EXPERIENCE OF CAREGIVERS IN PROVIDING CARE TO TERMINALLY ILL CANCER PATIENTS AT OCEAN ROAD CANCER INSTITUTE, DAR ES SALAAM

Fatuma Kaloya, BScN

MSc (Oncology Nursing) Dissertation
Muhimbili University of Health and Allied Sciences
October, 2024

Muhimbili University of Health and Allied Science

Department of Clinical Nursing

EXPERIENCE OF CAREGIVERS IN PROVIDING CARE TO TERMINALLY ILL CANCER PATIENTS AT OCEAN ROAD CANCER INSTITUTE, DAR ES SALAAM

By

Fatuma Kaloya

A Dissertation Submitted in Partial Fulfilment of the Requirements for the Degree of Master of Science (Oncology Nursing) of

Muhimbili University of Health and Allied Sciences
October, 2024

CERTIFICATION

The undersigned certify that they have read and hereby recommended for acceptance by Muhimbili University of Health and Allied Sciences a dissertation entitled; **"Experience of Caregivers in Providing Care to Terminally Ill Cancer Patients at Ocean Road Cancer Institute, Dar es Salaam",** in (partial) fulfilment of the requirement for the degree of Master of Science (Oncology Nursing) of Muhimbili University of Health and Allied Sciences.

_____

Dr. Masunga Iseselo, RN, PhD

(Supervisor)

_____

Date

_____

Mr. Gift Lukumay, RN, MSc

(Co-supervisor)

_____

Date

DECLARATION AND COPYRIGHT

I, **Fatuma Kaloya**, declare that the work presented in this **dissertation** is my original work, and has not been submitted for a similar degree award in any other University.

Signature…… **Date** ……...

This dissertation is copyright material protected under the Berne Convention, the Copyright Act of 1999, and other international and national enactments, on that behalf, of intellectual property. It may not be reproduced by any means, in full or in part, except for short extracts in fair dealing; for research or private study, critical scholarly review, or 138 discourse with an acknowledgment, without the written permission of the Directorate of Postgraduate Studies, on behalf of both the author and the Muhimbili University of Health and Allied Sciences.

ACKNOWLEDGEMENT

I want to express special gratitude to Almighty God for His grace and blessing during the preparation of this dissertation, particularly for keeping me healthy.

I also want to thank my supervisors, Dr Masunga Iseselo and Mr. Gift Lukumay, for their vast knowledge and skills in many areas, and their assistance in writing this dissertation was invaluable.

I am deeply thankful to my family, especially my parents, husband, and children for their unwavering support and encouragement throughout my studies. Their confidence in my abilities inspired me to persevere and strive for excellence.

ABSTRACT

Background: Cancer is a significant cause of death worldwide and is among the top two causes of death after heart disease; its treatment has far-reaching consequences, affecting not only patients but also caregivers and family members. Caregivers face numerous physical and emotional challenges when providing care to people suffering from life-threatening illnesses such as cancer. At Ocean Road Cancer Institute, around 65000 patients are attended regularly per year, including 10000 new cases and more than 55000 follow-up cases from all over the country and nearby countries. Around 300 are admitted yearly to the critical care unit. This research shed light on the understanding of caregivers' experience of providing care to terminally ill cancer patients in Dar es Salaam,

Objectives: The study aimed to explore caregivers' experiences in providing care to terminally ill cancer patients at Ocean Road Cancer Institute (ORCI).

Methodology: A descriptive phenomenology study design was conducted among caregivers of terminally ill cancer patients at ORCI in Dar es Salaam. A sample size of 10 participants was obtained. After reaching information saturation, the study adopted a non-probability sampling procedure and employed a purposive sampling technique. The data was collected using an in-depth method. A semi-structured interview guide with an audio recorder was used to collect the data. Data were transcribed verbatim and then translated from Swahili to English. Thematic analysis was used to analyze the data.

Results: The study identified several facilitators and challenges caregivers face, including social support networks, new experiences and skills, adapting to patient problems, and good adherence to medical guidance in facilitators caring for terminally ill patients. Physical and emotional exhaustion, financial problems, reduced social interaction, which can lead to loneliness, and emotional stress were the main challenges in caring for terminally ill cancer patients.

Conclusion: The study reveals that caregivers of terminally ill cancer patients experience a complex interplay of facilitators including social support, acquiring new experience, adapting to patient behavior good adherence to medical guidance and challenges which include physical

and emotional exhaustion, financial problem and reduced social interaction. These challenges often lead to overwhelming feelings, with inadequate support systems exacerbating their burdens. Caregivers need specialized attention to address these issues, alongside material support, that considers their emotional and psychological well-being. Study recommended further studies on social-economic effect of caregiving terminally ill cancer patients.

TABLE OF CONTENT

CERTIFICATION i
DECLARATION AND COPYRIGHT ii
ACKNOWLEDGEMENT iii
ABSTRACT iv
TABLE OF CONTENT vi
LIST OF TABLES ix
LIST OF FIGURES x
LIST OF ABBREVIATION xi
DEFINITION OF TERMS xii
CHAPTER ONE 1
INTRODUCTION 1
1.1 Background 1
1.2 Problem Statement 4
1.3 Rationale of the Study 6
1.4 Research Questions 6
1.4.1 Broad Question 6
1.4.2 Specific Questions 6
1.5 Objectives of the Study 7
1.5.1 Broad Objective 7
1.5.2 Specific Objectives 7
1.6 Conceptual Framework 7
CHAPTER TWO 9
LITERATURE REVIEW 9
2.1 Empirical review 9
2.1.1 Facilitator for caregivers when providing care to terminally ill cancer patients 9
2.1.2 Challenges for Caregivers in Providing Care to Terminally Ill Cancer Patients 10
2.2 Research Gap 13

CHAPTER THREE 14
MATERIALS AND METHODS 14
3.1 Study Design 14
3.2 Study Area 14
3.3 Study Population 14
3.4 Sampling Technique and sample size 15
3.5 Data Collection Methods 15
3.6 Trustworthiness 17
3.7 Data Management and Analysis 17
3.8 Ethical Consideration 20
CHAPTER FOUR 21
FINDINGS OF THE STUDY 21
4.1 Socio-Demographic Information of the Participants 21
4.2 Themes and Sub-themes 22
CHAPTER FIVE 32
DISCUSSION OF THE FINDINGS 32
5.1 Introduction 32
5.2 Discussion of the Findings 32
5.3 Limitations and Mitigation of the Study 35
CHAPTER SIX 36
CONCLUSION AND RECOMMENDATION 36
6.1 Conclusion 36
6.2 Recommendations 36
6.2.1 Practical Recommendations 36
6.2.2 Policy Recommendations 37
6.3 Areas of Further Study 37
REFERENCES 38
APPENDICES 46
Appendix I: Informed consent English and Swahili versions 46

Appendix II: Interview Guide for the Family members and relatives.....49
Appendix III: Mahojiano kwa ndugu wa familia 51
Appendix IV: Intellectual Property Rights Contract 52
Appendix V: Ethical clearance letter-MUHAS 53
Appendix VI: Permission letter –ORCI.....55

LIST OF TABLES

Table 1: Socio-Demographic Information of the Participants 21

Table 2: Themes and Subthemes Emerged.....22

LIST OF FIGURES

Figure 1: Conceptual framework.....8

Figure 2: Analysis Framework 19

LIST OF ABBREVIATION

WHO	World Health Organization
HIV	Human Immunodeficiency Virus
AIDS	Acquired Immunodeficiency Syndrome
CKD	Chronic Kidney Diseases
NCDs	Non-Communicable Diseases
COVID-19	Corona Virus Disease 2019
ORCI	Ocean Road Cancer Institute
QOL	Quality of Life
MAID	Medical Assistance in Dying
NGOs	Non-Government Organizations
TSHs	Tanzania Shillings
ISP	Independent Study Project
FCG	Female Caregiver
MCG	Male caregiver

DEFINITION OF TERMS

Caregivers are individuals who provide care and support to people who are unable to fully care for themselves due to physical or health conditions (for this case cancer, or terminally ill patients). Caregivers play a crucial role in assisting terminally ill cancer patients with various activities of daily living and ensuring their well-being. (Cardinali, Migliorini, & Rania, 2019).

Cancer patients are diagnosed with diseases characterized by the uncontrolled division and growth of abnormal cells in the body (ReFaey et al., 2021). It affects various organs and tissues in different stages. While some patients can be treated successfully and achieve remission and cure; others face more challenging prognoses mostly when cancer is advanced.

Terminally ill patients are individuals who are diagnosed with considered incurable illnesses or medical conditions that are likely to lead to their death. This is the advanced stage of a progressive and life-ending disease in term of stage suppose to at cancer stage iv where medical professionals anticipate their condition's demise(Anderson & White, 2017). At this stage, the focus is mainly on palliative care to manage symptoms and improve quality of life instead of seeking a cure. Mostly, terminally ill patients choose to have hospice care to get comfort and support during the end-of-life stage (Johannesen, Timm, & Roin, 2023). Their families and relatives are significant aspects of care especially psychologically, while healthcare workers collaborate to adhere to physical and emotional needs.

Coping strategies are an essential mechanism for caregivers to accommodate emotional, physical, and mental challenges while providing the best possible support to their relatives. Caring for cancer terminally ill patients can be emotionally, physically, and mentally challenging for caregivers; and they need coping strategies including Seeking and accepting opportunities for help, Setting personal health goals, Focusing on one’s ability, Safe and responsible medication administration, Social engagement and Support good nutrition (Chona, et al., 2023).

Supporting system; refers to the framework or network in which an individual, organization, or entity is designed to provide assistance, encouragement, and aid to other individuals in attending cancer terminally ill patients(Chona, et al., 2023). The system can offer emotional, physical, or information support; in form of personal, social, and professional spheres to support caregiving among cancer terminally ill patients.

CHAPTER ONE

INTRODUCTION

1.1 Background

Cancer is a significant global health issue and a major contributor to premature mortality across all countries. According to the World Health Organization, cancer is one of the top two causes of death before the age of 70 in most countries with heart disease leading (Sung et al., 2021). While mortality rates for heart disease and stroke have declined, cancer rates have continued to rise, making it a leading cause of death (ReFaey et al., 2021). In 2020, there were about 19.3 million new cancer cases and nearly 10 million cancer-related deaths globally. By 2040, the global cancer burden is expected to increase by 47%, reaching 28.4 million cases (Jedy-Agba et al., 2020). According to a study conducted by McIlfatrick (2021) in Sub-Saharan Africa, over 600,000 people die annually from terminal illnesses like cancer and CKD. The reported cases of cancer in Africa are increasing, with an estimated annual increase of over 2 million new cases (Kajungu, 2022).

It is projected that by 2030, in Africa, there will be a 70% rise in new cancer cases due to both population growth and an aging population (Chona et al., 2023). Female breast cancer is now the most commonly diagnosed cancer, followed by lung, colorectal, prostate, and stomach cancers (Ferlay et al., 2021). Also, the reported cases of cancer in Africa are increasing with an estimated annual increase of over 2 million new cases (Kajungu, 2022) Tanzania is not exceptional with the prevalence of chronic diseases and untreatable illnesses, with more than 1300 new cases of colorectal cancer reported a year (Akoko et al., 2023; Magwesela et al., 2021). In 2020, there were 40,464 new cases of cancer reported (Makene et al., 2022). The most common type of cancer was cervical cancer, which accounted for 25% of cases, followed by breast cancer at 10%, and prostate cancer at 9% (Makene et al,2022). Increased prevention and control measures for such diseases also contribute to a rise in patients, As the occurrence of cancer rises, there will be an increased demand for caregivers. Caregivers must play a crucial role in providing care to terminally ill patients, whether they are admitted or receiving outpatient

care. Families need to organize and plan for the care of their loved ones to ensure they receive the best possible support during their treatment.

The introduction of caregiving to terminally ill patients can be traced back to ancient civilizations, the times when patients who had life-threatening diseases were cared for in their homes around family when the diseases worsened to reach the final stage (Kajungu, 2022). The system was modernized in British in the 1950s by Dame Saunders, who believed when an individual reached critical conditions with a terminal illness, they should be treated and prepared to die without suffering and with dignity (Dunsmore-Dawson, 2020). The role of providing care to individuals with terminal illnesses aims to promote adaptation among patients, their relatives, and family members to the existing scenario (Martí-García, et al., 2020). Numerous studies indicate that a significant percentage of patients with terminal illnesses prefer to die comfortably at home with their loved ones (Johannesen, et al., 2023). For instance, in Denmark, around 22% of terminal patients passed away at home, compared to 12% in Norway, 14% in Australia, and 12% in the North Atlantic Ocean region (Johannesen, et al., 2023). One of the driving factors for the family to allow patients to die in their homes is the quality of services and comfort that caregivers provide to terminal illnesses and chronic diseases (Sathiananthan, Crawford, & Eliott, 2021) Since primary caregivers are usually family members, it can be difficult for family members to balance their caregiving responsibilities with other obligations such as work or other family responsibilities. Caregivers necessity to prioritize self-care and seek support from their community or healthcare professionals when needed. In some cases, families may hire a professional caregiver to care for their loved ones at home. This can be a good option for families who are unable to provide full-time care themselves or who need additional support.

The task of caregiving is essential at both the family and professional levels, as it ensures the well-being of patients with terminal illnesses that pose a threat to their lives. (Hebert, et al., 2007). With the increase in proximity toward death when a patient is in the terminal stage of disease, there is an increase in suffering from emotional to physical stress for both patients and relatives, putting caregiving services in high demand around the globe (Anderson & White, 2017). For instance, it is estimated that over 12 million people in the United States spend more than 100 hours attending to and providing care for patients in their terminal stages (Saleh & O

Neil, 2018; Hebert, Arnold, & Schulz, 2007)Also, establishing a relationship between family members and caregiver is important in giving care to patients with a terminal illness; this enhances information sharing and communication on the curative methods that adopted in the treatment of the patients with chronic diseases (Robertson, Hjorleifsdottir, & Siguroardottir, 2022). This can hinder the economic well-being of families in developing countries, as they may not have access to the same resources and support systems that are available in developed countries.

Family or relative caregivers play a crucial role in providing care and support to terminally ill family members. In many cases, they are the primary source of care and support, providing emotional, physical, and psychological support to their loved ones. This experience not only improves the quality of care offered during the final stages of life but also serves as a foundation for developing effective intervention strategies and systems. (Hebert, et al.), 2007). The study conducted in Iceland by Caswell et al. (2015)showed that the caregiver's actions to terminal illness have significant importance in terms of the patient's perception and family experiences during the life-ending scenario. More studies indicated that patients with advanced cancer opted to receive care from a caregiver that focuses on optimizing the quality of life rather than medical treatment (Eerden, et al., 2014). Nonetheless, the demanding nature of this role can present challenges that significantly impact the well-being of caregivers and will affect the quality of care for terminally ill cancer patients. The Challenges shown by other studies are isolation, physical breakdown, sleep depression restriction on social activities, and lack of time for personal issues may lead to reducing the quality of treatment that patients receive in their terminal illness situations Wahid, et al. (2018).

While there is a growing body of literature on the challenges facing caregivers of terminally ill patients, there is a remaining significant knowledge gap in the context of developing countries' studies specifically cancer patients at ORCI in Dar es Salaam Tanzania. The existing studies have prioritized general aspects of caregiver economic, sociocultural, and quality of life; neglecting caregivers' facilitator and challenges when providing care to patients. This study aims to explore the experiences of caregivers involved in providing care to terminally ill cancer patients. Also, it will explore diverse strategies that can empower caregivers to provide

exceptional care, ultimately ensuring the comfort and dignity of both patients and their family members.

1.2 Problem Statement

Terminal ill cancer patients is among individuals that need careful and closer care, caring for those patients is a vital and complex responsibility that ensures dignity and comfort during their final days. Cancer has become one of the deadly diseases in the world, for example in Tanzania, it estimated that each year more than 30,000 new cancer patients are diagnosed (Makene, et al., 2022). However, despite increasing of cancer patients Tanzania has been facing several shortages of resources such as specialized institutions to cope with raising cases of cancer specialized professionals to support terminally ill cancer patients (Asenga & Naburi, 2023). Due to such limitation, caring for cancer terminal ill patients has been falling to families and closer individuals to patients that become the main caregivers (Chona, Msengi, Gosse, Ambikile, & Krakauer, 2023). Due to demanding nature of cancer ill patients, caring impact extends beyond the patient, significantly affecting caregivers who experience both physical and emotional challenges when caring for someone with a life-threatening illness (Johannesen, Timm, & Roin, 2023).

The challenges of caregiving to terminal ill cancer patients have been pressing issues in developing countries like Tanzania, where cultural and social norms position families as the primary caregivers for terminally ill patients, despite limited healthcare resources (Dlamini, Hlongwana, Dlamini, & Ginindza, 2019). Tanzania's healthcare system, like many others in sub-Saharan Africa, has focused on preventive and curative healthcare, while palliative care services have been given less attention (Kajungu, 2022). This neglect leaves families with inadequate support to manage the complex needs of terminally ill patients, exacerbating the physical, emotional, and financial strain on caregivers.

Different past studies have shown that caregivers of cancer patients often face overwhelming responsibilities, managing household tasks, emotional support, and financial decisions while coping with the progression of the disease (Akpan-Idiok & Asuquo, 2021; Caswell et al., 2015).

Caregiving can last for several years, depending on the patient's response to treatment or until the patient’s death (Mohamed, 2015). While some caregivers find deep personal satisfaction in their roles, many report significant burdens that negatively affect their physical health, psychological well-being, economic stability, and social lives (Chona et al., 2023). At Ocean Road Cancer Institute, around 65000 patients are attended regularly per year, including 10000 new cases and more than 55000 follow-up cases from all over the country and nearby countries. Around 300 are admitted yearly to the critical care unit (ORCI, 2023).

While numerous past studies have examined the experiences of caregivers in different settings and contexts outside Tanzania, most research has focused on populations with different cultural and healthcare contexts from Tanzania (LeSeure & Chongkham-ang, 2015). There is limited understanding of how Tanzanian caregivers, particularly in resource-limited settings like Dar es Salaam, navigate the challenges of caring for terminally ill cancer patients. Existing research has not fully explored the specific obstacles Tanzanian caregivers face, their coping mechanisms, or how they utilize available support systems. Furthermore, the evolution of caregiving over time and the unique challenges posed by limited cancer care infrastructure in Tanzania have been inadequately addressed (Dunsmore-Dawson, 2020).

This research seeks to fill the gap in the literature by shedding light on the experiences of caregivers involved in providing care to terminally ill cancer patients in Dar es Salaam. Through exploration, the study aims to contribute valuable insight that can inform target interventions and practices that improve the well-being of caregivers and enhance the quality of care provided to cancer patients in Tanzania.

1.3 Rationale of the Study

Since each terminally ill patients suffer differently and the disease has a different aspect of personal dignity and comfort, the findings of this study have a significant contribution to understanding the experience of the caregiver as the individual who spends more time with the patients. This finding enabled stakeholders dealing with cancer and the government to understand the challenges that facing caregivers during the provision of care to terminally ill patients. Moreover, these insights can inform hospital management to develop the necessary mechanism to enhance caregiver well-being and improve the quality-of-care services. This specificity ensures that appropriate actions can be taken at the appropriate levels of government to uplift the dignity of patients and provide the necessary comfort and support for both caregivers and patients alike.

1.4 Research Questions

1.4.1 Broad Question

What are the experiences of caregivers in providing care to terminally ill cancer patients?

1.4.2 Specific Questions

1. What are the facilitators for caregivers providing care to terminally ill cancer patients?
2. What are the challenges faced by caregivers when providing care to terminally ill cancer patients?

1.5 Objectives of the Study

1.5.1 Broad Objective

To explore the experiences of caregivers in providing care to terminally ill cancer patients.

1.5.2 Specific Objectives

The study specifically aimed to;

1. To explore facilitators for caregivers providing care to terminally ill cancer patients at Ocean Road Cancer Institute.
2. To describe the challenges faced by caregivers when providing care to terminally ill cancer patients at Ocean Road Cancer Institute.

1.6 Conceptual Framework

The conceptual framework is developed from the literature review, where a researcher borrows ideas from a list of previous studies that have been reviewed to form a framework for the recent studies. Based on this framework, the study explored the experience of caregivers in providing care to terminally ill cancer patients. The facilitators and challenges faced by caregivers in supporting terminally ill patients will impact the overall outcome determined by successful coping and support systems. Facilitators of caring terminally ill was focus on social support network, acquiring new experience and skills, adapting the patient's behaving as well as good adherence to medical guidance. Challenges faced by caregivers are physical and emotional exhaustion, financial problems and reduced social interaction. This framework guided responding to research questions by following themes and respective aspects for each objective to be used when answering research questions.

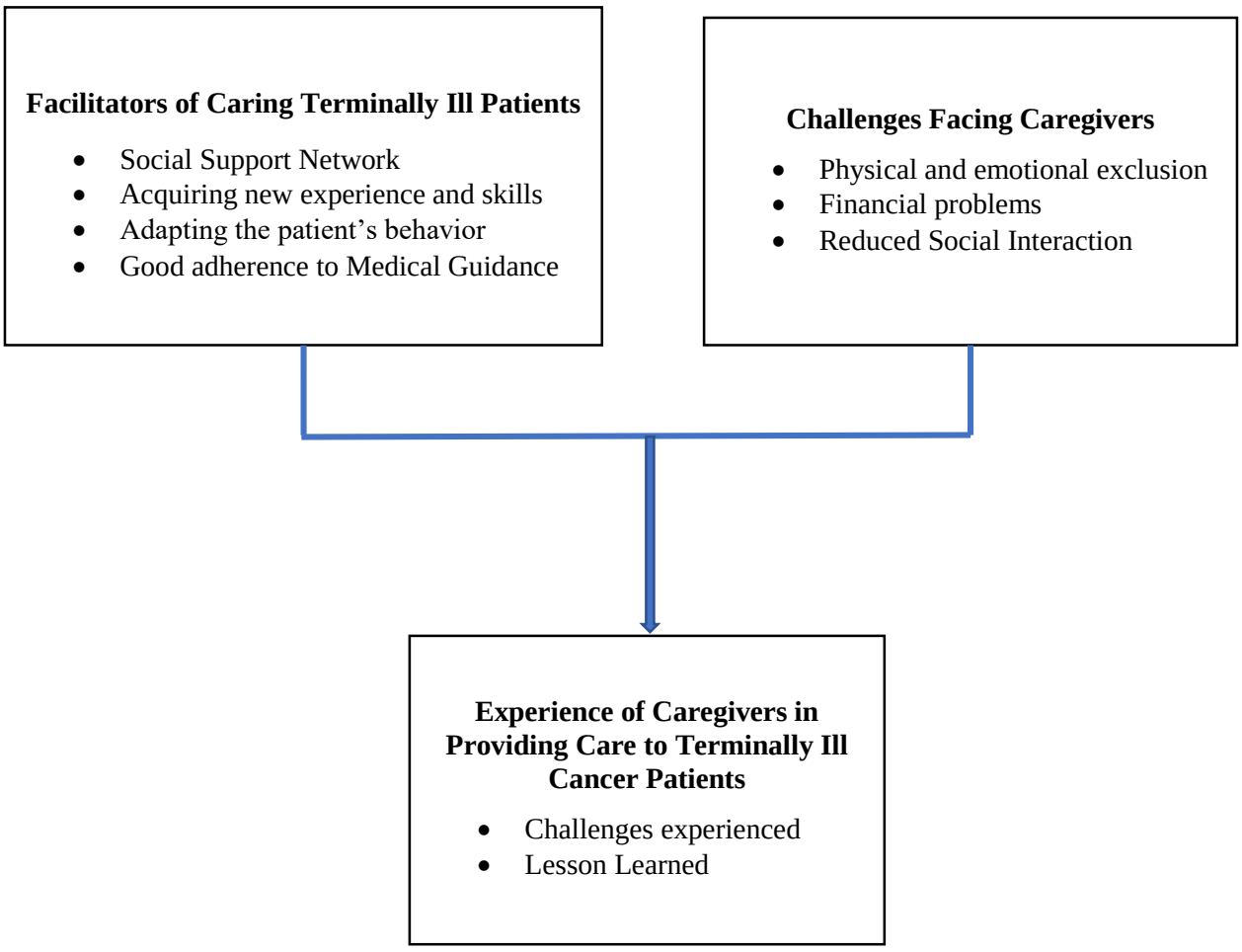


Figure 1: Conceptual framework

Source: Adopted from a study of (Lelei, 2019)

CHAPTER TWO

LITERATURE REVIEW

2.1 Empirical review

2.1.1 Facilitator for caregivers when providing care to terminally ill cancer patients

The provision of care in home settings has gained increasing global attention due to the preference of many terminally ill patients to receive care within the familiar confines of their homes. Caring for terminally ill cancer patients is a demanding and emotionally exhausting task. A qualitative study by Peeranuch (2015) at Payap University in Thailand revealed that caregivers' experiences consist of two main elements: the context of these experiences and the structured phenomena. The objectives of caregivers—what they hoped to accomplish while providing care for cancer patients—were the researchers' main emphasis as they extracted data. Deliberate or purposeful activities that result from people's expectations for the future and their interpretations of current circumstances are referred to as intentional actions. For example, balancing emotions was one of the recognized intentions. This required intentional acts like keeping a hopeful attitude, looking for optimism, finding ways to divert their attention from tense situations, and equating their predicament with the worst-case circumstances of others. In a study done in India by (Khan et al 2011) titled What does the informed caregiver of terminally ill cancer patients need, the study aimed to look for the needs of caregivers. The result shows that most of the caregivers were middle-aged and had not at all the former skill of attention open-handed. The caregivers were fulfilled by the material and health provision given to them by their conduct crew. Maximum had an “extra idea.” Caregivers had unmet wishes plus homecare, emotional support, and economic help. Resolved that informal caregiver offer the greatest of nurture and inner care to the patient.

Another study was conducted in Canada. by Allison (2017) found that facilitators must offer support, education, and resources to caregivers, aiding them in handling their duties and preserving their well-being. The finding of this study Based on insights gained from a two-decade research journey focused on caregiver experiences, three interconnected themes come to

light: the burden on caregivers, caregiver training, and the significance of the palliative navigator's role A study by (Maija et al., 2022). recommended that facilitators and caregivers encourage learning and cultivate positive relationships between families and healthcare providers. While caregivers and team members were able to identify facilitators and barriers at the individual (i.e., caregivers are motivated to learn, but overwhelmed and focused only on the patient) and interpersonal levels (i.e., relationships are a valuable resource, but communication is sometimes challenging), team members were more likely to identify system-level barriers (i.e., constraints within the larger healthcare structure). To implement family-centered care in cancer settings, it is incumbent on the healthcare system to pursue standardization of communication, programs that facilitate family integration and support, and advocate for policy change the facilitators for caregivers of patients who are terminally ill are the topic of argument for all the authors. They lure consideration to the importance of caregivers and the chances that arise with charitable care. When it originates to generous terminally ill patients' medical, inner, and physical support, caregivers are vital. These shelters attractive care of remedies, serving with normal responsibilities, and providing establishment. After giving care, caregivers could be able to follow professions in patient advocacy, counseling, and healthcare. The knowledge and abilities acquired while providing care might lead to new skilled occasions and personal expansion.

2.1.2 Challenges for Caregivers in Providing Care to Terminally Ill Cancer Patients

Every aspect of providing care to an individual presents’ challenges known only to the one who faces them. Numerous studies have explored the challenges faced by caregivers providing support to individuals with chronic illnesses, including cancer, HIV, and non-communicable disease (Krug et al 2018). Johnston (2017) conducted a qualitative study in Western Kenya involving 35 informal caregivers from Kisumu. The study identified several major challenges, such as financial constraints for treatment and living expenses, interrupted medical care, emotional stress due to multiple responsibilities, stigma, and misconceptions about disease transmission. It was suggested that government prioritization should focus on securing resources for psychological support and inclusion for caregivers.

However, Rahimi, et al., (2021) conducted a study focusing on family caregivers of COVID-19 patients. Using a phenomenological qualitative approach, they interviewed 13 family caregivers. The study revealed challenges including unmet needs, physical and psychological strain, and care facilitation. It was recommended that information and financial support be provided while fostering community support for patients and family caregivers. Each study shows different challenges faced by caregivers while taking care of terminally ill cancer patients with individual conditions.

Also, the study by Kajungu, (2022) aimed to understand how healthcare providers in Dar es Salaam, Tanzania, are currently delivering palliative care to patients with colorectal cancer. The findings of this study showed that several factors were influencing the quality of palliative care for these patients including poor availability of medical supplies, inadequate palliative care training, insufficient facilities for care, and standardized protocols and guidelines for palliative care. In a similar theme, another study by Krug et al. (2018) conducted research in Germany to understand the barriers and enablers of optimal support for family caregivers in palliative care. Through qualitative methods, including focal group discussions, they identified challenges related to communication within the patient-caregiver-professional network. The study recommended enhanced communication and collaboration between healthcare providers, patients, and caregivers.

Another study by Johannesen, et al., (2023) conducted qualitative research in the Faroe Islands, exploring the experiences of caregivers providing end-of-life care to severely ill relatives with cancer dying at home. The study found that family specifically family members with a healthcare background together with nurses were supporting caregivers in managing the care of the dying relative at home, the factors that made the caregivers feel their efforts meaningful. It was recommended to establish an endless interdisciplinary palliative team that would help to increase the number of people who want to die at home and succeed in doing so by giving the caregivers emotional and advisory support. This increased the responsibilities of family members while taking care of terminally ill patients. Moreover, the study by Chona, et al., (2023) aimed to explore the experiences and the specific needs of cervical cancer patients at the Ocean Road Cancer Institute (ORCI) in Dar es Salaam, Tanzania. The research findings show

that there are several challenges related to their understanding of cervical cancer and the attitudes of those around them regarding the disease. Those challenges are categorized into five themes including knowledge and attitude about cervical cancer, suffering from a disease process, socio-economic disruptions, psychological problems, and sexual and reproductive concerns. This study is based on the patient's experience as a unit of analysis and not on caregivers.

Through the compared literature, the study outlined the challenges and supports reported by the caregivers that attend to the terminally ill patients. Facilitators or positive experience highlighted in other studies include of family and healthcare support as well as community resources. Yet, the literature also points out that there is a need for structured training session for caregivers on how to handle patients in the critical illness as most of caregivers lack formal caregiving knowledge

(Khan et al., 2011; Maija et al., 2022). Constant stress, economic challenges, and restricted social contacts are some of the main experiences reported in the studies of both the developed and the developing countries that the present study intends to corroborate (Johnston, 2017; Rahimi et al., 2021). This suggest that there is need for the health care systems to put in place organized support structures to cater for not only the psychological but the physical needs of the caregiver. Based on the various findings from the literature, there is a call for enhancing policy strategies such as a program to increase accessibility of caregiver training, better workshop between nurse and caregivers and financial support either through subsidies or social programs (Krug et al., 2018; Allison, 2017). Also, advancing community-based care models, as well as engaging interdisciplinary teams, optimal care outcomes and decreasing caregiver's loads could be achieved, according to the findings reported by Johannesen et al. (2023). From the above research findings, it is suggested that future research and policy intervention should focus on developing caregiver support frameworks that cut across the caregiver's complex problems in human resource-constrained environments such as Tanzania.

2.2 Research Gap

Therefore, based on the empirical review, in the context of Tanzania, no recent study examined the caregiver's experience as the individual who spends more time with the patients, focusing on home caregivers as the unit of analysis. The current study bridged the existing knowledge gap, provided insights into the caregiver challenges, and contributed to developing more effective policies and practices that improve the well-being of caregivers and enhance the quality of care provided to cancer patients in Tanzania.

CHAPTER THREE

MATERIALS AND METHODS

3.1 Study Design

This research used a qualitative approach and employed a descriptive phenomenology design to answer the research question about caregivers' experience of providing care to terminally ill cancer patients. The study uses this research design as it allows deep exploration of the caregivers' lived experiences and insights into their unique perspectives (Thomas, 2021). This approach focuses on uncovering the structures and patterns of these experiences, making it well-suited to provide context-specific insights that can inform practical strategies for supporting caregivers in similar settings.

3.2 Study Area

The research was conducted at ORCI, in the Ilala District of the Dar es Salaam Region. This facility offers both inpatient and outpatient services for individuals dealing with cancer. Also, ORCI extends its services to patients from various regions within Tanzania and out of the country (referral hospitals for cancer patients). It chose the Ocean Road Cancer Institute as several factors drove the research site. ORCI is famous for its specialized focus on cancer treatment, making it a center of relevant expertise and resources.

ORCI is the only comprehensive facility in Tanzania that specializes in cancer care. Currently, it serves about 28,000 cancer patients (ORCI, 2024). Several cases attended by ORCI require caregivers. The institute's commitment to cancer care aligns with the study's objective to explore the experience of caregivers in providing care to cancer terminally ill patients.

3.3 Study Population

The study population were those caregivers that had a patient in the ORCI, the targeted caregivers that are not medical practitioner that responsible for treating patients. The caregivers were adult's family members and relatives directly involved in the caring activities regardless

of gender. Also, the caregivers with outpatients that were involved in clinics, chemotherapy, and radiotherapy attendants. The following inclusion criteria were used for participation in the study.

i. Caregiver caring for cancer patients admitted or outpatient
ii. Caregivers aged between the ages of 18 and above
iii. Only caregivers who provided care for at least six months were involved in the study, as they have more experience with the challenges and issues facing caregivers. (Blinka et al 2022)

3.4 Sampling Technique and sample size

A study utilized a purposive sampling technique whereby adult family members and relatives aged between 18 years and above of both genders with at least six months of caregiving experience were recruited using the purposive selection method. Employed caregivers made appointments, and a researcher obtained their consent to participate in the study. The participants were obtained purposefully, depending on how much elaborative information they could offer on caregiving. The study involved ten participants who were recruited using a purposive sampling procedure. The procedure was conducted until the researcher found no new themes or information could be identified, which showed that analyzing sample data reached a data saturation point. The study backs up the decision to stop at ten (10) (Olson, 2016; Smith et al., 2012; Guest, Bunce, & L, 2006), which described that generally, saturation occurs in the first six to twelve interviews, although this depends on the nature of the research. This research achieved themes and data saturation redundancy in the tenth interview. The study observed that at this point, it was impossible to introduce new concepts into the research that could be collected through interviews; this explains why the subject sampling was stopped at ten participants.

3.5 Data Collection Methods

The researcher conducted in-depth interviews with participants to understand their perspectives, experiences, and insight. A semi-structured interview guide was used during data collection.

The guide was prepared in English and then translated into Swahili, the language commonly used by the participants. The main question focused on the experience of caregivers when providing care. The specific area that was interviewed included (1) what challenges caregivers face? (2) what are the facilitators for caregivers? The in-depth interviews were conducted conveniently on the Ocean Road Cancer Institute premises to avoid interrupting other institute activities. For outpatient caregivers, the interviews were conducted in a tea room (the time when it was not in use). The room was arranged in such a way that mimic the home environment. The room was well-ventilated, had adequate light, and was far from the chemotherapy room. For inpatient caregivers, the in-depth interviews were conducted in the lecture hall when not in use. The rooms for the interviews were also conducive, with well-ventilated and adequate light to capture nonverbal cues from the participants. All surrounding environments in the room, from seating arrangements to furniture such as tables and chairs, were customized to ensure that interviewers were comfortable. All employed participants accepted to be audio-recorded, and Kiswahili language was used.

Specific probes followed those questions to get a deeper understanding of the phenomenon. The follow-up questions were also used to clarify the concept. The first four participants were used to pre-test the interview guide. This was vital to determine if the questions in the interview were clear and understandable and could be answered by the participants. Data from the four pretest interviews were excluded from the current study sample size. Excluding pretest interviews helps maintain the study's rigor and ensures that conclusions are based on data collected under uniform conditions. To ensure the credibility of the research, the study was enhanced through the use of reflexivity of the researcher, who kept a reflexive journal, which was used to record every activity involved in data collection for each interview. The researcher used most of the interviewing skills to increase cooperation and a sense of acceptance among the participants. The interview continued until new participants obtained no information. The study reached data saturation in the 10th interview with participants when there was no new them emerging from those interviews rather than redundancy of information. The duration for the interview ranged from 30-45 minutes for one participant, and the data collection process took 14 days before the information saturation was reached.

3.6 Trustworthiness

Several quality control measures were applied during the data collection to ensure trustworthiness. To ensure credibility, the interview guide was pre-tested with respondents to solve any issues with the interview guide. This helped the researcher refine and ensure the clarity of the questions and the relevance of the findings collected through the revised interview guide. The consistent technique fostered a conducive environment for open and honest experience sharing from the respondent. Interviews were audio recorded after the respondent's consent, then transcribed from English to Kiswahili because the Kiswahili language is expected of participants. These reduced language barriers and ensured that all participants were comfortable and accurately expressing themselves. The interview location was carefully considered because it should provide participants with free and no distractions, private and comfortable.

Confirmability: This was ensured by clearly explaining how the data was collected and analyzed. The consistent technique fostered a conducive environment for the respondent to share open and honest experiences.

Transferability: Interviews were audio recorded after the respondent's consent, then transcribed from English to Kiswahili because the Kiswahili language is expected of participants; this reduced the language barrier and ensured all participants were comfortable and accurately expressing themselves. The interview location was carefully considered, with the fact that it should provide participants with free and no distractions and be private and comfortable.

3.7 Data Management and Analysis

The data analysis process was started after interviewing the participants. This helped to expand the probes according to the information elicited from the participants. The researcher transcribed the audio-recorded data verbatim; several procedures took place. The researcher read each transcript to countercheck and ensure the accuracy of the information in the original audio data. Some corrections, such as typing errors, were made to enhance the clarity of the transcripts; translation of the transcripts was made following the thematic analysis steps described by Braun. & Clarke (2006). The researcher read and re-read all transcripts carefully, line by line, to be

immersed in the data and get the first impression of the whole document. All transcripts from the data were collected and coded manually on the margin of paper.

A thematic analysis approach was used for data analysis, combining deductive and inductive methods. Deductive codes were generated based on the main concepts highlighted in the research question and study title. Inductive codes were developed by repeatedly reading the transcripts to identify significant statements from participants. This process allowed for the coding of data not captured by the deductive approach. Ultimately, no significant differences emerged between the categories formed by the two coding methods. The researcher refined all codes from both processes to ensure that all patterns and meanings in the participants' text were included.

The thematic analysis approach systematically examines data to identify patterns and meaningful concepts. The process begins with the researcher familiarizing themselves with the data by transcribing audio, reading through the text, and taking initial notes based on identified themes and research questions. The next step is coding, highlighting text sections, and creating shorthand labels or codes to describe the content. Following this, themes are generated by combining several codes into potential themes, allowing them to emerge from the data naturally. The researcher then reviewed the themes to ensure they accurately represent the data. Finally, the researcher defines and names each theme, clearly articulating its meaning and how it contributes to understanding the data. This includes providing descriptive narratives for each theme, supported by quotes and examples from the data, to create a comprehensive and coherent story that captures the essence of each theme.

To ensure the themes accurately reflected the data, the researcher revisited the transcripts and compared the themes with the original data to verify that no significant information was overlooked. During this process, some themes were divided into subthemes for clearer representation. The final themes and subthemes were reported and substantiated with key quotes from participants. This approach facilitated the identification and exploration of recurring themes, patterns, and relationships within the caregivers' narratives (Kothari, 2017).

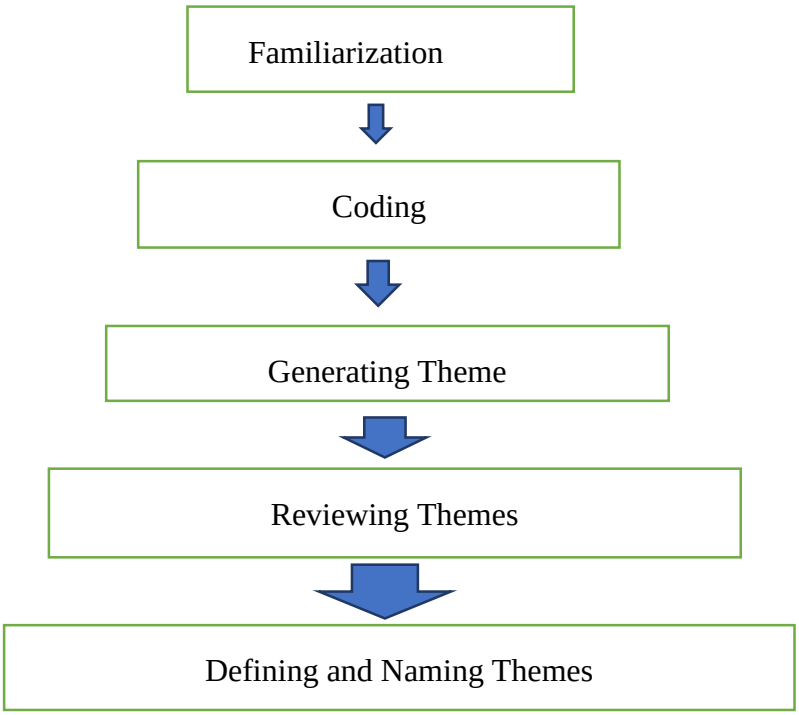


Figure 2: Analysis Framework

3.8 Ethical Consideration

The study obtained ethical approval from the Institutional Review Board (IRB) of Muhimbili University of Health and Allied Sciences with Ref. No. DA.282/298/01.C/2105 to ensure that the research adheres to established ethical guidelines and principles. Also, the study requested permission from ORCI to ensure the reinforcement of the moral foundation of this research. Participants were carefully informed about the study's purpose, procedures, potential risks, and benefits before participating; this process ensured that participants fully understood their roles in the research. All data collected for the study, including interview transcripts and documents, were treated with the utmost confidentiality. Participants were informed that confidentiality would be protected by removing identifying personal information and guarding against unauthorized access or disclosure. They were also informed about the right to withdraw from the study at any point if they experience discomfort. They we empowered to make informed decisions about their participation, knowing that their decision, whether to participate or decline, does not impact their relationship with the Ocean Road Cancer Institute or their access to care.

CHAPTER FOUR

FINDINGS OF THE STUDY

4.1 Socio-Demographic Information of the Participants

Ten (10) participants were included in this study whereby six out of the 10 participants were male. Five participants were within the age range of 41-54 while half of the participants had completed primary education. The demographic distribution of the participants is further presented in **Table 1.**

Table 1: Socio-Demographic Information of the Participants

	Age	**Gender**	**Education Level**	**Type of Cancer Patient Cared For**
1	35	Female	Bachelor degree	Cervical Cancer
2	32	Female	Primary education	Cervical Cancer
3	50	Male	Primary education	Skin Cancer
4	53	Male	Primary education	Prostate Cancer
5	30	Male	Informal education	Prostate Cancer
6	44	Female	Informal education	Vulva cancer
7	54	Male	Primary education	Lung Cancer
8	23	Male	Informal education	Bone Cancer
9	45	Male	Secondary/TVET education	Esophageal Cancer
10	30	Female	Secondary/TVET education	Cervical Cancer

4.2 Themes and Sub-themes

Two themes were identified in this study namely: Facilitators of caring terminally ill patient. This theme with three subthemes namely; receiving Social and family support, acquiring new cancer-related skills, and adapting patient's behavior and good adherence to medical guidance. The second theme is challenges in caring for terminally ill patients, which had three sub-themes which are financial problems, physical and emotional exhaustion, and reduced social interaction. Table 2

Table 2: Themes and Subthemes Emerged

Themes	**Sub-themes**
Facilitators of caring for terminally ill patients	1. Social Support Network 2. Acquiring new experience and skills 3. Adapting the patient's behavior 4. Good adherence to Medical Guidance
Challenges caring for terminally ill patients	• Physical and emotional exclusion • Financial problems • Reduced Social Interaction

Facilitators of Caring Terminally Ill Patients

i) Social Support Network

Participants explained the importance of receiving support from various sources to live with their patients in the ward while providing the necessary care. It was reported that these networks were crucial in providing both material and emotional comfort to caregivers as they completed their daily responsibilities. Participants mainly relied on their families, friends, and the community for emotional and financial assistance. One caregiver elaborated that:

"*I have spread my phone number to sponsors so that I can get anything to manage myself*" (male, 50 years):

Participants elaborated that family support was the most prominent system, which assisted them by offering empathy. They stated that assistance from family members can range from assisting with washing clothes to motivating the individual and providing financial support. The combination of these support types was described as crucial in reducing participants' stress levels and enhancing their capacity to care their loved ill patient. This was evidenced in the following statement:

> *"My siblings have been extremely supportive throughout this journey. They help with household chores and provide emotional support, which lightens the load and makes caregiving more manageable."* (Female, 44years)

Some participants mentioned that their family members are essential in providing companionship, practical assistance, and encouragement as they fulfill their caregiving responsibilities. One participant explained that family support is crucial in helping them manage their duties more effectively, as in the statement below

> *'My husband has been my helper throughout this experience. He takes on extra responsibilities at home and provides unwavering emotional support, which has been invaluable in coping with the challenges of caregiving"* (Female, 30 years).

Participants highlighted the importance of community support in helping them cope with caring stress. According to the participants, community support could take various forms, such as assistance with daily responsibilities, emotional backing, and provision of food and other essentials. The participants described that a strong community connection significantly facilitated the caring process, preventing them from feeling isolated and allowing them to rely on others for help. The participants also reported that not just neighbors but also other community members step in to assist, highlighting the significance of community support:

"In our community, we have a strong network of support. Neighbors and members of our church have been incredibly helpful in providing meals and emotional support during this challenging time." (Male, 50 years)

Participants described that religious support was a key component of their spiritual resilience during the caring process. They recognized it as a significant source of encouragement and noted that religious institutions offered hope, spiritual support, and comfort. They said that they often turned to their religious communities for support in the form of prayers, religious rituals, and general assistance. They mentioned that this support played a vital role in strengthening caregiving activities and providing them with spiritual relief. One caregiver explained the role of religious institutions in providing support by stating that:

> *"Our local mosque has been very supportive. They visit regularly to offer prayers and words of encouragement, which has been a source of strength for both me and the patient."* (Female, 32 years)

Participants stated that maintaining their spiritual practice had been crucial in coping with the emotional strain of caregiving, as it gave them a sense of peace and helped them stay grounded during challenging times by explaining that:

> '*Maintaining my spiritual practice has been crucial in coping with the emotional strain of caregiving. It gives me peace and helps me stay grounded during difficult times."* (male.50 years)

The participants explained that donations from private sources had become a significant source of hope that facilitated caregiving. They emphasized that these contributions helped cover the substantial expenses incurred during treatment. The support typically included covering a wide range of costs, such as medication, medical treatment, and sometimes even basic needs. By relieving these financial burdens, donor assistance allowed caregivers to focus on their patients' well-being, both physically and emotionally, without the constant fear or concern over financial stability. They also reported that financial support from private donors was crucial for covering

medical expenses and alleviating financial burdens. The participant stressed the importance of this financial support system in an interview by stating:

> *"We are grateful for the financial assistance provided by private donors. It helps cover the cost of medications and medical procedures, easing the financial strain on our family during this difficult time."* (male, 53 years)

The participants found that providing financial support from donors helps caregivers to be free from worrying about bills and other expenses, which in turn reduces psychological stress. One caregiver said that this support is essential for their peace of mind, as noted during the interview saying

> *"The kindness of private donors has been helpful for us. It ensures that we can afford the necessary treatment and focus on providing the best care possible for our loved one."* (Female 44 years)

The study showed that caregivers mainly depend on family and community support, spiritual and emotional support, and financial help. Families provide practical and emotional assistance, while community and religious organizations offer significant practical and emotional support, helping caregivers deal with emotional challenges. Financial support from donors was found to be crucial for managing expenses related to terminal illness care. The study highlighted that understanding the support system reveals the significant strength and expansion of networks to better support caregivers and improve the quality of their services to their relatives and loved ones

ii) Acquiring new experience and skills

Participants highlighted that practical caregiving skills are crucial. According to participants, Practical skills were critical for everyday jobs like feeding, dressing, bathing, and subsidiary measures to the patients. They said that maintaining the recipient's comfort, dignity, and quality of life was contingent on completing these tasks as in the statement below:

"*When I wake up, I pray and do cleanness while preparing porridge for her, after 3 hours she will have breakfast, and at noon if there is food she will eat and fruits. Then she takes her medicines and at night the same"* (Female, 30 years).

The dependency of the patient on caregivers lead to heaviness as well as filling of burdens which created positioned the caregivers to dedicate almost their entire time caring for their beloved one in terminally ill cancer. Furthermore, it ushered the emotional bond due to the experience obtained from the care. The participant explained that;

"Caring for terminally ill patients, especially with cancer, is physically and psychologically exhausting; it needs much humility in taking care of them because, at times, you may find the pus discharge in an open wound that you would have to clean him." (Male, 53 years)

The participants also highlighted that caring for cancer patients helped them acquire new skills related to patient care, which they didn't have before. They also believed that caring for their loved ones could make them ambassadors to others concerning cancer-related issues.

"I have learned to lead a good and humble life with everyone. Because one minute you may be okay, and the next you might wake up sick. So, through these patients, I have made a self-assessment and learned about providing first aid to a person. I can insert a drip into a person as the first aid" (Male, 53 years*).*

iii) Adapting patients' behavior

The participants reported that, patients tend to have anger in some circumstances, so the caregivers tend to leave them for a while so as they can regain to normal behavior. But also they used to encourage them by giving them hope.

> *"When my old man becomes aggressive, first I will talk to him to calm him down by explaining the situation, if he continues to be angry, I will stay quiet for a while and take a walk to let him rest himself"* (Male, 30 years)

The participants reported that self-distraction was an essential coping strategy for handling the stress of caregiving. They mentioned using this approach to deal with caregiving's emotional and physical challenges. The caregivers explained that taking walks or short breaks help them

avoid burnout and manage their responsibilities more effectively, especially during misunderstandings or when patients become aggressive and angry. One of the participants said:

> *"She had anger issues, which was emotionally stressful for me. She became very angry when in pain. She complained a lot. She might ask me to turn her to the other side or help her sit, but when I touched her, she complained that I was hurting her."* (Female, 32 years)

The participants stated that adapting patient behavior involved engaging in activities such as reading, listening to music, or watching television, which helped them avoid thinking about the caregiving process. The activities allowed them to take breaks from the demanding situations of caring for patients, reducing stress, and preventing burnout. The participants also explained that stepping away from their everyday responsibilities enables them to better handle tasks after taking a break and regaining focus. One caregiver stressed the significance of these breaks for maintaining their effectiveness in caregiving, stating:

> "*Taking a few minutes to pray to my father or read a book helps me unwind and gather my thoughts. It makes a big difference in how I handle stressful situations*." (Male, 53 years)

iv) Good adherence to Medical Guidance

Participants reported that they often use instructions from medical personnel as a coping mechanism, and most rely on guidance from medical professionals to enhance their caregiving skills. This not only improves the quality of care but also reduces the stress and uncertainty faced by caregivers. They described the importance of medical personnel's instructions, making them feel more confident and competent in managing their responsibilities. Participants stressed that following professional advice also ensures that they provide the best possible care for their loved ones, further contributing to their peace of mind and emotional stability. One caregiver noted describing that:

" Most of the time, I follow the instructions provided by the doctors who prescribed the medicine. I ensure timely administration and the correct dosage as instructed by nurses.' (Male, 23 years)

Participants reported that being an excellent listener to medical personnel was a psychological coping style aimed at perceiving the situation differently, which can be more constructive. This strategy assists people in having purpose and passion in life no matter the challenges they encounter, the enjoyment they get from being caregivers, or the improvements their loved ones are making, albeit slight. Stress and burnout rates are high in caregivers due to the negativity they experience from the patient's behavior and unsuccessful caregiving outcomes; therefore, focusing on positive experiences and positive outcomes enhances the patient's well-being.

> *"I have learned that humility is important and do not force doctors to discharge patients. You must be keen on listening to your nurses and doctor's advice. By focusing on the positive aspects of my task and giving hope in the progress made by my patients, I found meaning and motivation to continue to perform my daily tasks positively."* (Male, 54 years)

Challenge caring for terminally ill cancer patients

i) Physical and emotional exhaustion

Participants mentioned that taking care of their patients was extremely difficult, both physically and emotionally. It demanded a lot of patience and compassion because they felt tired. This tiredness affected their ability to fulfill their duties. They expressed that the exhaustion could come from physical, mental, and emotional factors. The participant also stated that their emotional strain and physical tiredness were a result of continuously carrying out demanding and exhausting responsibilities, as evidenced. by the following statement;

> *"Caring for terminally ill patients, especially with cancer, is physically and psychologically exhausting. It requires much humility to care for them because, at times, you may find the pus discharged in an open wound that you would have to clean. Sometimes, we need to consult the doctors when challenges persist."* (Male, 53 years)

Participants explained that the numerous tasks and responsibilities they undertake for their patients created a dependency that leads to feelings of heaviness and burden. This challenge restricted their ability to engage in other social activities to care for their loved ones. One of the participants explained that;

> *As I have said, after the chemo, she experienced a lot of diarrhea and vomiting, which made her weak. She could not go to the toilet by herself and would often soil her sick bed. She would complain when you tell her to try to go to the toilet. This meant I needed to wash the patient's clothes and clean the environment*."(Female, 30 years)

Moreover, participants described encountering emotionally challenging situations while caring for patients, which in turn negatively affected the patients in different ways. The participants highlighted that caregiving was often associated with emotional difficulties, mainly when patients were in critical conditions. They added that such patients frequently relied on caregivers to assist with lifting and mobility tasks. Moreover, the participants emphasized that the challenges increase when patients experience memory loss and temper issues due to pain, resulting in disrespectful behavior, such as calling caregivers derogatory names. This ultimately impacts the emotional well-being of the caregivers. One of the male caregivers explained that:

> *When I was starting to take care of my patient, I was feeling very emotional and depressed due to the high intensity of caring; also, in the beginning, the language that my patient used was not good for me. The old man has a problem with memory loss. For example, you may take him out of the shower, and shortly after, he will forget and think he needs another shower. So, I have to take him back to the bathroom, which is an exhausting routine."* (Male, 30 years)

Participants reported facing complex and devastating emotional burdens and depression. The ongoing demands of caregiving, combined with the distress of witnessing a loved one's suffering, lead to considerable psychological stress. Furthermore, daily exposure to a relative's severe symptoms or pain may cause caregivers to feel a sense of hopelessness and demoralization.

ii) Financial problem

Participants verbalized that they encountered financial difficulties in meeting caregiving needs that could facilitate the fulfillment of their responsibilities. In the caregiving context, they reported that financial constraints limited their ability to afford expenses associated with caregiving, such as medical care, basic living needs, logistical expenses, and the loss of income due to caregiving responsibilities. Financial challenges were one of the constraints experienced by many participants. These challenges were determined to have a significant effect on the ability of caregivers to meet their own needs and the needs of their loved ones in critically ill conditions. One of the caregivers stated;

> *"Money is a primary challenge in caregiving cancer patients; once the patient is in critical condition, it changes the entire lifestyle of the patient and caregiver, which will need more financial resources for paying medication bills and basic needs like food and medical equipment like gloves for handling patients. A shortage of financial resources impacts the quality of life of caregivers, as sometimes we lack money to buy our food and have to eat patient's leftovers."* (Male, 45 years)

Also, another participant shared the financial challenges she faced by explaining how the financial issues impacted her quality of life and limited her ability to offer sufficient care in the following statement:

"Money is a prominent issue that I am facing; most of my basic needs are to be financed by myself since I have to spend much time caring for my patients; it limits my ability to generate income to finance those needs. Thus, financial strain is one of the challenges that I can properly acknowledge since I have experienced it" (Female, 30 years)

iii) Reduced Social Interaction

Participants reported that social isolation impacted their lives. They often felt isolated from their social circles due to their responsibilities in caring for a loved one. The absence of social interaction exacerbated the participant's feelings of loneliness and difficulty in caring. The

participant's experience underscores the critical need for social support systems to help alleviate the burdens faced by those caring for terminally ill patients. One participant described:

> *"Taking care of a critically ill patient is exhausting, and there is no time to rest. It was hectic the first time I started, but at least now I have started to get used to it. However, my joints are tired because I cannot rest.* (Male, 53 years)

Also, the participants expressed the important role of social support in caregiving and how it is affected by feelings of loneliness. Participants often experience isolation and lack the support they need to cope with their responsibilities. This lack of social interaction can restrict their access to crucial resources and information, affecting their ability to make well-informed decisions about patient care, by saying:

> *"I feel like I am the only one taking care of everything. My friends and family are supportive, but they are not here when I need someone to talk to or help me with the daily tasks"* (Male, 45years).

Furthermore, participants expressed encountering challenges in providing comfort as their loved one's condition worsens due to a terminal illness. It's important to note that their friends and family may not fully understand their situation and therefore cannot offer the needed support, leading to increased feelings of loneliness. Female caregiver, saying that

> *"I miss my friends I used to talk to and share with but they have no idea what I am going through, I stand alone."* (Female, 32 years)

CHAPTER FIVE

DISCUSSION OF THE FINDINGS

5.1 Introduction

The study aimed to explore caregivers' experiences in providing care to terminally ill cancer patients. Facilitators caring for terminally ill patients were among two themes identified in this study. This theme compiles four subthemes to answer research objectives: social support network, new experience and skills, adapting patients' behavior, and good adherence to medical guidance. Challenges caring for terminally ill cancer patients were another theme reported in this study with physical and emotional exhaustion, financial problems, and reduced social interaction as the main challenges in providing care.

5.2 Discussion of the Findings

The facilitator caring for terminally ill patients, was vital in this study to enhance the researcher's understanding of other experiences participants obtained. A social support network was among the things participants did to their patients, such as bathing, brushing, washing clothes, and feeding patients; this means that once someone had a problem, they needed support from relatives or close friends to maintain dignity. It also shows solidarity among siblings. This was supported by a Study done by (Khan et al., 2011) from India, which resolved that informal caregivers offer the greatest of nurture and inner care to the patient. Therefore, there are similarities in the findings between these two studies. Acquiring new experience and skills was important for rapidly and capably appearing to caregivers get ready to change their behavior, change time to walk up early and having concurate activities which will help them even if after finish taking care to their patients, this was supported by the qualitative study done by Maija (2022) Caregivers recognized several detailed requirements and paid lively attention to learning to achieve their innovative responsibilities. It has similarities when compared with the current study findings.

The adaption to patient's problems, was very significant to caregivers since cancer patients had some troublesome, like being angry unexpectedly, so the caregiver sometimes trained themselves how to copy the situation like leaving the patients alone until the anger is relieved, giving them words of encouragement to the patients it also acts as coping strategies while caring to terminally ill cancer patients. these findings were contradicting with a study done by (Peeranuch et al, 2015) whereby caregivers were felt being overwhelmed due to patients anger and unexplained problems. Good adherence to medical guidance is essential in providing care to terminally ill patients. Caregivers receive clear and clarified information that helps them to cope with simplified medication on admission and drug adherence to patients during discharge. This motivates caregivers when doing medical procedures, which improves health outcomes, so once medical personnel instructs a patient or caregiver about health issues, it should be simple for the receiver to execute that message. Allison (2017) had to educate and train those caregivers for a good outcome for the patient's condition. Both Studies aimed to improve patients' well-being despite different modes of delivering that information to caregivers.

Concerning the challenges of caring for critical cancer patients, physical and emotional exhaustion was one of the aspects largely reported. Changing patient conditions is a headache for caregivers. Patients need to be turned, fed, and even toileted; many caregivers described this as challenging. This was supported by. Melinda Smith, M.A (2024). Study of Caregiver stress and burnout, states that, if caregiving stress is not managed, it can negatively impact your health, relationships, and mental well-being, potentially resulting in burnout, characterized by emotional, and physical exhaustion. Emotional exhaustion also challenges the participants especially when the patient has memory loss and may demand things from caregivers that may have already been done. Patricia, et al. (2024) conducted a study to support the current study, titled Impact of Dementia on informal care: a systematic review of family caregivers' Perceptions. The findings offer insights into the comprehensive experience of caregiving for a person with dementia, revealing both the positive and negative aspects underlying the caregiver role.

Despite this, caregivers often find strength in their dedication to helping their loved ones through such a challenging time, which contributes to the quality of life and their ability to provide supportive services to patients in terminal conditions. This is supported by Johannesen, et al. (2023). The study found that family specifically family members with a healthcare background together with nurses were supporting caregivers in managing the care of the dying relative at home, the factors that made the caregivers feel their efforts meaningful. Both studies show the importance of caring for their loved ones. Financial problems were also reported in this study, which was a significant challenge encouraged by caregivers. This can be explained by the fact that most of the participants require money and come from rural areas, and all of their basic needs rely on purchasing. Being in the hospital for a long time makes them bankrupt in managing their loved ones. The results of this study align with previous studies. Krug et al. (2018) and Johnston (2017) indicated several significant challenges, such as financial constraints for treatment and living expenses, interrupted medical care, emotional stress due to multiple responsibilities, stigma, and misconceptions about disease transmission. Both studies show the magnitude of financial constraints.

Reduced social interaction has also been reported in this study. It may be caused by too much commitment from the caregiver which will end up with loneliness while taking care of their loved one. The participants emphasized how critically difficult taking care of terminally ill patients. They do not have time for socialization or to find money. This is supported by the study by, Rahimi, et al., (2021) conducted a study focusing on family caregivers of COVID-19 patients. The study revealed challenges including unmet needs, physical and psychological strain, and care assistance. In the same way, caregivers in the current study are facing challenges that are similar to those reported by Rahimi, et al. Despite the challenges of caring for terminally ill patients, participants in the current study continue to dedicate themselves to caring for their loved ones during this difficult time.

5.3 Limitations and Mitigation of the Study

1. The researcher encountered some limitations in the study. They were not proficient in qualitative data analysis, so it took a long time to understand the terminology, design, and report the results, which may have hindered the efficiency of the study. However, they were able to mitigate this by working closely with supervisors to identify and address any limitations, ultimately contributing to the knowledge of qualitative research and meeting the required criteria.
2. ORCI serves as the main referral hospital, receiving patients from across the country and providing comprehensive and specialized care for cancer patients. However, not all cancer patients in Tanzania have access to ORCI, as other satellite hospitals offer care and treatment to patients with cancer, including those with caregivers. Therefore, generalization is neither intended nor appropriate.

CHAPTER SIX

CONCLUSION AND RECOMMENDATION

6.1 Conclusion

The study aimed to explore the experience of caregivers in providing numerous facilitators and the challenges faced by caregivers in caring for terminally ill cancer patients. Two themes included facilitator caring for terminally ill patients with its sub-theme including a social support network, acquiring new experience and skills, adapting patient's problems, and good adherence to medical guidance. Physical and emotional exhaustion, financial constraints, and reduced social interaction are subthemes from the main themes of the challenge of caring for terminally ill patients Despite these difficulties caregivers often find themselves overwhelmed by the demanding nature of caregiving, with limited support available to alleviate their burdens. More importantly, the caregivers should be observed especially based on the nature of exposure following their care of terminally ill cancer patients which needs close attention in both emotions and psychological leave alone material demands. Furthermore, financial concerns should be accounted for to cultivate the best environment in the course of care. This can be made possible by integrating family and spiritual aspects. In another way Encouraging members to have caregivers' family social fund and positive to generate usage of these fund will be very supportive in handling with caregiving difficulties.

6.2 Recommendations

6.2.1 Practical Recommendations

1. In Tanzania, where access to specialized healthcare services may be limited, establishing primary palliative nurse roles can significantly improve the coordination and delivery of palliative care services. These nurses can liaise between tertiary care facilities like the Ocean Road Cancer Institute and local dispensaries or health centers, ensuring that patients and caregivers receive consistent support and guidance throughout their care journey.

2. Given the cultural importance of community and family support in Tanzania, promoting caregiver support groups can be particularly impactful. These groups can provide caregivers a platform to share their experiences, receive emotional support, and access valuable coping strategies from peers facing similar challenges.

6.2.2 Policy Recommendations

1. The social support should implement strategies to help critically ill patients improve their health (family level). This is necessary due to the challenges faced by the relatives who care for these patients. Many patients at ORCI come from outside Dar es Salaam and end up being caregivers for extended periods, depleting their savings completely.
2. Access to essential palliative care medications, including morphine, is essential for managing pain and improving the quality of life for cancer patients in Tanzania. Subsidizing these drugs can make them more affordable and accessible to patients and caregivers, particularly those facing financial constraints.

6.3 Areas of Further Study

This study focused on determining the experience of caregivers in providing care to terminally ill cancer patients and found that there are several challenges facing them, the study recommended further studies on the socio-economic effect of caregiving terminally ill patients to caregivers and their overall well-being.

REFERENCES

Akpan-Idiok, P. A., & Asuquo, E. F. (2021). The exceptional role of women as primary caregivers for people living with HIV/AIDS in Nigeria, West Africa.

Anderson, E. W., & White, K. M. (2017). "It Has Changed My Life": An Exploration of Caregiver Experiences in Serious Illness. *American Journal of Hospital and Palliative Medicine*, Volume 35, Issue 2. pp 266-274.

Asenga, N. E., & Naburi, E. H. (2023). Knowledge, attitudes, challenges and coping strategies amongst caregivers of children with cerebral palsy in Dar es salaam, Tanzania. *Tanzania medical journal*.

Atanuriba, G. A., Apiribu, F., Salif, Y., Laari, T. T., Bonsu, A. B., Ozomeku, V. M., . . . Amooba, P. A. (2023). How do caregivers of children living with HIV/AIDS cope, and where do they get support? A qualitative study in Ghana. *Lifestyle Magazine*, Volume 8.

Aubeeluck, A. E. (2019). An international validation of a clinical tool to assess carers quality of life in Huntington's disease. *Frontiers in Psychology*.

Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic analysis and code development.* Sage.

Cardinali, P., Migliorini, L., & Rania, N. (2019). The caregiving experiences of fathers and mothers of children with rare diseases in Italy: Challenges and social support perceptions. *Frontiers in Psychology*.

Caswell, G., Pollock, K., Harwood, R., & Porock, D. (2015). Communication between Family Carers and Health Professionals about End-of-Life Care for Older People in the Acute Hospital Setting: A Qualitative Study. *BMC Palliative Care*, Vol. 14(35). pp 1-14.

Chalya, P. L., Mchembe, M. D., Mabula, J. B., Rambau, P. F., Jaka, H., Mheta Koy, E. M., & Masalu, N. (2013). Clinicopathological Patterns and Challenges of Management of Colorectal Cancer in a Resource-Limited Setting: a Tanzanian Experience. *World Journal of Surgical Oncology*, Vol 11, No. 88. pp 1-9.

Cheluvappa, R., & Selvendran, S. (2022). Palliative Care Nursing in Australia and the Role of the Registered Nurse in Palliative Care. *Nursing Reports*, Vol. 35, Issue 4. pp 601-611.

Chen, H.-M., Huang, M.-F., Yeh, Y.-C., Huang, W.-H., & Chen, C.-S. (2014). Effectiveness of coping strategies interventions on caregiver burden amomg caregivers of elderly patients with dementia. *Wiley online library*, 20-25.

Chona, E. Z., Msengi, E. A., Gosse, R. A., Ambikile, J. S., & Krakauer, E. L. (2023). The lived experiences and caring needs of women diagnosed with cervical cancer: A qualitative study in Dar es Salaam, Tanzania. *PloS one*, Vol. 18(8), e0289925.

Creswell, J. W. (2016). *Qualitative inquiry and research design: Choosing among five approaches.* Sage publications.

Dlamini, M., Hlongwana, K., Dlamini, S., & Ginindza, T. (2019). Factors Influencing Palliative Care Utilization Among Patients With Cancer: A Cross- Sectional Study. *Research Square (Has Not Been Reviewed by a Journal)*, Vol. 1. pp 1-21.

Dunsmore-Dawson, J.-A. (2020). *Family caregivers' experiences in the palliative care context: A longitudinal, qualitative study.* Sheffield, England: Sheffield Hallam University.

Eerden, M. v., Csikos, A., Busa, C., Hughes, S., Radbruch, L., Menten, J., . . . Groot, M. (2014). Experiences of Patients, Family and Professional Caregivers with Integrated Palliative Care in Europe: Protocol for an International, Multicenter, Prospective, Mixed Method Study. *BMC Palliat Care*, Vol. 13, Issue 52. pp 13-52.

Ferlay, J., Colombet, M., Soerjomataram, I., Parkin, D. M., Piñeros, M., Znaor, A., & Bray, F. (2020). Cancer statistics for the year 2020: An overview. *International Journal of Cancer*, Volume149, Issue4: pp 778-789.

Gambe, R. G., Clark, J., Meddick-Dyson, S. A., Ukoha-Kalu, B. O., Nyaaba, G. N., & Murtagh, F. E. (2023). The roles and experiences of informal carers providing care to people with advanced cancer in Africa—A systematic review and critical interpretive analysis. *PLOS Glob Public Health*, Vol. 3(4): e0001785.

Haugland, B. S., Hysing, M., & Sivertsen, B. (2020). The burden of care: A national survey on the prevalence and demographic characteristics among young adult carers attending higher education in Norway. *Frontier Psychology*.

Hebert, R. S., Arnold, R. M., & Schulz, R. (2007). Improving Well-Being in Caregivers of Terminally Ill Patients. Making the Case for Patient Suffering as a Focus for Intervention Research. *Journal of pain and symptom management*, Vol. 34(5), 539–546.

Hudson, P., Morrison, R. S., Schulz, R., Brody, A. A., Dahlin, C., Kelly, K., & Meier, D. E. (2020). *Improving Support for Family Caregivers of People with a Serious Illness in the United States: Strategic Agenda and Call to Action.* New York, United States: Mary Ann Liebert, Inc.

Johannesen, J., Timm, H., & Roin, A. (2023). Caregivers' experiences of end-of-life caregiving to severely ill relatives with cancer dying at home: A qualitative study in the Faroe Islands. *Scandinavian Journal of Caring Science*, Early View.

Johannesen, J., Timm, H., & Roin, A. (2023). Caregivers' experiences of end-of-life caregiving to severely ill relatives with cancer dying at home: A qualitative study in the Faroe Islands. *Scandinavian Journal of Caring Science*, Early View.

Johnston, H. (2017). *Caring for caregivers: challenges facing informal palliative caregivers in Western Kenya.* Independent Study Project (ISP) Collection. 2684.

Jonnesen, E. J., Timm, H., & Roin., A. (2023). Caregivers' experiences of end-of-life caregiving to severely ill relatives with cancer dying at home: A qualitative study in the Faroe Islands. *Scandinavian Journal of Caring Science/Early View*, https://doi.org/10.1111/scs.13165.

Kajungu, A. (2022). *Exploring Patients, Family, and Providers Attitude. Experience Practices on Palliative Care among Colorectal Cancer Patients in Dar es Salaam, Tanzania.* Dodoma, Tanzania: The University of Dodom.

Kara Health. (2022, December 27). *A Short Read on the History of Hospice Care*. Retrieved from Kara Health: https://kara.health/a-short-read-on-the-history-of-hospice-care/

Kazemi, A., Azimian, J., & Mafi, M. (2021). Caregiver burden and coping strategies in caregivers of older patients with stroke. *BMC Psychology*, 51.

Kothari, C. (2017). *Research Methodology: Methods and Techniques.* New Delhi: New Age International (P) Ltd.

Krug, K., Ballhausen, R. A., Bolter, R., Engeser, P., Wensing, M., Szecenyi, J., & Klimm, F. P. (2018). *Challenges in supporting lay carers of patients at the end of life: results from focus group discussions with primary healthcare providers.* https://doi.org/10.1186/s12875-018-0816-4: BMC Family Practice.

Lazarus, R., & Folkman, S. (1984). *Stress, Appraisal, and Coping.* New York. USA: Springer.

Lelei, F. (2019). *Experiences of Home-based Caregivers of Advanced Cancer Patients from a Regional Faith-based Palliative Care Center in Kenya.* Nairobi, Kenya: Kabarak University.

LeSeure, P., & Chongkham-ang, S. (2015). The Experience of Caregivers Living with Cancer Patients: A Systematic Review and Meta-Synthesis. *MDPI*, Volume 5, Issue 4: pp 406-439.

Loth, C., Namisango, E., Powell, R., Pabst, K., Leng, M., Hamada, M., & Radbruch, L. (2020). From Good Hearted Community Members we get Volunteers" - An Exploratory Study of Palliative Care Volunteers Across Africa. *BMC Pallitive Care, Vol. 19, No,1*, 1-10.

Makene, F. S., Ngilangwa, R., Santos, C., Cross, C., Ngoma, T., Mujinja, P. G., . . . Mackintosh, M. (2022). Patients' pathways to cancer care in Tanzania: documenting and addressing social inequalities in reaching a cancer diagnosis. *BMC Health Ser vices Research*, Volume 22(1): pp 189-198.

Margaret, K., Ngigi, S. K., & Mutisya, S. (2018). Sources of Occupational Stress and Coping Strategies among Teachers in Borstal Institutions in Kenya. *Edelweiss: Psychiatry Open Access*, Volume 2 Issue 1: 18-21.

Martí-García, C., Fernández-Alcántara, M., López, P. S., Ruiz, C. R., Martín, R. M., & Garcia-Caro, M. P. (2020). Experiences of Family Caregivers of Patients with Terminal Disease

and the Quality of End-of-Life Care Received: A Mixed Methods Study. *Peer Journal for Life & Environment Research*, Vol. 8, e10516.

McIlfatrick, S., Slater, P., Beck, E., Bamidele, O., McCloskey, S., Carr, K., . . . Hasson, F. (2021). Examining Public Knowledge, Attitudes and Perceptions towards Palliative Care: A Mixed Method Sequential Study. *BMC Palliative Care*, Vol. 20, No. 44. pp 1-17.

McKay, P., Rajacich, D., & Rosenbaum, J. (2002). Enhancing palliative care through Watson's carative factors. *Can Oncol Nurs J*, 12(1):34-44. doi: 10.5737/1181912x1213438.

Mohamed, F. S. (2015). The Lived Experience of Caregivers Providing Home Care for Terminal Cancer Patients: A Phenomenological Study. *26th international Nursing Research Congress* (pp. 1-22). San Juan, Puerto Rico: Sigma Theta Tau International .

Mujjuzi, I., Mutegeki, P., Wosukira, S. N., Namat, F., Alayo, P., Amanya, S. B., & Nyeko, R. (2021). Care burden and coping strategies among caregivers of paediatric HIV/AIDS in Northern Uganda; A cross-sectional mixed method study. *AIDS research and treatment*.

Mwangi, S. (2022). *Quality of Life for Family Caregivers to Cancer Patients in Kenyatta National Hospital, Nairobi City County, Kenya.* Majengo Mvita, Kenya: Kenyatta University.

Mwanjala, M. N., Urio, L. J., & Mtebe, M. V. (2022). Prevalence and predictors of renal dysfunction among people living with HIV on antiretroviral therapy in the Southern Highland of Tanzania: a hospital-based cross-sectional study. *Pan African Medical Journa*, Volume 14, Article 137; pp 1-12.

Ngwa, W., Addai, B., Adewole, I., Ainsworth, V., Alaro, J., & Alatise, O. (2022). Cancer in sub-Saharan Africa: ALancet Oncology Commission. *The Lancet Oncology Commission*, Vol. 23(6): pp 251–312.

Nowell, L. S., Norris, J. M., & Moules, N. J. (2017). Themati Analysis; striving to meet the trustworthness criteria. *International Journal of Qualitative Methods* , 16(1), 1609406917733847.

NVivo. (2024, June 17th). *Using Nvivo.* Retrieved from www.help-nv.qsrinternational.com: https://help-nv.qsrinternational.com/12/win/v12.1.115-d3ea61/Content/concepts-strategies/using-nvivo-for-qualitative-research.htm#:~:text=Using%20NVivo%20to%20organize%20and,ideas%20in%20memos%20and%20maps.

Parkin, D., Ferlay, F., & Jemal, A. (2018). *Cancer in Sub-Saharan Africa: IARC Scientific Publication No. 167.* Lyon, France: International Agency for Research on Cancer.

Puymbroeck, M. V., & Rittman, M. R. (2005). 'quality of life predictors for caregivers at 1 and 6 months post stroke: Results of path analyses. *JRRD*.

Rahimi, T., Dasttyar, N., & Rafati, F. (2021). *Experiences of family caregivers of patients with COVID-19.* https://doi.org/10.1186/s12875-021-01489-7: BMC Family Practice.

ReFaey, K., Tripathi, S., Grewal, S. S., Bhargav, A. G., Quinones, D. J., Chaichana, K. L., . . . Quinones-Hinojosa, A. (2021). Cancer Mortality Rates Increasing vs Cardiovascular Disease Mortality Decreasing in the World: Future Implications. *Mayo Clinic proceedings. Innovations, quality & outcomes,* Vol. 5(3), 645–653.

Rhee, J., Garralda, E., Namisango, E., Luyirika, E., DeLima, L., & Powell, R. (2018). An Analysis of Palliative Care Development in Africa: A Ranking Based on Region-Specific Macroindicators. *Journal of Pain and Symptom Management,* Vol. 56(2): pp 230–8.

Robertson, S., Hjorleifsdottir, E., & Siguroardottir, P. (2022). Family Caregivers' Experiences of End-of-Life Care in the Acute Hospital Setting. A Qualitative Study. *Scandnavia Journal of Caring Sceinces* , Vol 36, Issue 3. pp 686-698.

Saleh, F., & O Neil, C. (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 Study,* Vol. 6, No. 3. pp 57-71.

Sathiananthan, M. K., Crawford, G. B., & Eliott, J. (2021). Healthcare professionals' perspectives of patient and family preferences of patient place of death: a qualitative study. *BMC palliative care*, Vol. 20(1): pp 147-152.

Saunders, B., Sim, J., Waterfield, J., & Kingstone, T. (2018). Can Sample size in Qualitative Research be Determined a Priori? *International Journal of Social Research Methodology, 21(5),* 619-634.

Smolej, E., Malozewski, M., McKendry, S., Diab, K., Daubert, C., Farnum, A., . . . Cameron, J. (2023). A qualitative study exploring family caregivers' support needs in the context of medical assistance in dying. *Palliative and Supportive Care*, Vol. 21: pp 254 260.

Thomas, C. (2021). *Research Methodology and Scientific Writing* . Berlin, Germany: Springer Nature .

Tshepang, P., Isaac, O. M., & Leepile, A. S. (2021). Coping mechanisms used by families of mental health care users in Mahikeng sub-district,North West Province in South Africa. *Health SA=SA Gesondheid*.

Uren, S. A., & Graham, T. M. (2013). Subjective Experiences of Coping Among Caregivers in Palliative Care. *The Online Journal of Issues in Nursing*, Vol. 18 No. 2: pp 1-12.

Wahid, A. S., Sayma, M., Jamshaid, S., Kerwat, D., Oyewole, F., Saleh, D., . . . Payne, S. (2018). Barriers and Facilitators Influencing Death at Home: A Meta-ethnography. *Palliative Medicine* , Vol. 32(2). pp 314-328.

Walavalkar, A., Craswell, A., & Gray, N. A. (2022). Experiences of Caregivers of Patients With Conservatively Managed Kidney Failure: A Mixed Methods Systematic Review. *Canadian Journal of Kidney Health and Disease*, Vol. 9; pp 1-12.

Watson, J. (2023, January 12). *Jean Watson: Theory of Human Caring*. Retrieved from Nurses labs:https://nurseslabs.com/jean-watsons-philosophy-theory-transpersonal-caring/#:~:text=Watson's%2010%20carative%20factors%20are,%2C%20(7)%20promoting%20teaching%2D

Wei, H., & Watson, J. (2019). *Healthcare interprofessional team members' perspectives on human caring: A directed content analysis study.* Int J Nurs Sci.

Zhou, Z., Wang, Y., Yu, Y., Feng, P., Li, T., Tebes, J. K., & Luan, R. (2021). Association of caregiving knowledge and skills with caregiver burden, psychological well-being and coping styles among family caregivers of people living with Schizophrenia in China. *Front Psychiatry*.

APPENDICES

Appendix I: Informed consent English and Swahili versions

Introductions

Thank you for the opportunity to speak with you. My name is FATUMA KALOYA; master's student at MUHAS with registration number HD/MUH/T.490/2022: and I am here as researcher conducting data collection. The main objective of this research is to explore the experiences of caregivers involved in providing care to terminally ill cancer patients. Me and my team would like to learn more about the effectiveness, efficiency and general experience of caregiver who saving terminal ill patients. As part of this research, we will be conducting an interview in communities with others like you to find out more about how this issue, what might not be working as effectively. The findings of this research will provide insights on real life situation, the challenges you are facing when serving these patients.

You have been selected as one of the most important servant of cancer terminal ill patient. This exercise will take between 30-45 minutes. Your response to the interview will be recorded on a tablet which has a password and is only accessible to the research team.

Confidentiality

All the information we collect from you during this interview will be kept confidential to the best of our ability, and only the research team will review and analyze it. The data will be kept in a secure server and will be anonymized. Your privacy will be protected. We will not include any information in report that would identify your involvement in this interview. Only data that has been combined with that from other people and sources will be reported.

Right to Refuse or Withdraw

The decision to participate in this study is entirely up to you. You may refuse to participate in this interview and have the right not to answer any question and stop taking the interview at any point. You will not be penalized if you choose not to answer or withdraw your participation, and your willingness to participate or not.

Benefits and Risks

There are no direct benefits to you from participating in this evaluation. It is, however, expected that the information you provide, when combined with information from others. There are no known risks to you by participating in this research.

Right to Ask Questions and Report Concerns

If you have any questions now feel free to communicate with the university, or in case you have question during interview feel free to ask the interviewer.

Do you agree to participate in this study on the date _____ time _____?

1. Yes, 2. No

If yes, kindly sign this consent form on this day of _, may ,2024.

Signature; _____

Names; _____

Position; _____

Organization; _____

Utangulizi

Nashukluru kupata fulsa ya kuzungumza na Wewe. Majina yangu ni FATUMA KALOYA; Mwanafunzi wa chou kikuu cha Muhimbili (MUHAS) mwenye namba za usajiri HD/MUH/T.490/2022: nipo hapa kufanya utafiti na kukusanya taarifa. Lengo kuu la tafiti hii ni kuangazia uzoefu wa ndugu kwa wagonjwa waliozidiwa wenye saratani wanaotibiwa katika Taasisi ya Saratani ya Barabara ya Bahari. Mimi na timu yangu tunahitaji kujifunza Zaidi ufanisi na uzoefu wenu kwa ujumla mnapohudumia wagonjwa hawa. Majibu ya tafiti hii yatatoa picha halisi ya Maisha mnayopitia, changamoto mnazopitia mkiwahudumia hawa wagonjwa.

Umechaguliwa kama mmoja kati ya watu muhimu Zaidi wanao hudumia hawa wagonjwa. Zoezi hili litachukua takriban dakika 30-45. Majibu yako yatarekodiwa kwenye kishikwambi ambacho kina neno la siri na itatumiwa na wahusika tu.

Appendix II: Interview Guide for the Family members and relatives

Care among Terminal Ill Patient

1. How did you become involved in providing care to the terminally ill cancer patient at Ocean Road Cancer Institute?
    (i) Probe about motivations and circumstances that led to caregiving role
    (ii) probe about daily task and responsibilities
    (iii) Probe about terminal ill patient's status psychologically, spiritually, physical, social and cultural

Challenges

2. What specific challenges have you encountered in providing care to terminally ill cancer patients?
    (i) Probe about:
    Lacking capacity
    Probe about emotional and physical stress
    Probe about financial strain
    Probe about sleep deprivation
    Probe if he/she has been afraid to ask help
    Probe about depression and isolation
    (ii) How do these challenges impact your overall well-being and ability to give care?

Coping Strategies

3. How do you personally cope with the challenges you face in providing care?
    Probe about:
    How do you prioritize self-care when fulfilling your duties?
    How are you focusing on your abilities?
    How are you seeking and accepting opportunities for help?

4. Do you set your personal health goals?

   Probe about how she/he stet personal goals
5. How do you adhere to safe and responsible medication administration?
6. What strategies have you employed to manage and improve your caregiving experience?
7. How do you communicate with other relatives regarding the patient's care?
8. How are you involved in decision-making for the patient's care?
9. From your perspective, how do you ensure the patient's dignity is maintained?
10. Is there anything else you would like to share about your experiences as a caregiver?
11. Any advice for other caregivers in similar situations?

    Are there specific areas where you feel additional support needed?

Appendix III: Mahojiano kwa ndugu wa familia

1. Vipi ulianza kutoa huduma kwa wagonjwa waliozidiwa wenye saratani wanaotibiwa katika Taasisi ya Saratani ya Barabara ya Bahari? (i) kuulizia nini kilichokusukuma kuchukua jukumu la kutoa huduma (ii) Kuuliza kuhusu majukumu Yake ya kila siku
2. Vikwazo gani maalum umekutana navyo katika kutoa huduma kwa wagonjwa wa saratani walizidiwa kutokana na maradhi? (i) Kuuliza kuhusu msongo wa kihisia na kimwili, ukosekanaji wa kifedha, na vikwazo vingine vyovyote vilivyokabiliwa.
3. Vipi unakabiliana na changamoto unazokutana nazo katika kutoa huduma?
4. Vipi kuna malengo yeyote uliyojiwekea kuhusu afya yako binafsi?uliza jinsi gani amejiwekea
5. Jinsi gani unazingatia utoaji wa dawa kwa usalama katika jukumu lako kama mtoa huduma?
6. Njia gani unatumia kusimamia na kuboresha uzoefu wako wa kutoa huduma?
7. Vipi unawasiliana na watoa huduma wengine kuhusu huduma ya mgonjwa?
8. Vipi unahusika katika kufanya maamuzi kuhusu huduma ya mgonjwa?
9. kwa mtazamo wako, jinsi gani unahakikisha hadhi ya mgonjwa inahifadhiwa?
10. Je, kuna kitu kingine ungependa kunishirikisha kuhusu uzoefu wako kama mtoa huduma?
11. Ungependa kutoa ushauri gani kwa watoa huduma wengine katika hali kama hiyo?

Appendix IV: Intellectual Property Rights Contract

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES

DIRECTORATE OF POSTGRADUATE STUDIES

INTELLECTUAL PROPERTY RIGHTS CONTRACT

1.0 INTRODUCTION

This contract is made between Prof./Dr./…….....……. in his/her capacity as the Director, Postgraduate studies on behalf of the Muhimbili University of Health and Allied Sciences (herein referred to as MUHAS), P. O. Box 65001, Dar es Salaam and Dr./Mr./Miss/Mrs./Ms: ……. a postgraduate Student registered for……..... (*Name of the programme*) offered by the School/Institute of……...…….

Registration Number …….....

2.0 As a Postgraduate student registered at MUHAS, I declare that all research findings and innovations done during my studentship shall be the property of the University and shall be protected under the Berne Convention, World Intellectual Property Organization, the Copyright act 1999 and according to the MUHAS Intellectual Property Right Policy. The Dissertation/Thesis shall not be reproduced by any means, in full or in part, except for short extracts in fair dealings, for research or private study, critical scholarly review or discourse with an acknowledgement, without the written permission of the Directorate of postgraduate studies, on behalf of MUHAS.

(Students full name)……...……..

(Student's signature)……..... (Date)……...……...

(Director, Postgraduate Studies' full name)……..……...…...

(Director, Postgraduates studies signature)……..... (Date)……...….....

(Witness' full name)……..... (Date)……...……..

(Witness'signature)…….....(Date)……..……...

Appendix V: Ethical clearance letter-MUHAS

UNITED REPUBLIC OF TANZANIA

MINISTRY OF EDUCATION, SCIENCE AND TECHNOLOGY

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES

OFFICE OF THE DIRECTOR – RESEARCH, PUBLICATIONS AND INNOVATION

Ref. No.DA.282/298/01.C/2105 Date: 18/03/2024

MUHAS-REC-03-2024-2105
FATUMA KALOYA
MUHAS

RE: APPROVAL FOR ETHICAL CLEARANCE FOR A STUDY TITLED: EXPERIENCE OF CAREGIVERS IN PROVIDING CARE TO TERMINALLY ILL CANCER PATIENTS AT OCEAN ROAD CANCER INSTITUTE, DAR ES SALAAM

Reference is made to the above heading,

I am pleased to inform you that the Chairman has on behalf of the University Senate, approved ethical clearance of the above-mentioned study, on recommendations of the Senate Research and Publications Committee meeting accordance with MUHAS research policy and Tanzania regulations governing human and animal subjects research.

APPROVAL DATE: 18/03/2024
EXPIRATION DATE OF APPROVAL: 18/03/2025

STUDY DESCRIPTION:
Purpose:

The purpose of this qualitative study is to explore the experiences of caregivers in providing care to terminally ill cancer patients.

The approved protocol and procedures for this study is attached and stamped with this letter, and can be found in the link provided: https://irb.muhas.ac.tz/storage/Certificates/Certificate%20-%2015347.pdf and in the MUHAS archives.

The PI is required to:

1. Submit bi-annual progress reports and final report upon completion of the study.
2. Report to the IRB any unanticipated problem involving risks to subjects or others including adverse events where applicable.
3. Apply for renewal of approval of ethical clearance one (1) month prior its expiration if the study is not completed at the end of this ethical approval. You may not continue with any research activity beyond the expiration date without the approval of the IRB. Failure to receive approval for continuation before the expiration date will result in automatic termination of the approval for this study on the expiration date.
4. Obtain IRB amendment (s) approval for any changes to any aspect of this study before they can be implemented.
5. Data security is ultimately the responsibility of the investigator.
6. Apply for and obtain Data Transfer Agreement (DTA) from NIMR if data will be transferred to a foreign country.
7. Apply for and obtain Material Transfer Agreement (MTA) from NIMR, if research materials (samples) will be shipped to a foreign country.
8. Apply for and obtain permission to publish the results from National Institute for Medical Research. The application should be before submitting to a publisher and not concurrently through the email publications@nimr.or.tz.
9. Any researcher, who contravenes or fail to comply with these conditions, shall be guilty of an offence and shall be liable on conviction to a fine as per NIMR Act No. 23 of 1979, PART III section 10 (2)
10. The PI is required to ensure that the findings of the study are disseminated to relevant stake holders.
11. PI is required to be versed with necessary laws and regulatory policies that govern research in Tanzania. Some guidance is available on our website https://drp.muhas.ac.tz/.

20/02/24

Dr. Kasusu Nyamuryekung'e

University of Health and Allied Sciences
DIRECTOR
Research, Publications & Innovations
Box 65001

Ag. Chairperson, MUHAS Research and Ethics Committee

Appendix VI: Permission letter –ORCI

UNITED REPUBLIC OF TANZANIA
MINISTRY OF HEALTH
OCEAN ROAD CANCER INSTITUTE

ORCI OCEAN ROAD CANCER INSTITUTE

On Reply Please Quote:
Ref: 10/VOL.XXI/216B

Date: 9th April, 2024

INSTITUTIONAL ACADEMICS, RESEARCH, PUBLICATIONS AND ETHICS COMMITTEE

Fatuma Kaloya
Reg no: HD/MUH/T.490/2022
MSc. Oncology Nursing
School of nursing
MUHAS

Re: Approval to collect data for the study "Experience of Care givers in providing care to terminally ill cancer patients at Ocean Road Cancer Institute,Dar es salaam."

Reference is made to the above heading, this is to let you know that the Institute Academics, Research, Publications and Ethics Committee has granted you permission to conduct this study. For a period of one year ending; April 2025.

Upon successful completion of the study, you are obliged to submit a copy of the final document of this research project to the IARPEC.

Yours Sincerely,

OCEAN ROAD CANCER INSTITUTE ACADEMIC UNIT P.O. Box 3592 DAR ES SALAAM

Dr. Mamsau Ngoma
Academic Unit, ORCI.

Ocean Road Cancer Institute; Junction of Luthuli / Baraka Obama Roads; P.O. Box 3592; Dar Es Salaam -Tanzania;
Tel: +255-22-2127597; Fax: +255-22-2118704; Email: info@orci.or.tz; Website: www.orci.or.tz

turnitin

Digital Receipt

This receipt acknowledges that Turnitin received your paper. Below you will find the receipt information regarding your submission.

The first page of your submissions is displayed below.

Submission author:	Fatuma Kaloya
Assignment title:	Fatuma Proposal
Submission title:	FATUMA- RESEARCH
File name:	FATUMA-DISSERTATION.docx
File size:	1.63M
Page count:	60
Word count:	12,877
Character count:	73,706
Submission date:	19-Jul-2024 10:40AM (UTC+0300)
Submission ID:	2281101285



Copyright 2024 Turnitin. All rights reserved.

FATUMA- RESEARCH

ORIGINALITY REPORT

20%	17%	10%	10%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

PRIMARY SOURCES

1	Submitted to Muhimbili University of Health and Allied Sciences Student Paper	5%
2	www.ncbi.nlm.nih.gov Internet Source	3%
3	www.muhas.ac.tz Internet Source	2%
4	dspace.muhas.ac.tz:8080 Internet Source	2%
5	www.researchgate.net Internet Source	1%
6	discovery.researcher.life Internet Source	1%
7	TOMOYO SASAHARA, MITSUNORI MIYASHITA, MASAKO KAWA, KEIKO KAZUMA. "Factors associated with difficulties encountered by nurses in the care of terminally ill cancer patients in hospitals in Japan", Palliative and Supportive Care, 2005 Publication	1%