Paying for transportation during my patient clinic attendance strains me.					
2	Paying for accommodation during my patient clinic attendance strains me.					
3	Buying chemotherapy drugs for my patient strains me.					
4	Paying for the many laboratory and radiological investigations ordered for my patient strains me.					
5	Supporting my patient financially has made my financial status worse.					

d. HEALTH SYSTEM FACTORS

Kindly tick the most that applies to you		Strongly disagree 1	Disagree 2	Somewhat agreee 3	Agree 4	Strongly agree 5
1	It strains me and my patient getting around Cancer Treatment Centre.					
2	It strains to wait long before my patient is attended to.					
3	Non-involvement in treatment decisions and care plan by healthcare professionals strains me in caring for my patient.					
4	It strains to schedule timely clinic appointments for my patient.					
5	Healthcare professionals communicate to me and my patient in a way that we strain to understand or get the meaning.					

6	I strain in understanding what treatment side effects to monitor or how to manage them at home.					
7	I lack information on cancer as a disease, treatment and its progression which strains me in caring for my patient.					
8	Shortage of cancer drugs at this hospital strains me and the patient in buying the drugs.					
9	There has been breakdown of radiotherapy machines and lack of radiotherapy services which strains me and my patient.					
10	I am strained because healthcare workers don not assess my general health and my capacity in caring for my patient.					
11	I experience strain due to lack of healthcare workers support, information or skills training me on how to take care of my patient at home.					
12	I experience some caregiving challenges or concerns at home which strain me and wish I could call a healthcare worker for guidance.					
13	I experience strain due to lack of a home visit by a nurse or doctor to enhance my skills in caregiving or address any concerns to ease the strain.					
14	I experience strain due to traveling long distance in search for cancer treatment services.					
15	I experience strain in getting my patient assessed by a specialized healthcare professional like oncologist.					
16	Cost of cancer treatment/care services offered at this hospital strains me and my patient.					

21. Based on your experience as a family caregiver, Kindly rate the following statements in a scale of 1 to 5 (where 1= Strongly disagree, 2= Disagree, 3= Somewhat agree, 4= Agree, 5= Strongly disagree) in regard to what you experience when bringing your patient at Kenyatta Cancer Treatment Centre?
22. Do you have a designated health care professional or hospital mobile number you could call in case of an emergency or a concern regarding patient care at home?

    1. Yes [ ]   2. No [ ]

23. If yes to the above question, have you ever called for any help or concern?

    1. Yes [ ]   2. No [ ]

e. COPING SKILLS

24. How do you cope with caregiving? Tick all that apply.

    1. Remaining positive [ ]
    2. Keeping to self [ ]
    3. Bible reading and praying a lot [ ]
    4. Reducing my social engagements [ ]
    5. Drinking alcohol [ ]
    6. Smoking cigarette [ ]
    7. Going for counseling [ ]
    8. Sharing the issues with others [ ]
    9. Crying [ ]
    10. Others, specify…………………………………………………………

Thank you for your time and participating in this study

Appendix XV: Dodoso kwa watunzaji katika familia

Nambari…../……/…....Tarehe…………………

Mshiriki mpendwa, umekaribishwa sana na majibu yako yanathaminiwa.

Kichwa cha utafiti: “Sababu zenye kuchangia changamoto za majukumu baina ya watunzaji kwenye familia ya wagonjwa wa saratani, ambao ni watu wazima, katika hospitali kuu ya Kenyatta”

Maagizo:

Kumbuka kuwa jina lako au maelezo yoyote ya kibinafsi hayataandikwa popote katika dodoso hii

Weka alama kwenye kijisanduku [ ] kando ya jibu lililosahihi

Pia kuna nafasi iliyoachwa kukuwezesha kuandika majibu yako kama ipasavyo

Sehemu ya I: Taarifa Za Kibinafsi Za Washiriki

1. Jinsia yako ni?
   1. Kiume [ ] 2. Kike [ ]
2. Umri wako, kwa miaka, ni? Weka alama kwa jibu lililosahihi
   1. Kati ya miaka 18 na miaka 35 [ ]
   2. Kati ya miaka 36 na miaka 60 [ ]
   3. Zaidi ya miaka 61 [ ]
3. Kiwango cha elimu?
   1. Sina elimu [ ] 2. Elimu ya msingi [ ] 3. Elimu ya Sekondari/Chuo [ ]
4. Hali ya ndoa?
   1. Siko kwa ndoa (Sijaolewa, Mjane/Nimefiwa, Nimetalakiwa) [ ]
   2. Nimeolewa [ ]
5. Hali ya kazi?
   1. Sina ajira [ ]
   2. Nimeajiriwa rasmi (Wakati wote, Kwa vipindi, Nimejiajiri) [ ]

6. Mapato ya kila mwezi (kwa pesa za Kenya)?
   1. Chini ya elfu 20 (Mapato ya chini) [ ]
   2. Kati ya zaidi ya elfu 20 na elfu 50 (Mapato ya wastani) [ ]
   3. Zaidi ya elfu 50 (Mapato ya juu) [ ]
7. (a). Je unaishi na mgonjwa katika Nyumba moja au kwenye maeneo moja?
   1. Ndio [ ] 2. La [ ]
   (b). Je, mgonjwa anaishi katika maeneo gani?
   1. Kaunti ya Nairobi [ ]
   2. Kaunti nyingine yoyote [ ] :……………………………………………….
8. Uhusiano wako na mgonjwa?
   1. Mzazi [ ] 2. Mwenziwe wa ndoa [ ] 3. Mtoto wake wa kiume/kike [ ]
   4. Rafiki/Jirani [ ] 5. Ndugu yake [ ]
   6. Zingine; Taja;…………………………………………………………
9. Muda uliomtunza mgonjwa?
   1. Kati ya majuma 2 hadi mwaka moja [ ]
   2. Zaidi ya mwaka moja na chini ya miaka tatu [ ]
   3. Zaidi ya miaka tatu [ ]
10. Makadirio ya masaa ya utunzaji kwa kila siku?
    1. Chini ya masaa 5 [ ]
    2. Zaidi ya masaa 5 [ ]

Sehemu ya II: Majukumu ya Mtunzaji

11. Yafuatayo ni majukumu ambayo umekuwa ukitekeleza au ambayo unatekeleza kwa mgonjwa huu. Tafadhali, eleza kiwango cha kauli hizi ukitumia kipimo cha 1 hadi 5 (ambapo 1 = Sikubaliani kabisa, 2= Sikubaliani, 3= Nakubaliana kiasi fulani, 4= Nakubaliana, 5= Nakubaliana kabisa) kuhusiana na matatizo unayoyapata unapomtunza mgonjwa huu.

	Tafadhali weka alama kwa ile inayojufaa zaidi	Sikubaliani kabisa 1	Sikubaliani 2	Nakubaliana kiasi fulani 3	Nakubaliana 4	Nakubaliana kabisa 5
1	Ninatatizika kwa mambo ya usafiri haswa kupanga na kulipia usafiri					
2	Ninatatizika kuweza kumsaidia mgonjwa kifedha					
3	Ninatatizika kufanya kazi za kinyumbani kama vile kutayarisha lishe, kumpa chakula, kuenda sokoni na kuweka nyumba ikiwa safi					
4	Ninatatizika katika mambo ya kushughulikia matibabu ya mgonjwa kama vile kumpa dawa, kumkumbusha anywe dawa na kununua dawa					
5	Ninatatizika kukaa nikitazama athari za matibabu hapa nyumbani.					
6	Utunzaji wa mgonjwa huyu unaadhiri majukumu yangu mengine ya nyumbani.					

Sehemu ya III: Mambo yanayochangia kutatizika kwenye majukumu

a. Mambo/sababu zinazohusiana na mgonjwa mwenyewe

12. Jinsia ya mgonjwa?

1. Kiume [ ]		2. Kike [ ]

13. Umri wa mgonjwa?
    1. Kati ya miaka 18 na miaka 35 [ ]
    2. Kati ya miaka 36 na miaka 60 [ ]
    3. Zaidi ya miaka 61 [ ]
14. Historia ya matibabu ya mgonjwa

13a. Aina ya saratani……………...

13b. Hatua ya saratani ilipotambuliwa;…...Hatua ya sasa (kama inajulikana);……...

13c. Aina ya matibabu ambayo umepata; Weka alama kwa yote uliyopata.

1. Tiba ya kemia [ ]
2. Tiba ya miale [ ]

15. Aina ya bima ya afya alionayo mgonjwa? Weka alama kwa kila inayokuhusu.

1. Bima ya NHIF [ ] 2. Bima ya matibabu ya kibinafsi [ ] 3. Hana yoyote [ ]

16. (a) Kando na saratani, je mgonjwa wako ako na ugonjwa sugu mwingine wowote au ugonjwa unaohitaji matibabu ya muda mrefu? 1. Ndio [ ] 2. La [ ]?

(b) Kama umejibu ndio (16. a); weka alama kwa kila inayofaa.

1. Shinikizo la damu [ ] 2. Ugonjwa wa sukari [ ] 3. Ugonjwa wa ukimwi [ ]

4. Ugonjwa wa figo [ ] 5. Ugonjwa wa misuli na mifupa [ ]

6. Zingine; Taja…………………………………………………

17. Tafadhali, eleza kiwango cha kauli hizi ukitumia kipimo cha 1 hadi 5 (ambapo 1 = Sikubaliani kabisa, 2= Sikubaliani, 3= Nakubaliana kiasi fulani, 4= Nakubaliana, 5= Nakubaliana kabisa) kuhusiana na matatizo unayoyapata kulingana na hali ya sasa ya mgonjwa kama ilivyo orodheshwa hapa chini.

	Tafadhali weka alama kwa ile inayojufaa zaidi	Sikubaliani kabisa 1	Sikubaliani 2	Nakubaliana kiasi fulani 3	Nakubaliana 4	Nakubaliana kabisa 5
1	Hali ya sasa ya kimwili na					

	utenda kazi wa mgonjwa wangu inanitatiza.					
2	Mgonjwa anaugua maradhi mengine ambayo pia yananitatiza.					
3	Mbinu ya matibabu, ya sasa, ya mgonjwa wangu inanitatiza.					
4	Hatua ya sasa ya saratani ya mgonjwa wangu inanitatiza.					
5	Mahusiano yangu ya sasa na mgonjwa wangu inanitatiza.					

b. Mambo/sababu zinazohusiana na kisaikolojia na mahusiano

18. Je, uko kwenye kikundi cha mahusiano chochote haswa cha wanaougua saratani na watunzaji wao?

    1. Ndio [ ]　　2. La [ ]

19. Kulingana na uzoefu wako kama mtunzaji, tafadhali, eleza kiwango cha kauli hizi ukitumia kipimo cha 1 hadi 5 (ambapo 1 = Sikubaliani kabisa, 2= Sikubaliani, 3= Nakubaliana kiasi fulani, 4= Nakubaliana, 5= Nakubaliana kabisa) kuhusiana na unayoyapitia unapomtunza mgonjwa huyu.

Tafadhali weka alama kwa ile inayofaa zaidi.		Sikubaliani kabisa 1	Sikubaliani 2	Nakubaliana kiasi fulani 3	Nakubaliana 4	Nakubaliana kabisa 5
1	Nimetengwa kimahusiano na familia yangu, marafiki na hafla za					

	kijamii, jambo ambalo hunitatiza.					
2	Huwa nakosa usingizi au usingizi wangu hutatizika kwa sababu ya utunzaji, jambo ambalo hunitatiza					
3	Kwa kipindi cha majuma mawili yaliyopita, nimekuwa nikijihisi mwenye kutatizika kisaikolojia na mwenye dhiki, jambo ambalo hunitatiza.					
4	Huwa sipati tena usaidizi wowote wa kimahusiano kutoka kwa familia na jamaa, jambo ambalo hunitatiza.					
5	Huwa nahisi wasiwasi na kupata uchovu mwingi, jambo ambalo hunitatiza.					

c. Mambo/sababu zinazohusiana na kiuchumi

20. Tafadhali, eleza kiwango cha kauli hizi ukitumia kipimo cha 1 hadi 5 (ambapo 1 = Sikubaliani kabisa, 2= Sikubaliani, 3= Nakubaliana kiasi fulani, 4= Nakubaliana, 5= Nakubaliana kabisa) kuhusiana na matatizo ya kifedha au kiuchumi unayoyapata kama mtunzaji kwenye familia?

Tafadhali weka alama kwa ile inayofaa zaidi		Sikubaliani kabisa 1	Sikubaliani 2	Nakubaliana kiasi fulani 3	Nakubaliana 4	Nakubaliana kabisa 5
1	Kulipia usafiri wakati mgonjwa wangu anaudhuria matibabu, hunitatiza.					

2	Kulipia malazi wakati mgonjwa wangu anaudhuria matibabu , hunitatiza.					
3	Kununua madawa ya matibabu ya mgonjwa wangu, hunitatiza.					
4	Kulipia vipimo vingi vya maabara na uchunguzi za matibabu ya miale zilizoagizwa, hunitatiza.					
5	Kumsaidia mgonjwa wangu kwa njia ya kifedha kumefanya hali yangu ya kiuchumi kuzorota/kuwa mbaya zaidi.					

d. Mambo/sababu zinazohusiana na mfumo wa afya

21. Kulingana na uzoefu wako kama mtunzaji, tafadhali, eleza kiwango cha kauli hizi ukitumia kipimo cha 1 hadi 5 (ambapo 1 = Sikubaliani kabisa, 2= Sikubaliani, 3= Nakubaliana kiasi fulani, 4= Nakubaliana, 5= Nakubaliana kabisa) kuhusiana na mambo unayoyapitia wakati unapomleta mgonjwa wako katika Kituo cha Matibabu ya Saratani cha Kenyatta.

		Sikubaliani kabisa 1	Sikubaliani 2	Nakubaliana kiasi Fulani	Nakubaliana 4	Nakubaliana kabisa 5
1	Mimi na mgonjwa wangu huwa tunatatizwa nakuzunguka katika Kituo cha Matibabu ya Saratani.					
2	Huwa inatatiza kungoja kwa muda mrefu kabla ya mgonjwa wangu kuhudumiwa.					
3	Kutoshirikishwa katika maamuzi na mipangilio ya matibabu na wauguzi hutatiza utunzaji wangu wa mgonjwa.					
4	Huwa inanitatiza kupanga ratiba za kliniki za mgonjwa wangu kwa wakati unaofaa.					
5	Wauguzi huwasiliana nami na mgonjwa wangu kwa njia ngumu kuelewa au kufahamu kile wanachomaanisha.					
6	Huwa inanitatiza kuelewa zile athari za matibabu ambazo nafaa kufuatilia na jinsi ya kuzimudu tukiwa nyumbani.					
7	Nakosa ufahamu halisi kuhusu ugonjwa wa saratani, matibabu yake na jinsi huwa unaendelea, jambo ambalo hunitatiza katika utunzaji wangu wa mgonjwa.					
8	Mimi na mgonjwa huwa tunatatizwa na ununuzi wa dawa za saratani kutokana na upungufu wa dawa za saratani katika hospitali hii.					

9	Kuharibika kwa mashine maalum za matibabu ya miale na ukosefu wa huduma za matibabu ya miale huwa zinatutatiza mimi na mgonjwa wangu.					
10	Huwa inanitatiza kuwa wahudumu wa afya huwa hawaangazii hali yangu ya kiafya na uwezo wangu wa kumtunza mgonjwa huyu.					
11	Huwa natatizika kutokana na ukosefu wa msaada, habari au mafunzo ya ustadi, toka kwa wahudumu wa afya, kuhusiana na jinsi ya kumtunza mgonjwa huyu tukiwa nyumbani.					
12	Huwa napata changamoto za utunzaji wa mgonjwa tukiwa nyumbani na ambazo hunitatiza. Huwa natamani ningeweza kuwasiliana na wahudumu wa afya ili wanielekeze.					
13	Huwa natatizika kwa kukosa kutembelewa na wauguzi nikiwa nyumbani ili wanisaidie kuboresha ustadi wangu wa utunzaji au kuondoa wasiwasi wowote ninaoweza kuwa nao.					
14	Huwa natatizika kutokana na safari ndefu nikitafuta huduma za matibabu ya saratani kwa ajili ya mgonjwa wangu.					
15	Huwa natatizika katika kumpata/kuwapata wauguzi ambao ni wataalamu wa ugonjwa wa saratani ili waweze kumhudumia mgonjwa wangu.					
16	Gharama ya matibabu ya ugonjwa wa saratani yanayopatikana katika hospitali hii huwa inatutatiza mimi na mgonjwa wangu.					

22. Je, uko na mhudumu wa afya aliyeteuliwa au nambari ya simu ya hospitali ambayo unaweza piga kukiwa na tukio la dharura au swali lolote kuhusu utunzaji wa mgonjwa mkiwa nyumbani?

    1. Ndio [ ]   2. La [ ]

23. Ikiwa jibu lako ni Ndio kwa swali lililotangulia, umeshawahi itisha usaidizi wowote au kuuliza swali lolote?

    1. Ndio [ ]   2. La [ ]

e. Mbinu za kustahimili

24. Je, huwa unastahimili kivipi utunzaji wa mgonjwa? Weka alama kwa njia zote unazotumia.

    1. Kuwa na mtazamo mzuri [ ]

    2. Kuweka habari hizo kwa binafsi/Kutosemezana habari hizo na wengine [ ]

    3. Kusoma bibilia na kusali sana [ ]

4. Kupunguza shughuli za mahusiano yangu [ ]

5. Kunywa pombe [ ]

6. Kuvuta sigara [ ]

7. Kwenda kwa ushauri nasaha [ ]

8. Kubadilishana mawazo na mambo na wengine [ ]

9. Kwa kulia [ ]

10. Zingine, taja…………………………………………………………………….

Ahsanti kwa wakati wako na kwa kushiriki katika utafiti huu

Appendix XVI: ECOG Performance Status

Grade	**ECOG**
0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work
2	Ambulatory and capable of all self care but unable to carry out any work activities. Up and about more than 50% of waking hours
3	Capable of only limited self care, confined to bed or chair more than 50% of waking hours
4	Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair
5	Dead
Adopted from Oken *et al*. (1982)	

Thank you for your time

Appendix XVI: Hali ya utendaji kwenye ECOG

Daraja	**ECOG**
0	utendaji kamilifu, anaweza kuendeleza utendaji wa majukumu yote yaliokuwemo kabla ya kuugua bila matatizo yoyote
1	Anashindwa kutekeleza majukumu yanayohitaji nguvu nyingi za kimwili lakini anaweza tembea na kufanya kazi rahisi au zisizo hitaji nguvu nyingi, kwa mfano, kazi rahisi za kinyumbani au za kiofisi
2	Anaweza kujitembeza na anao uwezo wa kujitunza kikamilifu mwenyewe lakini anashindwa kufanya kazi yoyote. Yupo kwenye shughuli mbalimbali zaidi ya asilimia hamsini ya masaa ya kuamka
3	Hana uwezo wa kujitunza kikamilifu mwenyewe, na anakaa kwenye kitanda au kiti kwa zaidi ya asilimia hamsini ya masaa ya kuamka
4	Amelemazwa kabisa. Hawezi jitunza hata kidogo, na anakaa kwenye kitanda au kiti wakati wote
5	Amekufa au ameaga
Imetolewa kwa Oken *et al*. (1982)	

Ahsanti kwa wakati wako

Appendix XVII: Focus group discussion guide

A. Introduction

- ❖ Greet and welcome the group participants.
- ❖ Acknowledgement of participants.
- ❖ Introduction of research title and research objectives.

1. **Consent-** Review the informed consent form and acknowledgement of voluntary willingness of participants to participate in the discussion.
2. **About the focus group discussion and ground rule.**
    i. The session will last for about 30 minutes.
    ii. Respect for each participant’s ideas and opinions.
    iii. We are interested in getting your experiences, ideas and opinions. Both positive and negative experiences are valuable.
    iv. The session will be tape recorded as well as notes will be taken down to gather more detailed information and to double check the data for accuracy.
3. **Clarification for any questions or concerns**; from participants before the session starts, then turn tape recorder on.

B. Focus group discussion questions.

1. In your own opinion, what challenges do you face when caring for this patient? Which of these strains you? (Probes: physical strain, psycho-social strain, economic strain).
2. In your own opinion, how has caregiving affected your other responsibilities? (Probes: family responsibilities, job, social activities)
3. In your own opinion, does the patient argument the support you provide or what makes it hard for care provision? (Probes: Patient physical strength (bathes self, feeds self, ambulates self), has a medical insurance, warm relations/appreciative of care provided, use abusive words)
4. In your own opinion, what challenges do you face at the hospital when bringing your patient for clinic attendance? Which of these strains you? (Probes: Affordability of cancer treatment, system navigation and integration, communication and information, waiting time, staff shortage, skills training for FCGs).

5. Present a summary to participants; summary of the key points from the discussion! Is there anything else? Any questions?

Thank you for your active participation in this study!

Appendix XVIII: Focused group discussion guide [Kiswahili Version]

A. Utangulizi

- Wasalimie na uwakaribishe washiriki wa majadiliano ya vikundi.
- Tambua washiriki wa majadiliano ya vikundi.
- Elezea kuhusu kichwa cha utafiti na malengo ya utafiti huu.

1. **Idhini ya kushiriki –** Hakikisha majibu katika fomu ya idhini ya kushiriki na kuwa uamuzi wao wa kushiriki katika majadiliano ya vikundi ni wa hiari.
2. **Kuhusu majadiliano ya vikundi na sheria zitakazotumika.**
    i. Kipindi cha majadiliano kitachukua muda wa dakika thelathini.
    ii. Kuwe na kuheshimu maoni ya kila mmoja.
    iii. Tuko na haja ya kupata uzoefu wako na maoni yako, yawe mazuri au mabaya, yote ni muhimu.
    iv. Majadiliano haya yatarekodiwa kwenye mkanda na pia kuandikwa ili kusaidia kuhakikisha usahihi wa taarifa/maelezo yakayotolewa.
3. Elezea/fafanua kuhusu maswali yoyote au wasiwasi wowote; kutoka kwa washiriki wa majadiliano ya vikundi kabla ya majadiliano kuanza, halafu fungulia mkanda.

B. Maswali ya majadiliano ya vikundi.

1. Kwa maoni yako binafsi, je, ni changamoto gani huwa unapitia unapomtunza mgonjwa huyu? Ni gani kati ya haya huwa inakutatiza? (Chunguza: matatizo ya kimwili, matatizo ya kisaikolojia na kijamii, matatizo ya kiuchumi).
2. Kwa maoni yako binafsi, utunzaji wa ngonjwa umeadhiri kwa njia ipi majukumu yako mengine? (Chunguza: majukumu ya kifamilia, kikazi, kijamii)
3. Kwa maoni yako binafsi, je mgonjwa huwa anaunga mkono usaidizi wako au nini hufanya iwe ngumu unapo mtunza? (Chunguza: kama vile kujiosha, kujilisha, ana bima ya matibabu, kujitembeza mwenyewe, anashukuru kwa utunzaji anaopata, anatusiana)

4. Kwa maoni yako binafsi, ni changamoto zipi huwa unapata wakati wa kumleta mgonjwa hospitalini? Ni gani kati ya haya huwa inakutatiza? (Chunguza: kukimu gharama ya matibabu ya saratimu, ujumuishaji na utenda kazi wa mfumo wa matibabu, mawasiliano na habari, muda wa kungoja, upungufu wa idadi ya wafanyakazi, mafunzo ya ustadi kwa FCGs).
5. Toa muhtasari wa majadiliano kwa washiriki; muhtasari wa vidokezo muhimu za majadiliano hayo ya vikundi! Je, kuna jambo lingine lolote? Je, kuna maswali yoyote?

Ahsanti kwa kushiriki katika utafiti huu!!

Appendix XIX: Key Informant Interview Guide

Dear Respondent,

Having been supplied with the study participant’s information and consented to participate in this study, you are warmly invited to participate in this study on the “Factors contributing to Role Strain among Family caregivers of Adult Patients suffering from Cancer at Kenyatta National Hospital”. You have been selected to participate in this study owing to your expertise in cancer care and experience with patients with cancer and their family caregivers. During the interview, the discussion sessions may be tape recorded. Also note that the Information that you will provide in this study will be treated with ultimate confidentiality and will remain anonymous.

Welcome.

1. Gender: Male [ ] Female [ ] No. of years working at KNH Cancer centre [ ]
2. Briefly describe the health care workers staffing levels, specialization levels and current work load at KNH cancer treatment centre. (medical officers, nursing officers, medical social workers, radiographers).
3. Are there any formulated policies at KNH Cancer centre to guide assessment of role strain and integration of family caregivers of adult patients with cancer in the unit of care? Yes [ ] No [ ]
4. Based on your experience at Kenyatta National Hospital Outpatient Cancer Treatment Centre (KNH CTC), what would you say about each of the following and how they affect delivery of cancer treatment? Which of these contributes to the strain experienced by the family caregivers of cancer patients? Are there any strategies that have been put in place to address the challenges?
    a. Human resources (specialized health care workers in oncology)
    b. Information and communication among health care workers and patient/family caregivers.
    c. Affordability of cancer treatment and care

d. Availability of Cancer drugs, Laboratory equipments and radiotherapy machines.
e. System navigation
f. Waiting time and treatment delays
g. Integration of family caregivers in the unit of care and assessment of role strain among family caregivers
h. Patient-Family caregiver support groups.
i. Skills training of family caregivers and home visiting by health care workers.

5. Is there anything else that we may have left out which could be of benefit to this study?

Thank you for your active participation in this study!!

Appendix XX: Protocol to handle potential psychological distress

Protocol to handle potential psychological distress	
Scan for psychological distress	During data collection process (filling of structured questionnaire or during focussed group discussion), the researcher/research assistants will actively look out for study participants who may portray heightened emotional distress or behaviour that suggest participating in the discussion/interview is too stressful. Behaviour suggestive of psychological distress;(crying continuously, shaking, uncomfortable, anxious, irritable, agitation)
Action	1. Stop the discussion/interview or the participant from filling the questionnaire. 2.Interviewer will offer immediate support; i. Keep the participant company and should not be left alone. ii. Allow the participant to cry and reassure it is good to do so. iii. Encourage the participant to verbalize his/her concerns. iv. Empathize and be sensitive to the participant’s concern. v. If calm and the situation has normalized, assess if the participant is comfortable to proceed with the data collection process. vi. If uncomfortable or not willing to proceed with the data collection process, terminate the participant’s participation and ensure the following; a. Accompany the participant to a quiet room and ensure privacy. b. Researcher to offer counselling and reassurance to the participant. c. Researcher to seek the participant’s consent for referral and refer based on the referral protocol.

Follow-up	Researcher to seek participant’s consent and obtain phone number for follow-up via phone call. Or Encourage the participant to call back using the researcher contacts (0723 366 099).

Appendix XXI: Referral protocol

Referral protocol	
Who will be referred?	After data collection, the family caregivers with severe role strain (18-26) as assessed using the modified caregiver strain index (M.C.S.I) tool or those who may develop uncontrollable emotional distress during data collection will be referred.
Action	1. Researcher will offer counselling and reassurance to the participant in a quite private room as well as share brief health messages with the participant before referral is executed. 2. Researcher must seek the participant's consent before referral for medical check-up, professional counselling services, social work services or linking with social support group/family meeting within Kenyatta national hospital or encourage the study participant to seek the services at their point of preference. 3. Participant will be issued with a referral form. 4. Participant has the right to decline referral. 5. Participant will bear the cost of services to be rendered up on referral.
Follow-up	Researcher to seek participant's consent and obtain phone number for follow-up via phone call. Or Encourage the participant to call back using the researcher contacts (0723 366 099).

Appendix XXII: Referral form

Referral form

Date of referral: Day__ __/Month__ __/Year__ __ __ __

Client name:……………………………………..Age:……………Sex: [ ] Male [ ] Female

Client contacts:…………………………………………………………………………

Referred from: Kenyatta National Hospital Oncology Outpatient Clinic

Referred to:…………………………………………………………………………….

Referral notes: The above named is a family caregiver of a patient who is currently undergoing treatment at K.N.H Oncology Outpatient clinic and is here by referred for further services and support due to;

[ ] Severe role strain (Was assessed using Modified Caregiver Strain Index).

[ ] Uncontrollable emotional distress.

Service(s) referred for;

[ ] Clinical examination [ ] Medical social worker services

[ ] Counselling services [ ] Social support group

[ ] Palliative care/Family meeting

[ ] Cancer information and symptom management.

Name and signature of person referring:………………………………………

Contacts for further information: 0723 366 099/ moriemmuriuki@gmail.com

Appendix XXIII: Health messages to share with family caregivers

<table>
<tr><th colspan="2">Health messages to share with family caregivers</th></tr>
<tr><td colspan="2">Immediately after collecting the data from the family caregivers and their respective patients, the researcher/research assistant will share brief health messages with the individual participant. These health messages/information will be based on the following;</td></tr>
<tr><td>Family caregiver self care</td><td>Attention to own health care needs; seeking medical attention for any symptoms or concerns, seeking professional psychological counselling services.</td></tr>
<tr><td>social and spiritual support</td><td>Create time for self, enjoy adequate sleep, join others and build social networks, seek spiritual nourishment, enrol and regularly attend social support groups and family meetings, effective family communication),</td></tr>
<tr><td>Health financing</td><td>Importance of health insurance.</td></tr>
<tr><td>Nutrition nourishment</td><td>Should ensure adequately gets balanced healthy diet, no skipping of meals.</td></tr>
<tr><td>Enhance caregiving skills</td><td>Encourage to seek information from health care workers on issues of concern like cancer as a disease, management of drug side effects, wound and stoma care, practical aspects of caregiving like lifting the patient out of the bed or turning the patient in bed, decision making and problem solving skills, hiring of extra hand to assist with caregiving load and navigating the service delivery system.</td></tr>
</table>

Appendix XXIV: Permission rights to use Modified Caregiver Strain Index (MCSI) tool

The publisher has provided special terms related to this request that can be found at the end of the Publisher's Terms and Conditions.

License Number	4576530647663
License date	Apr 26, 2019
Licensed Content Publisher	Oxford University Press
Licensed Content Publication	Journals of Gerontology - Series B: Psychological Sciences and Social Sciences
Licensed Content Title	Analysis of the Reliability of the Modified Caregiver Strain Index
Licensed Content Author	Thornton, Megan; Travis, Shirley S.
Licensed Content Date	Mar 1, 2003
Licensed Content Volume	58
Licensed Content Issue	2
Type of Use	I don't see my intended use
Requestor type	Educational Institution/Non-commercial/ Not for-profit
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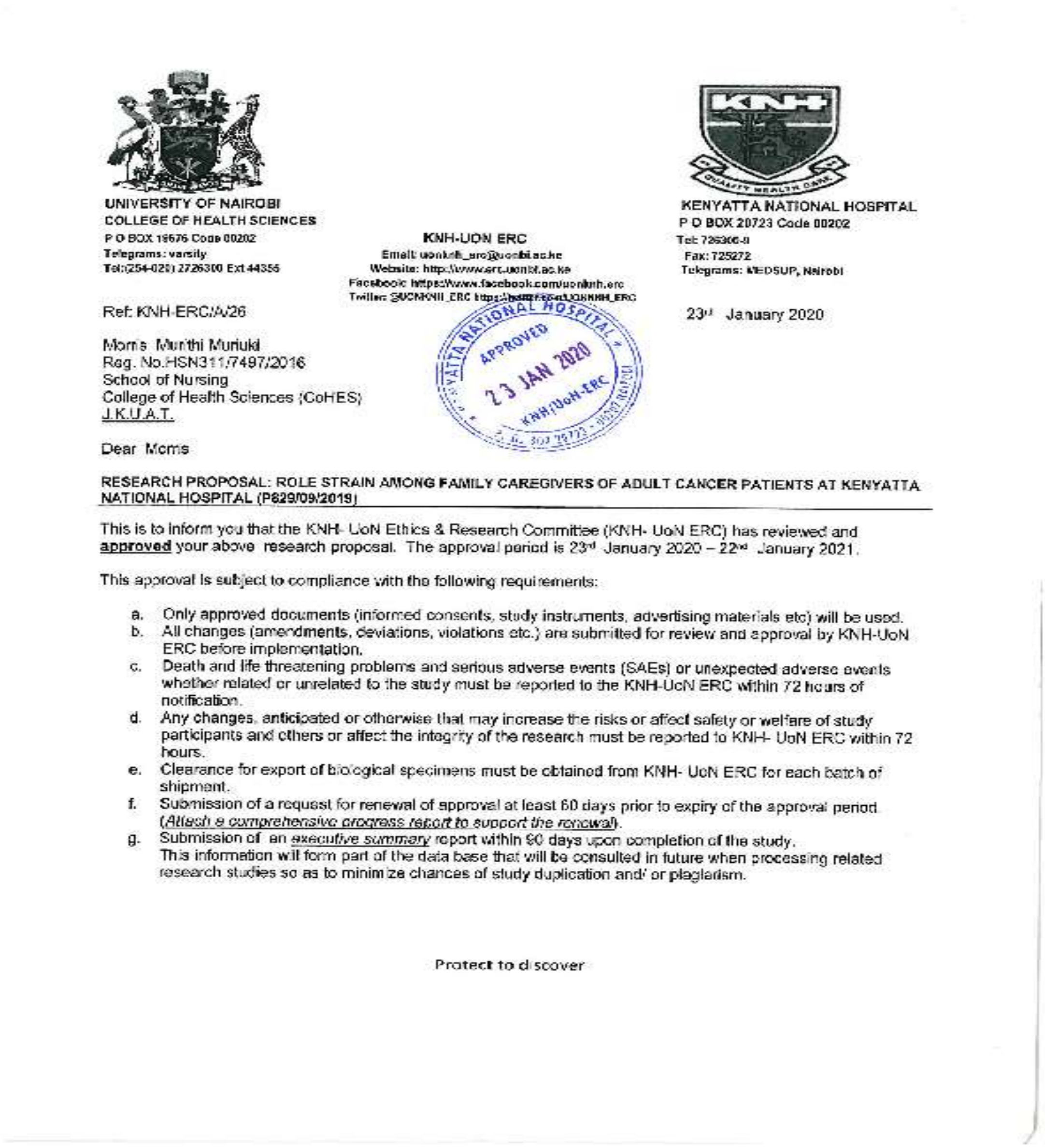
Appendix XXV: KNH-UON ERC Study approval letter



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Ref: KNH-ERC/A/26

23rd January 2020

Morris Murithi Muriuki
Reg. No.HSN311/7497/2016
School of Nursing
College of Health Sciences (CoHES)
J.K.U.A.T.

APPROVED
23 JAN 2020
KNH/UoN-ERC

Dear Morris

RESEARCH PROPOSAL: ROLE STRAIN AMONG FAMILY CAREGIVERS OF ADULT CANCER PATIENTS AT KENYATTA NATIONAL HOSPITAL (P829/09/2019)

This is to inform you that the KNH- UoN Ethics & Research Committee (KNH- UoN ERC) has reviewed and **approved** your above research proposal. The approval period is 23rd January 2020 – 22nd January 2021.

This approval is subject to compliance with the following requirements:

a. Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
b. All changes (amendments, deviations, violations etc.) are submitted for review and approval by KNH-UoN ERC before implementation.
c. Death and life threatening problems and serious adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH-UoN ERC within 72 hours of notification.
d. Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH- UoN ERC within 72 hours.
e. Clearance for export of biological specimens must be obtained from KNH- UoN ERC for each batch of shipment.
f. 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*).
g. Submission of an *executive summary* report within 90 days upon completion of the study.
This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/ or plagiarism.

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