ESTIMATING THE CAREGIVER BURDEN AND ITS NATURE AMONG CAREGIVERS OF CHILDREN WITH LEUKEMIA AT MUHIMBILI NATIONAL HOSPITAL ONCOLOGY UNIT IN DAR-ES-SALAAM

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ESTIMATING THE CAREGIVER BURDEN AND ITS NATURE AMONG CAREGIVERS OF CHILDREN WITH LEUKEMIA AT MUHIMBILI NATIONAL HOSPITAL ONCOLOGY UNIT IN DAR-ES-SALAAM

By

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A Dissertation Submitted in Partial Fulfillment of the Requirement for the Degree of Master of Science in Oncology Nursing of the

Muhimbili University of Health and Allied Sciences

October, 2024

CERTIFICATION

The undersigned certifies that they have read and hereby recommend for examination by the Muhimbili University of Health and Allied Sciences for the dissertation entitled, **"ESTIMATING THE CAREGIVER BURDEN AND ITS NATURE AMONG CAREGIVERS OF CHILDREN WITH LEUKEMIA AT MUHIMBILI NATIONAL HOSPITAL ONCOLOGY UNIT IN DAR-ES-SALAAM", in (partial) fulfillment of the requirements for the degree of Master of Science in Oncology nursing of Muhimbili University of Health and Allied sciences.**

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DECLARATION AND COPYRIGHT

I, Romanus Mapunda, declare that this dissertation is my original work and that it has not been presented and will not be presented to any other university for a similar or any other degree award.

Signature……. Date……

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DEDICATION

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TABLE OF CONTENTS

CERTIFICATION i
DECLARATION AND COPYRIGHT ii
ACKNOWLEDGEMENT iii
DEDICATION iv
LIST OF TABLES viii
LIST OF FIGURES ix
LIST OF ABBREVIATIONS x
DEFINITIONS OF TERMS xi
ABSTRACT xii
CHAPTER ONE 1
1.0 INTRODUCTION 1
1.1 PROBLEM STATEMENT 3
1.2 THEORETICAL FRAMEWORK 4
1.3 RATIONALE OF THE STUDY 6
1.4 Main research question 7
1.4.1 Research question 7
1.5 Broad objectives 7
1.5.1 Specific objectives 7
CHAPTER TWO 8
2.0 LITERATURE REVIEW 8
2.1 Overview of childhood cancer and prevalence of caregiver burden 8
2.2 Nature of the Caregiver Burden 9
2.2.1 Economic aspect 9
2.2.2 Social aspect 10
2.2.3 Healthcare system aspect 12
2.3 Factors associated with the caregiver burden 12

2.3.1 Caregiver's and patient's characteristic 12
2.4 Summary 14
CHAPTER THREE 15
3.0 METHODOLOGY 15
3.1 Study design 15
3.2 Study setting 15
3.3 Study population 16
3.3.1 Inclusion criteria 16
3.3.2 Exclusion criteria 16
3.4 Variables 16
3.5 Sample size determination and sampling Procedure 17
3.5.1 Sample size determination 17
3.5.2 Sampling technique 18
3.6 Data Collection Methods 18
3.7 Pre-test of the study instruments 19
3.8 Data entry and cleaning 19
3.9 Data Analysis and Management 20
3.10 Ethical consideration 21
3.11 Dissemination of findings 21
CHAPTER FOUR 22
4.0 RESULTS 22
4.1 Social demographic and clinical characteristics of the caregivers 22
4.2 Prevalence of caregiver burden among caregivers of children with leukemia 23
4.3 Nature of caregiver burden 24
4.3.1 Factors associated with caregiver burden 26
4.3.2 The association between the caregiver burden with demographic and clinical factors 27
4.3.3 The association between caregiver burden with social, economic, and healthcare factors 30
CHAPTER FIVE 33

5.0 DISCUSSION 33
5.1 Discussion 33
5.2 Study limitations and mitigations 36
CHAPTER SIX 37
6.0 CONCLUSION AND RECCOMENDATION 37
6.1 CONCLUSION 37
6.2 RECOMMENDATION 37
7.0 REFERENCES 40
APPENDICES 44
Appendix I: Questionnaire 45
Kiambatanisho II: Dodoso 50
Appendix III. Consent form (English version) 55
Appendix IV. Fomu ya ridhaa (kwa kiswahili) 57
Appendix V: Ethical clearance 60
Appendix VII. Introduction letter 62
Appendix VIII. Permission letter 63
Appendix IX. Plagiarism certificates 64

LIST OF TABLES

Table 1; Social demographic and clinical characteristics of the caregivers 22
Table 2: Prevalence of Caregiver Burden 24
Table 3; Nature of Caregiver Burden 25
Table 4: Demographic and clinical factors associated with caregiver burden 28
Table 5: The association between the caregiver burden and social, economic, and healthcare factors 31

LIST OF FIGURES

Figure 1: Theoretical framework based on the Theory of Role strain by William J. Goode adopted and modified from Muliira JK and Kizza IB (24). 5

LIST OF ABBREVIATIONS

AOR	Adjusted Odds Ratio
ALL	Acute lymphoblastic leukemia
BMC	Bugando Medical Centre
COR	Crude Odds Ratio
CI	Confidence interval
FBI	Family Burden Interview
KCMC	Kilimanjaro Christian Medical Centre
MNH	Muhimbili National Hospital
MUHAS	Muhimbili University of Health and Allied Sciences
ORCI	Ocean Road Cancer Institute
P	P-value
SD	Standard Deviation
ZBI scale	Zarit Burden interview scale

DEFINITIONS OF TERMS

A burden can be defined as a heavy load or responsibility that weighs down on an individual. It is a feeling of being overwhelmed by something difficult to manage or cope with(1).

The caregiver is someone who provides for the needs of children or people who are ill or cannot provide for their own needs(2).

Caregiver burden is a concept that describes the physical, emotional, social, and financial problems that can be experienced by caregivers(3).

The nature of the caregiver burden refers to the various aspect or dimension of burden such as physical, emotional, financial, and social challenges that caregivers experience while providing care and support to someone diagnosed with cancer(2).

Characterizing the nature of caregiver burden involves identifying the aspects/characteristics under which the burden of care experienced by caregivers belongs. These include economic, social, emotional, and healthcare system aspects or characteristics(3).

Leukemia is a broad term covering a spectrum of diseases. They are a group of cancers of blood/bone marrow and are characterized by an abnormal proliferation (production by multiplication) of blood cells, usually white blood cells (leukocytes). It can be an acute or chronic neoplastic disease of the bone marrow in which unrestrained proliferation of white blood cells occurs and which is usually accompanied by anemia and thrombocytopenia. (4)

Zarit Burden Interview (ZBI) is a widely used tool to measure the level of burden experienced by caregivers of individuals with chronic illnesses, disabilities, or cognitive impairments(5).

Primary caregiver in the context of cancer refers to the main person who provides care and supports to a cancer patient, usually a family member, close friend, or in some cases, a paid professional(6).

ABSTRACT

Background: leukemia is a leading concern in pediatric cancers, with 694 incidence and a mortality count of 527 cases with five-year prevalence recorded was 1,500 cases (2.5 per 100,0000) (1). Despite the advancement in cancer treatment, leukemia demands close and prolonged care from family caregivers hence adding a burden on caregivers. This includes physical, mental, social, or financial strain which happens when the demand for care exceeds their available resources or social support. This in turn tends to affect the quality of care for children with leukemia. Despite these detrimental impacts the disease poses to caregivers, little has documented about the estimated caregiver burden and its nature in Tanzania.

Aim of the study: To Estimate the caregiver burden and its nature among caregivers of children with leukemia at Muhimbili National Hospital Oncology Unit in Dar-es-salaam.

Methodology: This quantitative cross-sectional study used simple random sampling to obtain 104 Primary caregivers of children undergoing leukemia treatments at MNH pediatric oncology unit. Data were collected through a researcher-administered questionnaire and a modified ZBI scale with 22 items, and SPSS version 23 was used to analyze the data. Descriptive statistics used to analyses social demographic, clinical characteristics and nature of the caregivers while Logistic regression (Bivariate and multiple analysis) were employed to identify factors associated with caregiver burden**.**

Results; Caregivers had a mean age of 30.5± 5.6SD, with most of them being female 70(67.3%). 60 (57.7%), experience a moderate to severe burden (47.9 ±12.3SD). Economic and social burdens were identified, with 54.8% of caregivers frequently facing financial strain while 53.8% lack family support and 62.5% lack support from friends. The age of the caregiver, relationship with the child, number of hospital admissions, inadequate social support and financial strain were associated with the caregiver's burden (aOR = 0.25, 95% CI: 0.066 – 0.971, p = 0.045), (aOR = 0.093, 95% CI: 0.09 – 0.96, p = 0.045), (aOR= 5.2, 95% CI: 1.29 - 7.94, p = 0.020), (aOR = 1.25, 95% CI: 1.066 – 2.917, p = 0.037), (aOR = 0.65, 95% CI: 0.081 – 0.849, p = 0.032) respectively.

Conclusion; This study find a high prevalence of burden (moderate to severe) among caregivers of children with leukemia. Economic and social aspects are identified as the nature of the burden. The age of the caregiver, relationship to the child, number of hospital admissions, inadequate social support and financial strains were significantly associated with caregiver burden. This study recommends a comprehensive care plan for caregivers, including regular burden assessments, and financial and social support to alleviate the burden on caregivers.

Key words: Caregiver burden, children, leukemia, nature and ZBI scale

CHAPTER ONE

1.0 INTRODUCTION

The advancement of medical science, the presence of new diagnostic tests, and the improved survival rates among children with leukemia have impacted multiple burdens of life for those caring for these children(9). These burdens have been negatively impacting the caregiver's overall well-being, including their physical, mental, economic, and social health(10). Globally, the incidence, prevalence, and mortality of leukemia have been increasing dramatically. According to the World Health Organization 2020, the annual incidence of leukemia was 474,519 cases, with a mortality of 311,594. The five-year prevalence is 1,340,506 cases. Within the sub-Saharan African region, an annual incidence of 21,343 cases was reported, accompanied by a mortality of 16,031 cases**.** In Tanzania, leukemia is a leading concern, ranking 13th overall in cancer incidence but is notably prevalent among younger populations. In 2020, Tanzania had 694 incidence and a mortality count of 527 cases with five-year prevalence recorded was 1,500 cases (2.5 per 100,0000) (11)

In India, a study examining the caregiver burden among of pediatric leukemia patients revealed that 50% of caregivers reported experiencing a moderate to severe burden based on the Zarit Burden Interview scale(12). The Zarit Burden Interview (ZBI) is a widely used tool to measure the level of burden experienced by caregivers of individuals with chronic illnesses such as cancer, disabilities, or cognitive impairments(5)

The caregiver burden can be based on different natures or aspects including economic, social, emotional, psychological, and healthcare setting burden (13). In Africa, a study done in Ghana showed that caregivers face challenges such as headaches when performing caregiving activities, decreased appetite, fatigue, compromised functional state, and loss of sleep. Based on socioeconomic aspects of the caregiving burden, caregivers take into consideration the effects of caregiving on social lives, family relationships, financial matters, and employment(14). Another study conducted at Kenya National Hospital reported that 57% of caregivers experienced severe caregiving burdens while most of the caregivers

had a low economic status, and 95% of them reported financial burdens as a result of caring for their children(15). In Tanzania, caregivers in Tanzania face financial strain, emotional stress, limited access to specialized care, and social isolation. They often experience disrupted work, poor health, and lack support, while low health literacy and limited palliative care worsen the burden(8). The study conducted at Muhimbili National Hospital reported that, the prevalence of psychological distress was high despite the high proportion of psychological support. (16). Efforts like financial aid and skill-building initiatives have been implemented to support caregivers.

These findings are highly relevant to the Tanzanian context, where caregivers of pediatric leukemia patients face similar challenges. Like in India and Kenya, the burden is closely tied to socioeconomic factors, with low-income families struggling the most due to high treatment costs and limited financial resources. In Tanzania, caregivers also endure prolonged treatment periods, leading to emotional, physical, and financial strain, much like those in Ghana who experience fatigue, sleep loss, and health issues. The similarities in financial and emotional burdens across these countries highlight the need for targeted interventions, such as financial support and healthcare infrastructure improvements, to alleviate caregiver burden in Tanzania

Since this study specifically targeted caregivers of leukemic pediatric, it was crucial to estimate the burden experienced by caregivers of children with leukemia, along with identifying associated factors and understanding the nature of this burden due to the long, intensive treatments, high dependence of children, and severe emotional and financial strain. Pediatric care is uniquely challenging, so this comprehensive understanding is essential for the well-being of caregivers and lays the groundwork for developing a “comprehensive caregiver support” package aimed at fostering healing and wellness for both the patient and the caregiver.

1.1 PROBLEM STATEMENT

Caring for a child with leukemia poses a burden to caregivers due to the lengthy treatments, increased responsibilities, and high treatment costs. Inappropriate handling of caregiver needs may lead to emotional instability, psychological distress, and tension among caregivers(17). Additionally, it can lead to job loss, strain, alcohol abuse, social withdrawal, health problems, sexual and marital difficulties (18). The extended treatment of Leukemic children takes 2-3 years of treatments to achieve complete remission which is quite different from other childhood cancers, coupled with the effects of chemotherapy and radiation increases the burden on caregivers. Interventions such as financial assistance and skills developments activities have been in place as approach to help caregivers. Despite these efforts, caregivers burden, its nature and associated factors in Tanzania are hardly known(19,20).

Most of the studies focused on the psychological and emotional nature of the caregiver burden (16,21); however, this study will investigate aspects such as the social, economic, and healthcare system aspects of the caregiver burden. This is due to a knowledge gap and limited information regarding these three aspects among caregivers of leukemic children. To date in Tanzania, not much is known about the prevalence of caregiver burden specifically to leukemic patient caregivers and comprehensive caregiver support that the Tanzanian healthcare system can make an effort to provide. This is pronounced given the fact that there are limited health facilities that can provide even the basic oncology care in the country; there are only MNH, BMC, and KCMC. Thus, this research aims to estimate the caregiver burden, along with identifying associated factors and understanding the nature of this burden. So this comprehensive understanding is essential for the well-being of caregivers and lays the groundwork for developing a “comprehensive caregiver support” package aimed at fostering healing and wellness for both the patient and the caregiver.

1.2 THEORETICAL FRAMEWORK

This study will adopt the Role strain theory developed by William J. Goode in 1960, and modified by Muliira JK and Kizza IB (22) which highlights the stains and conflicts individuals experience while fulfilling multiple roles. It examines the challenges and tensions individuals face when managing various social roles, such as being a caregiver, employee, or parent. According to the Role Strain Theory, an individual can experience strain when the demands and expectations of different roles become overwhelming. This strain can manifest in emotional, Health care systems, and social, and economic stress. Also, theory suggests that individuals may experience role conflict when the expectations of one role are incompatible with another, leading to tension and strain.

The theory is a direct fit with this study; the role strain of caregivers is influenced by caregiver's and patients' characteristics in which interaction of these factors can influence the caregiver burden. In this study, the caregiver burden is the dependent variable which includes little or no burden, mild to moderate, burden Moderate to severe burden while the independent variable is patient characteristics, caregiver characteristics, and nature of burden are independent variables. These independent variables can lead to the caregiver burden among caregivers of leukemia patients.

Caregiver characteristics, such as age, employment status, relationship with the patient, as well as the duration of caregiving and payment type can lead to the caregiver burden by influencing the level of responsibility, stress, and challenges experienced in caring for a leukemia patient. Patient characteristics such as age, number of hospital admissions, and stage of disease, also contribute to this caregiver burden by influencing the intensity of caregiving tasks, logistical challenges associated with hospitalizations, and emotional distress related to the patient's condition and prognosis. The nature of the caregiver burden, such as social, economic, and healthcare system burdens, stems from the existing caregiver burden. The specific variables on the nature of caregiver burden are social support, financial support, service delivery, information and communication, recreational facilities availability, and transport services availability. In this study, if these types of burdens are addressed can alleviate caregiver strain and improve their ability to provide care and vice versa as suggested by Role Strain Theory.

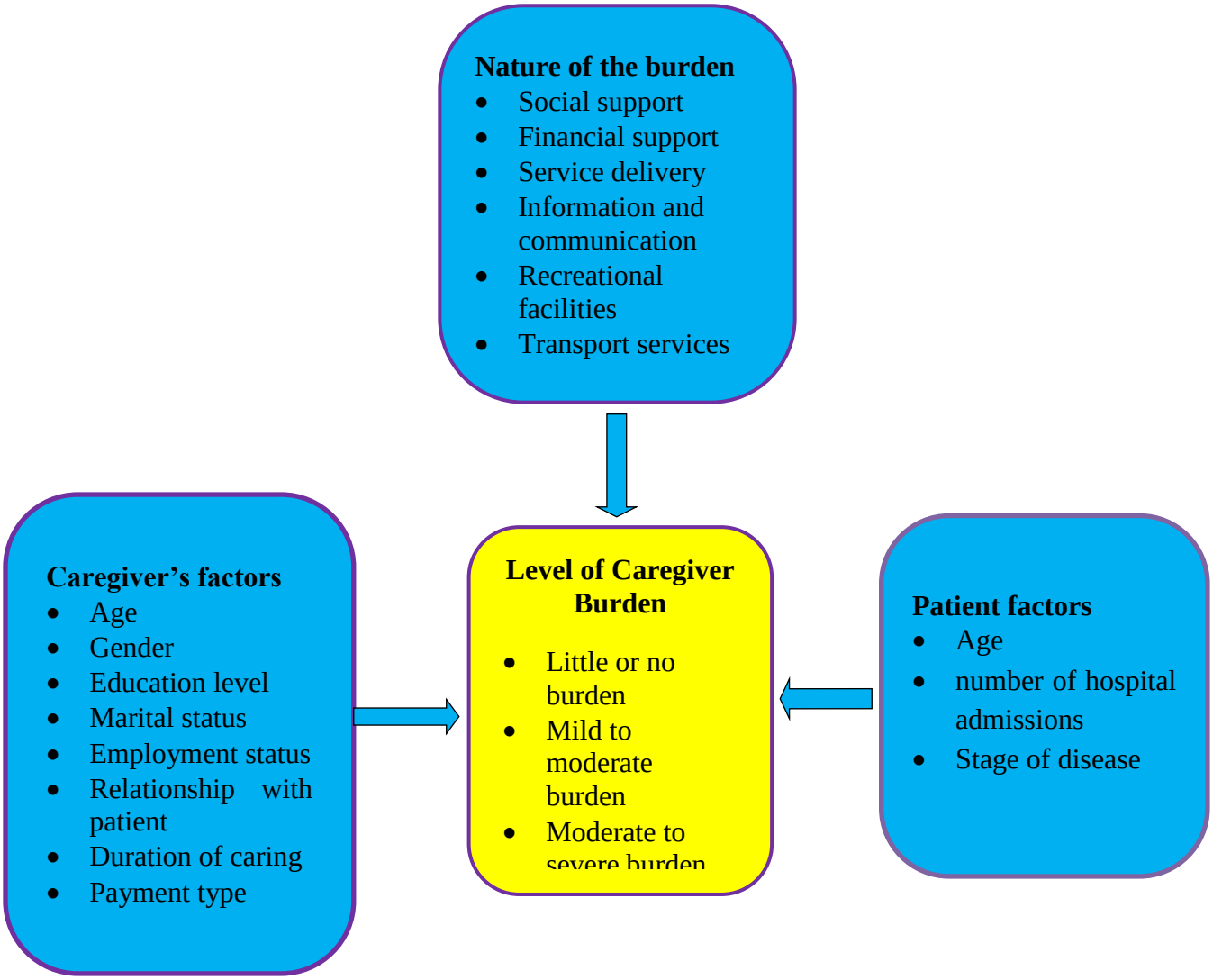


Figure 1: Theoretical framework based on the Theory of Role strain by William J. Goode adopted and modified from Muliira JK and Kizza IB (22)**.**

1.3 RATIONALE OF THE STUDY

Caregivers plays pivotal role in the provision of care for children with leukemia because they are the ones who provide social, physical, and economic support. Thus, it is important to estimate the caregiver burden and characterize the nature of the burden among caregivers of children with leukemia for the well-being of the caregiver to come up with a "Comprehensive caregiver support" as a package of intervention for promoting healing and wellness of both the patient and caregiver. This is in leukemic children, but it can serve well for other diseases with extended treatment modalities, such as other cancers and other non-communicable diseases that are currently predominating.

"Comprehensive caregiver support" will allow health professionals, including nurses, doctors, and social workers to provide focused interventions for the patient and care and promote healing as well as prevent other unforeseen and burnout health hazards, that have at times, led to neglect and abandonment of patients. These could be local guidelines for effectively addressing the challenges associated with caregiver burden and may feed into policy considerations.

1.4 Main research question

What are the estimated caregiver burden, its nature, and associated factors among caregivers of children with leukemia at the MNH oncology unit?

1.4.1 Research question

1. What is the estimated caregiver burden among caregivers of children with leukemia at the MNH oncology unit?
2. What is the nature of the caregiver burden facing caregivers of children with leukemia at the MNH oncology unit?
3. What are the factors associated with the caregiver burden among caregivers of children with leukemia at the MNH oncology Unit?

1.5 Broad objectives

To estimate the caregiver burden, its nature, and associated factors among caregivers of children with leukemia at the MNH oncology unit

1.5.1 Specific objectives

1. To estimate the caregiver burden among caregivers of children with leukemia at MNH, oncology unit.
2. To identify the nature of the caregiver burden facing caregivers of children with leukemia at the MNH oncology unit?
3. To determine factors associated with caregiver burden among caregivers of children with Leukemia at MNH, oncology unit.

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 Overview of childhood cancer and prevalence of caregiver burden

Leukemia is the most common type of cancer in children, accounting for about 30% of all childhood cancers. Acute lymphocytic leukemia (ALL) is the most common type of childhood leukemia, making up about 80% of all childhood leukemia cases. Children suffering from leukemia need a lot of help from their families because the treatment takes a long time and is tough(23). About 20% to 25% of mothers with children diagnosed with acute leukemia endure persistent post-traumatic stress disorder for up to two years with depression, anxiety, and stigmatization being the most reported disorders (6). Globally, there is limited data regarding the specific Prevalence of caregiver burden experienced by caregivers of pediatric patients with leukemia. The existing studies have focused on individual countries, and the reported prevalence of burden varies significantly across developed, developing, and underdeveloped nations.

In India, the study reported that most caregivers of children with cancer experienced a moderate to high care burden and it is associated with lower social support (6) A study from Turkey identified that 50% of caregivers of cancer patients generally experience a moderate burden, 23.8% had a medium level, 7.5% had a heavy burden while Caregivers who take care of dependent patients tend to have a higher burden (24). Additionally, the support received from family and someone special helps to reduce the burden. The burden on parents caring for children with cancer is substantial, affecting their physical, mental, and social well-being, this burden can hinder caregiving and worsen the patient's condition(25). The study conducted in Iran showed that most parents taking care of children with cancer experienced about 50% and 36% of caregivers had moderate to severe care burden, respectively (26). Factors such as the caregiver's gender, relationship with the child, marital status, education, occupation, hours spent caregiving, and child's age all influenced the level of burden experienced (26).

In sub-Saharan Africa, the level of burden varies from country to country. In Nigeria, one of the studies(27) indicated that (37.1%) of caregivers experienced a severe burden in

caregiving responsibility while in a study conducted in Kenya (Kenya National Hospital), the caregivers reported moderate to severe(58.6+/-11.2 SD) caregiver burden whereby more than half 57% had severe caregiver burden by using the Zarit caregiver burden interview scale. Also large number of the caregiver 95% coming from low socioeconomic status reported the financial strain (economic burden) as the major burden as they take care of their children(25).

In Tanzania, caregivers of cancer patients go through very difficult moments while caring for their patients, they feel stressed and worried, and they have problems getting enough support from others while they stay in the hospital and lack financial support and food(28). A study on psychological distress factors among caregivers of children receiving cancer therapy, at Muhimbili National Hospital showed that the prevalence of psychological distress remained elevated, even though there was a substantial level of psychological support available(16).

2.2 Nature of the Caregiver Burden

The nature of the caregiver burden of pediatric patients suffering from leukemia is multifaceted and encompasses various aspects. Caregivers often experience social, economic, psychological, and healthcare setting challenges as they provide care and support to children undergoing leukemia treatment(29). Here are aspects of the burden they face.

2.2.1 Economic aspect

Caregivers of cancer patients face a heightened financial burden due to the extensive care they offer and the expenses associated with cancer treatments. This financial burden arises from job disruptions, and caregiving expenses and may persist even after the patient's demise(29). Research conducted in India regarding the Caregiver burden and its effects on patients with ALL revealed that within the category of family burden index (FBI), the most significant burden was related to financial burden, with a closely trailing impact on family leisure disruption(29).

In Taiwan, families play a significant role in the care of patients with cancer; families are required to provide direct home care as well as economic, social, and emotional support, which places a significant strain on the time, finances, and health of these families(30).

Study results revealed that the primary domains of caregiver burden are disrupted schedules (Mean=3.19, SD=0.84), lack of family support (Mean=2.82, SD=0.85), health problems (Mean=2.67, SD=0.68), and financial problems (Mean=2.59, SD=0.84). In this study, the economic aspect was the least factor for the caregiver burden because, in Taiwan, national health insurance covers the population's healthcare costs, and patients with cancer receive additional subsidies related to major diseases (30). Another study done in Spain revealed that the nature of the burden facing caregivers involved emotional issues, followed by social, physical, and financial concerns (24)

Most cancer patients can receive healthcare services with the assistance of their loved ones. If the cost of health care becomes unaffordable, caregivers may be unable to continue financially supporting their loved ones, which will have an impact on their loved one's health(31). A study conducted in Nigeria – an urban African setting revealed that a substantial burden was identified in 49.5% of caregivers. The absence of financial support showed a significant association with elevated levels of burden and psychological distress among family caregivers attending a clinic with cancer–afflicted related in an urban Nigeria context(32).

In Kenya, a study reported moderate to severe caregiver burden where more than 57% had severe caregiving burden, and the majority of the respondents 95% reported financial burden as they cared for the children(15).

In Tanzania, a study revealed that caregiver burden reported a heavy burden as a result of caring for a family member with schizophrenia. Multiple regression analyses showed that poor family functioning and the caregiver being employed were associated with a high caregiver burden, while higher levels of hopefulness in the caregiver were associated with a low caregiver burden(33).

2.2.2 Social aspect

Social support for caregivers, which has been widely reorganized as an effective factor in reducing the caregiving burden in various studies, is essential in these individuals. Social support can take the form of support networks, family, friends, professionals, support groups, as well as material support. Being loved, receiving attention, feeling worthy, and

knowing that important people in their lives will assist them with their problems will provide social support(34). A study done in Iran showed that the average caregiving burden score of 43.95 ± 17.48, indicating moderate to severe burden. The caregiver's average social support was $60.25 \pm 23.81\%$ which is above the national average. In addition, there is a statistically significant negative relationship between caregiving burden and social support in primary family caregivers of cancer patients(34).

The study conducted in Norway revealed that caregivers experienced a mean burden score of 2.1(SD 0.79) specifically related to the lack of family support. This finding underscores the significant social aspect of the burden borne by caregivers of cancer patients. In this domain, the literature consistently highlights the multifaceted nature of caregiver burden, with social factors such as inadequate family support playing a crucial role(35). A study from India showed, that when the correlations of burden with support were evaluated, the study findings depicted that low social support was associated with a significantly higher burden as assessed using FBI (31).

In sub-Saharan countries, the study conducted in low-income countries shows that the majority of Family caregivers (75%) reported severe or very severe general caregiver burden. the most severely impacted domains of caregiver burden were disappointment (85.8%), isolation (72%), and general strain (70.6%) (36). Another study in Nigeria showed that caregivers (44.5%) reported a mild level of burden, while 4.4 % reported a severe level of burden. Caregiving affected the caregiver's physical health (mean = $2.58 \geq 2.00$) and social well-being (mean = $2.42 \geq 2.00$) of the caregivers. Social consequences included a lack of social activities, a lack of leisure time, a poor or non-existent relationship with friends, and a lack of family support(31). A study on the perception of the caregiver burden by informal caregivers of cancer in Nigeria showed that financial (41.1%) and social (46.7%) burdens were frequently and nearly always experienced. In terms of the magnitude of the burden, the social form of the burden had the highest weighted score of 228(37).

2.2.3 Healthcare system aspect

The hospital environment within a hospital setting plays a crucial role in the psycho-social well-being of caregivers of pediatric cancer patients. The absence of a dedicated recreation area, leisure activities, or poor environmental setting can significantly impact the caregiver's psychological state. Good environment Healthcare facilities can provide caregivers with opportunities for leisure and social interactions can alleviate stress, enhance their coping mechanism, and ultimately contribute to better care for the patients they support (32).

Information is a crucial part of psycho-social support; all parents want to know as much as they can about the prognosis, and course of treatment. The majority of parents use other information sources that could mislead them because they are not happy with the information they receive from healthcare professionals (30). One of the studies done in Norway revealed that over 50% of the caregivers noted a demand for health-related information concerning cancer, late effects, cancer rehabilitation, and the need for support from either peer or healthcare professionals to manage their new life situation(35)

2.3 Factors associated with the caregiver burden

The caregiver burden experienced by caregivers is influenced by various factors, which can be broadly categorized into patient factors, caregivers' characteristics, socioeconomic needs, and physical and emotional needs. Most research has identified patient factors such as demographic characteristics, the type of payment for treatment, disease characteristics, duration of hospitalization, and comorbidity as significant contributors to caregiver burden(38) Similarly, caregivers' characteristics, including their demographic factors, employment status, family income, relationship with the patient, age, and duration of care have been recognized as important factors associated with the level of burden experienced by caregivers. (27)

2.3.1 Caregiver's and patient's characteristic

The study from California on the factors associated with high burden in caregivers concluded that older adults experience fewer challenges compared to younger caregivers. The study upholds that older caregivers tend to have better mental well-being and experience less psychological distress related to caregiving and this is because older

caregivers perceive the caregiving role as less overwhelming and feel less restricted in their daily activities compared to younger caregivers(39), this study is contrary to the study from Nigeria which articulated that the gender and age of the caregivers were not statistically significantly associated with the perception of burden(40). The demographic characteristics have been identified as influencing factors in caregiver burden. According to a study from West Bengal, India, the majority of caregivers for children with leukemia were mothers aged 30-39 (69.4%), with the majority of them coming from lower socioeconomic statuses and 50% of them reporting moderate to severe burden. In this study, 60.5% of caregivers are from rural areas, and 55.3% had a secondary school(12).

Caregivers of leukemia patients carry a heavy weight of care. Age, gender, level of education, loss of employment as a result of caring obligations, income, relationship with the patient, length of the illness, and frequency of caregiving were found to be statistically significant correlates of the caregiving burden in leukemia (41). The study examined the burden on primary family caregivers to patients with oral cancer and its related factors, results of this study reveal that the primary family caregivers exhibited disrupted schedules represented the most prominent factor to their burden, followed by a lack of financial support.

Longevity of caregiving and number of hospital admissions has a significant impact on the caregiver burden. According to a study from Nigeria, family caregivers whose care recipients had previously been admitted several times are three times more likely to experience burden than those whose care recipients had not previously been admitted, with a burden rate of 81.6% higher for those who spent more than 48 hours per week providing care compared to those who did not (40).

Regarding age, sex of caregiver and patient caregivers relationship among the caregivers experienced a high caregiver burden, a study from Ethiopia presented that caregivers who are older than 40 years old are 4.01 times more likely to have a higher burden than caregivers who are between 20 and 40 years old (42). Female caregivers are 4.14 times more likely than male caregivers to have a high burden, and caregivers who are husband or wife

to the patient are 3.23 times more likely to have a high burden than those whose relation to the patient with child (AOR=3.23) and then other relatives (AOR=3.23) (42).

Regarding patient factors that affect caregivers' burden, research indicates that since pediatric patients are involved, irritability brought on by disease and stage of cancer (p=0.004) as well as caregiver financial constraints (p=0.001) play major roles in determining high caregiver burden (43). Additionally, the amount of care burden decreases with a year increase in patient age. The gender of the patient and the income of the caregiver had no significance in predicting the caregiver's burden (26).

A study from western Iran described some factors, related to caregivers, in comparison to those who were first-degree relatives, the caregivers who were the patient’s second-degree relatives experienced significantly less Care burden (P=0.005). According to the findings, the caregiving burden decreased as the education level increased (P=0.001) (26).

2.4 Summary

Pediatric leukemia is a life-threatening disease that places an immense burden on caregivers, leading to various health problems and psychological distress. Studies have highlighted the different aspects of burden such as financial, social, psychological, and healthcare system experienced by caregivers, with different research reporting varying levels of burden. Demographic factors such as age, gender, education level, employment status of caregiver, and their relationship to the patient influence the prevalence of caregiver burden, while the age, number of hospitalizations, and stage of disease of the patient have been influencing the caregiver burden. Also, some studies show a high level of burden, particularly among older caregivers and those closely related to the patient.

Most of the literature has described the prevalence of caregiver burden based on their localized areas and countries but few studies have been done in sub-Saharan African countries especially Tanzania to determine the prevalence of burden by ZBI or FBI. In Tanzania regarding this matter, there is limited knowledge on the prevalence of caregiver burden for caregivers of pediatric cancer patients, with limited attention to the specific aspect of the caregiver burden of children with leukemia.

CHAPTER THREE

3.0 METHODOLOGY

3.1 Study design

This study utilized a hospital-based analytical cross-sectional study design. A quantitative approach was employed to estimate caregiver burden and its nature among caregivers of children undergoing treatments for leukemia at MNH Dar-es-salaam, Tanzania. A cross-sectional quantitative study design has used to systematically quantify and measure the phenomena at a single point at a time without manipulating the environment or situation(44). This design is cost-effective and less time-consuming, capturing all available data in a short period using a structured questionnaire.

3.2 Study setting

The study took place at the pediatric Oncology unit of Muhimbili National Hospital in Upanga, Dar-es-salaam, Tanzania. MNH is a national referral and teaching hospital for MUHAS and other universities in the country; it is located at Upanga Dar-es-salaam, Tanzania. MNH is the tertiary and national referral with a capacity of 1500 beds. It provides medical care to patients from all regions of Tanzania, as well as those from outside the country especially countries around East African communities. The pediatric Oncology unit is located on the third floor of the pediatric block. It consists of two wards; Upendo and Tumaini, each with a capacity of 38 beds. These wards admit children between the ages of 0 and 18 who are suffering from cancer. The hospital attends 31 patients with leukemia per week and 248 for two months. All patients are paired with caregivers.

Caregivers, such as guardians or parents, are allowed to stay with their children in the ward. Other relatives are only permitted to visit. Parents in the final stages of treatment receive their care as outpatients in the clinics, so those who are coming far away from Dar es Salaam are helped by taking them to Ujasiri house near MUHAS for their remaining treatments and to leave the space for other new patients to admitted and treated.

3.3 Study population

Primary caregivers of children diagnosed and undergoing leukemia treatments at MNH pediatric oncology unit

3.3.1 Inclusion criteria

All primary caregivers aged above 18 years who responsible for providing care to children who are already diagnosed and undergoing leukemia treatments. Those who were willingly able to give their consent and decide to take part in the study were involved.

3.3.2 Exclusion criteria

Caregivers or children with severe medical conditions or comorbidity that could significantly impact the caregiver burden and the child's leukemia treatment experience were excluded from this study. Caregivers who were unable to communicate in the language of the study or who had communication impairments that would hinder data collection were excluded. Also, Caregivers with severe cognitive or mental health impairments that would prevent them from participating in the study were excluded from this study.

3.4 Variables

The dependent variable was the caregiver burden status (little or no burden, mild to moderate burden, moderate to severe burden, severe burden)

Independent variables; were the age patient and caregiver, gender, education level, marital status, employment status, relationship with the patient, duration of caring, payment type, number of hospitalizations, and stage of disease. The specific variables on the nature of caregiver burden are social support, financial support, service delivery, information and communication, recreational facilities availability, transport services availability

3.5 Sample size determination and sampling Procedure

3.5.1 Sample size determination

The sample size was obtained by using Cochran's formula for calculating sample size in a finite population(45)

$$n = \frac{N \times Z^2 \times p\,(100-p)}{(N-1) \times E^2 + Z^2 \times p \times (1-p)}$$

Where;

n = is the required sample size

N = is the population size

Z = is the Z-score (confidence level 1.96 for a 95% confidence level)

p = is the estimated proportion of the population

E = is the margin of error (0.05 for a 5% margin of error)

In this study, the proportion was derived from a cross-sectional study done in Kenyatta National Hospital, Kenya on caregiver burden and its associated effect among parents of children suffering from cancer in Kenyatta National Hospital. The study described that 57% of caregivers had a severe caregiver burden (46).

Population size N=160

Confidence level 95% (Z-score = 1.96)

Proportion p= 57% = 0.57

Margin of error E=0.05

$$n = \frac{N \times Z^2 \times p\,(100-p)}{(N-1) \times E^2 + Z^2 \times p \times (1-p)}$$

$$n = \frac{160 \times 1.96^2 \times 0.57\,(100-0.57)}{(160-1) \times 0.05^2 + 1.96^2 \times 0.57 \times (1-0.57)}$$

$$= \frac{123.0288}{1.3186}$$

$$= 93.32$$

The sample size was adjusted for those who would not complete the questions or non-respondents using the following formula**;**

n = n (1/R)
Where R= respondent rate
R= 90% = 0.9
n = 93.32

n = 93.32 (1/0.9) = 103.69
=104
The minimum sample size was 104

The adjusted sample size used was 104 caregivers

3.5.2 Sampling technique

A study employed a simple random sampling method to obtain the study participants at the oncology pediatric unit. This sampling method was chosen because it ensures every individual has an equal chance of being selected, this helped in selecting a sample that is more likely to be representative of the entire population making the results more generalizable, minimizing the selection bias, and reducing the potential for systematic errors(47). Participants who came for outpatient and inpatients were recorded from the register book, chemotherapy, and radiation sheets. From the records, the names of participants who met the inclusion criteria were written on a piece of paper and put in a box, and then the lottery method was used to pick 8-10 participants every day until the sample size reached.

3.6 Data Collection Methods

The data was collected through a structured questionnaire for 7 weeks (08^{th} May – 30^{th} June, 2024). Data was collected by the researcher and 1 research assistants who are medical personnel. The research assistant received 2 days of training on the tool. The questionnaire was developed in English version and translated into Swahili version the native language of the study participants. The questionnaire was divided into three sections.

The first part of the questionnaire contained the developed questions that were used to collect socio-demographic and associated factors of caregivers and children. The second part of the questionnaire measured the caregiver burden. The study adopted the modified Zarit burden interview scale with 22 items to measure the prevalence of caregiver burden. ZBI scale is composed of 22 items where each item scored on a Likert scale from 0 to 4 described as follows: 0 means never, 1 means rarely, 2 means sometimes, 3 means quite frequently and 4 means nearly always. ZBI scale has a total score range of 0 to 88 score where a 0-20 score means little or no burden, 21-40 is mild to moderate burden, 41-60 is moderate to severe burden, and ≥61 score is a severe burden(48). Validity and reliability of the Zarit Burden Interview in assessing caregiving burden, Cronbach's alpha value for the ZBI items is 0.93, and the intra-class correlation coefficient for the test-retest reliability of the Zarit burden score is 0.89(5). ZBI has been proven to be a valid and reliable method for assessing the burden on caregivers of cancer patients in lower-income countries, as evidenced by its use in Kenya(49).

The third part of the questionnaire was to characterize the nature of the burden. To characterize the nature of the burden, the set of developed questions that fit the three aspects of this study which are social, economic and healthcare system aspects of the burden was used.

3.7 Pre-test of the study instruments

To check whether the questionnaire was well understood, 30 patients (which is recommended for questionnaires pretest in cross-sectional studies (50) caregivers of children with leukemia at Muhimbili National Hospital were invited to participate in the piloting of the questionnaire.

3.8 Data entry and cleaning

The questionnaires were checked frequently whether have been filled appropriately and well completed, data was entered in SPSS computer package version 21 and data cleaning was performed by SPSS by using the edit data window, the missing values dialog box, and the outliers dialog box.

3.9 Data Analysis and Management

The data was analyzed using analytical statistics. Quantitative data was entered and analyzed using the SPSS computer package, version 23.

Both descriptive statistics were used to analyze the social demographic and clinical characteristics of the caregivers their results were summarized and presented as mean, standard deviation, median, and proportions as deemed appropriate

The caregiver burden was estimated by scoring all 22 items in the modified Zarit burden interview scale and grouped accordingly from little to very severe burden. After inputting respondents' scores for each item in the Likert scale, SPSS was utilized to calculate descriptive statistics such as mean, median, mode, standard deviation, and range. These descriptive statistics provided a comprehensive overview of the distribution and central tendency of the caregiver burden scores. By examining the mean score, can estimate the prevalence of caregiver burden. Moreover, the standard deviation indicated the degree of variability in the burden across the sample.

The nature of the caregiver burden with children treated for leukemia was determined by analyzing a developed set of questions that assess assessing nature of the caregiver burden. The specific variables on the nature of caregiver burden are social support, financial support, service delivery, information and communication, recreational facilities availability, and transport services availability. Summary statistics such as proportions, mean and median were used to present the nature of the caregiver burden.

Factors associated with the caregiver burden were identified through bivariate analysis. Those with a P value of less than 0.2 were subjected to the multivariate logistic regression model to determine the factors that were significantly associated with the prevalence of the caregiver burden. A P-value of less than 0.05 was considered significant. The results were presented through tables.

3.10 Ethical consideration

The Muhimbili University of Health and Allied Sciences Research and Ethics Committee provided ethical approval (Ref. No.DA.282/298/01.C/2175), MNH administration granted permission to conduct research at the MNH (Ref. No. HD/MUH/T.494/2022). All participants were informed about the study's purpose, benefits, and risks, as well as the voluntary nature of their involvement. They were also informed of their right to withdraw from the study at any time. Confidentiality was ensured by assigning participants numbers instead of using their real names during the introduction and questionnaire completion phases. Those who chose to participate were given a written consent form to sign before their involvement. The information obtained from those questionnaires was not shared with any third party except for research purposes only and was anonymous.

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3.11 Dissemination of findings

The findings of the study will be reported to MNH. Furthermore, study findings will be disseminated to MUHAS, published in peer-reviewed journals, and presented at scientific conferences, professional meetings, and seminars.

CHAPTER FOUR

4.0 RESULTS

4.1 Social demographic and clinical characteristics of the caregivers

The study involved 104 caregivers of children diagnosed and undergoing leukemia treatments at the MNH pediatric oncology unit. The study revealed a diverse demographic and clinical profile. 48(46.2%), Caregivers were in the age group 18-35, with a mean age of 30.5± 5.66SD with most of them being female 70(67.3%). Children's ages were between 4-9 years, 49 (47.1%) with a mean age of 6.23±1.32 years (95% CI 4.34-8.11). Female caregivers 70(67.3%) predominated. The highest education level attained by caregivers was standard seven 45 (43.3%). 66(63.5%) caregivers were married and 86(82.7%) were employed. The primary relationship with the child was the parent 76 (73.1%). The duration of care is mostly between 1 to 6 months 59(56.7%). Payment for healthcare is nearly equally split, with a slight majority using health insurance 51(51%). Most children have been admitted to the hospital only once 43(41.3%). Lastly, 62(59.6%) a significant number of caregivers do not know the stage of the child's condition.

Table 1; Social demographic and clinical characteristics of the caregivers

Variable	Category	Frequency (n=104)	Percentages (%)
Age of caregiver	18-35	48	46.2
(years)	36-45	27	26.0
	46 or above	29	27.9
Age of the child	0-3	17	16.3
(years)	4-9	49	47.1
	10-18	38	36.5
Sex of the caregiver	Male	34	32.7
	Female	70	67.3
Education	Standard seven	45	43.3
	Secondary education	33	31.7
	College and university	21	20.2

Marital status	Married	66	63.5
	Not married	38	36.5
Employment status	Unemployed	18	17.3
	Employed	86	82.7
Relationship with the child	Parent	76	73.1
	Sibling	12	11.5
	Guardian	16	15.4
Duration of caring	1 to 6 months	59	56.7
	7 months to 1 year	27	26.0
	2 years or above	18	17.3
Payment type	Cash payment	49	49
	Health insurance	51	51
Number of hospital admission	1 time	43	41.3
	2 times	29	27.9
	3 times or More	32	30.8
Stage of diseases	I know	42	40.4
	Do not know	62	59.6

4.2 Prevalence of caregiver burden among caregivers of children with leukemia

The study assessed the burden on caregivers of children diagnosed and treated with leukemia using the Zarit Burden Interview (ZBI) score revealed a significant caregiver burden. The mean score of caregiver burden was 47.9 ±12.3. Of the caregivers, 60 (57.7%), experienced a moderate to severe burden, while 24 (23.1%) reported a mild to moderate burden. A smaller portion, 17 (16.3%), face a severe burden, and only 3 (2.9%) experience little or no burden. The results are shown in table 2.

Table 2: Prevalence of Caregiver Burden

	Category	Frequency (n=104)	Percentage (%)
Caregiver burden	little or no burden	3	2.9
	mild to moderate burden	24	23.1
	moderate to severe burden	60	57.7
	severe burden	17	16.3

4.3 Nature of caregiver burden

The study on caregiver burden among caregivers of children diagnosed with leukemia revealed significant social, economic, and healthcare challenges. Socially, 52(50%) of caregivers reported getting average support from family, while 33 (31.8%) rated it as poor, with 48 (46.2%) lacking family support and 65 (62.5%) lacking support from friends. Additionally, 28 (26.9%) always felt isolated, and 45 (43.3%) experienced social life disruption.

Economically, 57 (54.8%) reported having a frequent financial strain, primarily due to medical bills 85(81.7%), transportation 49 (47.1%), and food expenses 36 (34.6%). Strategies to manage unexpected expenses included borrowing money 69 (66.3%) and using savings 45(43.3%). 64(61.5%) reported a significant effect of caregiving on income or employment.

Healthcare burdens included long waiting times for health services 72 (69.2%) and financial constraints 66(63.5%) as major barriers, though most felt well-informed about patient care 58(55.8%) and 69 (66.3%) rated good communication with healthcare professionals. Regarding the quality and accessibility of recreational facilities, 71(68.3%) reported to Satisfied with its quality and accessibility.

Table 3; Nature of Caregiver Burden

Variable	Category	Multiple responses	Participants (n=104)%
Social burden			
Perception of social support from family	Good		19(18.2)
	Average		52(50.0)
	Poor		33(31.8)
Feeling isolated or lonely in a caregiving role.	Always		28(26.9)
	Occasionally		28(26.9)
	Rarely		48(46.2)
Social life disruption	Significantly		45(43.3)
	Moderately		39(37.5)
	Slightly		20(19.2)
Source of social support	Family member	Yes	56(53.8)
		No	48(46.2)
	Friends Social	Yes	39(37.5)
		No	65(62.5)
	Support groups	Yes	14(13.5)
		No	90(86.5)
	Healthcare	Yes	76(73.1)
		No	28(26.9)
Economic burden			
Effect of caregiving on income or employment	Significantly		64(61.5)
	Moderately		25(24.1)
	No impacts		15(14.4)
Financial strain	Frequently		57(54.8)
	Occasionally		34(32.7)
	Rarely		13(12.5)
Main financial challenges	Medical bills	Yes	85(81.7)
		No	19(18.3)
	Transportation	Yes	49(47.1)
		No	55(52.9)
	Foods	Yes	36(34.6)
		No	68(65.4)
	None	Yes	8(7.7)
		No	96(92.3)
Management of unexpected expenses	Use savings	Yes	45(43.3)
		No	59(56.7)
	Borrow money	Yes	69(66.3)
		No	35(33.7)
	insurance coverage	Yes	37(35.6)
		No	67(64.4)

	Financial assistances	Yes	18(17.3)
		No	86(82.7)
Healthcare burden			
Barriers to accessing healthcare services	Long waiting	Yes	72(69.2)
		No	32(30.8)
	Financial constraints	Yes	66(63.5)
		No	38(36.5)
	Transportation issues	Yes	24(23.1)
		No	80(76.9)
	Lack of information	Yes	21(20.2)
		No	83(79.8)
	None	Yes	0.0(0.0)
		No	104(100.0)
Giving patient information	well informed		58(55.8)
	Somewhat informed		27(26.0)
	Not well informed		19(18.2)
communication with healthcare professionals	Good		69(66.3)
	Average		13(12.5)
	poor		22(21.2)
Quality and accessibility of recreational facilities	Satisfied		71(68.3%)
	Not Satisfied		33(31.7%)

4.3.1 Factors associated with caregiver burden

The caregiver burden was categorized into 2 major groups which are no to mild burden and moderate to severe burden to determine the factors associated with the caregiver burden. A score of 0-40 was considered a no to mild caregiver burden and 41-88 was considered a moderate to severe burden. The factors associated with caregiver burden were mainly into two major groups which are demographic and clinical factors and the social, economic, and healthcare factors.

4.3.2 The association between the caregiver burden with demographic and clinical factors

In the Bivariate analysis, variables that were statistically significant with a p-value of ≤ 0.2 included the age of the caregiver, age of the child, education level, relationship with the child, duration of caring, and number of hospital admissions. Other demographic and clinical characteristics such as sex of the caregiver, marital status, employment status, educational level, duration of caring, payment type, and stage of disease were not statistically significantly associated with moderate to severe burden.

In multivariate analysis of demographic and clinical factors associated with caregiver burden among caregivers revealed several significant associations. Variables that remained statistically significant with a p-value of ≤ 0.05 included the age of the caregiver. Caregivers aged 36-45 years were 0.254 times lower likely to have moderate to severe burden compared to those aged between 18 and 35 years. Additionally, those aged 46years and above were 0.231 times lower likely to have moderate to severe burden compared to those aged 18-35 years old with (95% CI 0.055-0.972, P = 0.046), and (95% CI 0.066-0.971, P = 0.045) respectively. So, caregivers aged between 18-35 years had a higher chance of having moderate to severe burden.

The relationship with the child, the data revealed that guardians are significantly 0.093 times lower likely to experience moderate to severe (95% CI: 0.009-0.956, P = 0.046) compared to the parents. So the guardian relationship demonstrated a notable and protective association with moderate to severe burden. Regarding number of hospital admissions, those admitted to the hospital three times or more showed a significant 5.2 times more likely to have moderate to severe burden (95% CI [1.291-20.940], p = 0.020) compared to those admitted only once, indicating a strong association. However, individuals admitted twice did not demonstrate a statistically significant association with the outcome (aOR = 1.550, 95% CI [0.583-4.121], p = 0.380)

Variables that were not statistically significant in the multivariate analysis included the age of the child and the education level of the caregiver.

Table 4: Demographic and clinical factors associated with caregiver burden

Variable	Category	Bivariate analysis			Multivariate analysis		
		cOR	95% CI	P value	aOR	95% CI	P value
Age of caregiver (in years)	18-35 years	REF					
	36-45 years	**0.254**	**0.066 -0.971**	**0.045**	0.254	**0.066-0.971**	**0.045**
	46 years and Above	0.231	**0.055 - 0.972**	**0.046**	0.231	**0.055-0.972**	**0.046**
Age of the child (years)	0-3	REF					
	4-9	**0.443**	**0.131-1.504**	**0.192**	0.443	0.131-1.504	0.192
	10-18	1.072	0.393- 2.928	0.892	1.072	0.393-2.928	0.892
Sex of the caregiver	Male	REF					
	Female	1.299	0.519-3.253	0.576			
Education	Standard seven	REF					
	Secondary education	0.871	0.239-3.175	0.834	0.871	0.239-3.175	0.834
	College & university	0.416	0.115-1.503	0.181	0.416	0.115-1.503	0.181
Marital status	Married	REF					
	Not married	0.828	0.329-2.084	0.688			
Employment status	Unemployed	REF					
	Employed	1.278	0.381-4.283	0.691			

Relationship with	Parent	REF					
the child	Sibling	0.175	0.022-1.406	0.101	0.175	0.022-1.406	.101
	Guardian	**0.093**	**0.009-0.956**	**0.046**	**0.093**	**0.009-0.956**	**.046**
Duration of caring	1 to 6 months	REF			REF		
	7 months to 1 year	1.607	0.509-5.070	0.118			
	2 years or above	1.429	0.388-5.264	0.142			
Payment type	Cash payment	REF					
	Health insurance	0.636	.262-1.546	0.318			
Number of hospital	1 time	REF					
admission	2 times	1.550	0.583-4.121	0.380	1.550	0.583-4.121	0.380
	3 times or more	**5.200**	**1.291-10.940**	**0.020**	**5.200**	**1.291-7.940**	**0.020**
Stage	I know	REF					
	Do not know	1.209	1.490-2.983	0.681			

4.3.3 The association between caregiver burden with social, economic, and healthcare factors

The study on social, economic, and healthcare factors associated with caregiver burden among caregivers of children with leukemia at the MNH oncology unit identifies several significant variables. In the bivariate and multivariate analysis, Economic and social factors showed associations. The financial strain showed a significant association with moderate to severe burden, whereby caregivers who experienced rarely and occasionally financial strain had 0.514 and 0.65 times lower likely to have moderate to severe burden with (95% CI: 0.081-0.449, P=0.032) and (95% CI: 0.074-0.322, P=0.014) respectively compared to caregivers who experiences frequently financial strains.

Social support from family showed significant associations with the moderate to severe. Caregivers with average social support were significantly 1.25 times more likely to have moderate to severe burden (95% CI**:** 1.066-2.917, P=0.037) compared to those with good support. Poor social support from family did not show a significant association (aOR = 0.485, p = 0.210).

Other variables that were not significant included social life disruption, the effect of caregiving on income or employment, management of unexpected expenses, barriers in accessing healthcare services, level of communication with healthcare professionals, and quality and accessibility of recreational facilities. These factors did not show a significant association with caregiver burden in the study. The results are shown in Table 5

Table 5: The association between the caregiver burden and social, economic, and healthcare factors

Variable	Category	Subcategory	Bivariate analysis			Multivariate analysis		
			cOR	95% CI	P value	aOR	95% CI	P value
Social support from family (n=104)	Good		REF					
	Average		1.974	0.659-5.917	0.225	1.246	**1.066-2.917**	**0.037**
	Poor		**4.073**	**1.091-15.203**	**0.037**	0.485	0.156-1.503	0.210
Feel isolated or lonely in your caregiving role (n=104)	Always		REF					
	Occasionally		4.500	1.199-9.894	0.260			
	Rarely		2.364	0.623-8.966	0.306			
Social life disruption (n=104)	Significantly		REF					
	Moderately		**5.318**	**1.553-18.209**	**.008**	5.318	1.553-18.209	0.078
	Slightly		1.841	0.605-5.602	.282	1.841	0.605-5.602	0.282
Source of social support (n=104)	Family member	Yes	REF					
		No	0.604	0.245-1.485	0.272	0.357	0.096-1.329	0.125
	Friends social support	Yes	REF					
		No	0.549	0.225-1.338	**0.187**	0.448	0.124-1.624	0.222
	Support groups	Yes	REF					
		No	1.333	0.342-5.192	0.678			
	Healthcare professionals	Yes						
		No	1.200	0.455-3.167	0.713			
Effect of caregiving on income or employment (n=104)	Significantly		REF					
	Moderately		2.419	0.761-7.687	0.134			
	No impacts		6.417	1.327-31.031	0.121			

Financial strain (n=104)	Frequently		REF					
	Occasionally		**0.614**	**0.093-0.8363**	**0.032**	**0.654**	**0.081-0.849**	**0.032**
	Rarely		**0.481**	**0.301-0.805**	**0.021**	**0.514**	**0.074-0.622**	**0.014**
Main financial challenges (n=104)	Medical bills	Yes	REF					
		No	0.477	0.127-1.785	0.271			
	Transportation expenses	Yes	REF					
		No	0.633	0.262-1.529	0.309			
	Foods	Yes	REF					
		No	0.867	0.348-2.159	0.759			
	None	Yes	REF					
		No	2.600	0.305-22.167	0.382			
Management of unexpected expenses (n=104)	Use savings	Yes	REF					
		No	2.197	0.859-5.620	**0.101**	3.005	0.958-9.431	0.059
	Borrow money	Yes	REF					
		No	0.981	0.387-2.484	0.967			
	insurance coverage	Yes	REF					
		No	1.824	0.688-4.835	**0.227**	2.082	0.442-9.805	0.353
	Seeks financial assistances	Yes	REF					
		No	1.278	0.381-4.283	0.691			
Barriers to accessing healthcare services (n=104)	Long waiting times	Yes	REF					
		No	1.174	.460-2.997	0.737			
	Financial constraints	Yes	REF					
		No	0.828	.329-2.084	0.688			
	Transportation issues	Yes	REF					
		No	1.441	0.480-4.333	0.515			
	Lack of information	Yes	REF					
		No	1.629	0.4955-2.358	0.422			
Giving patient information (n=104)	well informed		REF					
	Somewhat informed		1.598	0.507-5.033	0.424			
	Not well informed		1.096	0.307-3.911	0.888			
Communication with health care professionals (n=104)	Good		REF					
	Average		1.619	0.583-4.496	1.619			
	poor		6.857	0.747-12.962	6.857			

CHAPTER FIVE

5.0 DISCUSSION

5.1 Discussion

The study at Muhimbili National Hospital (MNH) demonstrated a significant caregiver burden among those caring for children with leukemia. This aligns with existing literature that identified leukemia as a major source of extensive caregiving demands due to the prolonged and intense nature of its treatment (23)

The findings revealed that a high 60 (57.7%) of caregivers experience a moderate to severe burden. This aligns with a study done in Kenya which reported that caregivers had moderate to severe burden and more than half 43(58.6%) had severe caregiver burden respectively(15,27). Contrarily, a study done in Ethiopia, reported lower caregiver burden 15 9 (10.6%) (42). The difference is due to different levels of governmental or non-governmental organization (NGO) support for caregivers. Ethiopia has more robust support systems, which could help reduce the overall burden on caregivers (26),(42). The consistent findings across diverse geographic locations imply a universal challenge in caregiving, highlighting common factors such as healthcare access, socioeconomic such as low health insurance coverage, and support systems that contribute to caregiver burden. Addressing this issue globally necessitates tailored interventions and support mechanisms designed to recognize and alleviate the multifaceted challenges faced by caregivers across different regions.

The economic burden identified at MNH, with over 54.8% of caregivers frequently facing financial strain, primarily due to medical bills, transportation, and food expenses, echoes findings from other countries. In Kenya, the majority 70 (95%) reported financial strain as they cared for their children(15). In Nigeria, there were significant levels of caregiver burden and was due lack of financial support (32). In contrast, the situation in Taiwan, where financial burden is less prominent, this highlights the critical need for improved financial support mechanisms for caregivers in our community, as many are likely to be

burdened by similar economic challenges as reported in other countries like Kenya and Nigeria.(30)

Regarding social support, 50% of caregivers reported getting average support from family, while 33 (31.8%) rated it as poor, with 46.2% lacking family support and 62.5% lacking support from friends, this underscore the critical role of social networks in mitigating caregiver burden . This aligns with findings in sub-Saharan Africa where social isolation and lack of family support significantly contribute to the caregiving burden (31,36). In Iran and Taiwan, moderate to severe burdens are often linked to inadequate social support, underscoring the crucial role of social networks in alleviating caregiver stress (28,32). This parallels findings in sub-Saharan Africa where social isolation and limited family support are prevalent among caregivers, contributing significantly to their burden. These findings highlight the need for stronger social and community support systems in Tanzania to alleviate the caregiving burden and improve the well-being of caregivers.

The study identified significant associations between Moderate to severe burden and certain demographic and clinical factors. Younger Caregivers (18-35) years showed a significant association with moderate to severe burden compared to those with older age. This is consistent with a study from California on factors linked to high caregiver burden found that older adults face fewer challenges than younger caregivers(39). This is because they view the caregiving role as less overwhelming and feel less restricted in their daily activities compared to younger caregivers. In contrast, a study from Nigeria concluded that the age of caregivers did not significantly influence their perception of the burden(40). These differences may reflect variations in cultural, economic, and social support structures, which can shape how caregivers of different ages experience and cope with caregiving responsibilities.

Regarding the relationship with the children with leukemia, a study revealed that parents had a higher chance of burden compared to those who are not first-degree relatives. This consistency with a study from western Iran and other studies showed Caregivers who are first-degree relatives of the patient had more care burden than those who were second-degree relatives significantly less Care Burden(26,51). This is likely because parents are

typically the primary caregivers and are deeply involved in every stage of their child's diagnosis, treatment, and overall care, which intensifies their emotional, physical, and financial stress. These results underscore the unique and profound challenges parents face when caring for children with chronic diseases like leukemia(26)

Number of hospital admissions has a significant impact on the caregiver burden. This study showed that caregivers who had more than three times more admissions have a higher chance of having a moderate to severe burden compared to those with single admissions. This is consistent with other studies which hold that family caregivers whose care recipients had previously been hospitalized several times are more likely to experience burden than those whose care recipients had not previously been hospitalized, this is due to the ongoing social and financial challenges associated with frequent hospital stays (40). The study is contrary to another study that reported that prior admissions is not associated with caregivers' burden, potentially due to differences in healthcare systems, support structures, or cultural factors in those studies.(30,25).

However, variables such as the caregiver's age, sex, education level, marital status, employment status, Duration of caring, payment type, and disease stage were not significant in the multivariate analysis. This contrasts with some studies where factors like the caregiver's gender and relationship with the patient significantly influenced burden levels (41,42).

Poor social support from family significantly increases caregiver burden, aligning with global findings that highlight the critical role of social networks in mitigating caregiver stress (32,33,21). Frequent financial strain also correlates with higher burden, corroborating studies from Nigeria and Kenya where financial difficulties are a major source of caregiver burden (15,32).

Interestingly, factors such as social life disruption, source of social support, effect of caregiving on income or employment, and healthcare service barriers were not significant. This may be due to confounding variables overshadowing their effects, a limited sample size that restricts detection of subtle associations. Additionally, coping mechanisms among caregivers, multicollinearity, and the specific context of the study may have diminished the

relevance of these factors. This suggests that while these elements contribute to the overall burden, their direct impacts are less pronounced at MNH context.

5.2 Study limitations and mitigations

The study faced the limitation of selection bias. To address this, simple random sampling was employed to minimize bias, and detailed descriptions were provided to support accurate data analysis, including reporting the precision of estimates. Additionally, there was a high likelihood that factors associated with caregiver burden could be influenced by confounding variables. To control for confounders, factors showing associations in the bivariate model were further analyzed using a multivariate model. The use of a quantitative design limited participants' ability to provide in-depth descriptions on the Nature of the burden, suggesting that a qualitative study should be conducted to further explore the nature of the burden. Furthermore, the study employed a cross-sectional design, which captures data at a single point in time, limiting the ability to determine causal relationships between variables and reducing the generalizability of the results to other populations.

CHAPTER SIX

6.0 CONCLUSION AND RECCOMENDATION

6.1 CONCLUSION

The study conducted at Muhimbili National Hospital (MNH) elucidates the profound burden borne by caregivers of children with leukemia. The findings indicated that a significant portion of caregivers experienced moderate to severe burdens. Economic (financial strains) and social nature of burden identified. The economic burden faced by caregivers, including high medical costs and Transportation, aligns with global literature and underscores the pervasive financial strain in caregiving roles. Additionally, the lack of adequate social support from family members and friends exacerbates the burden, mirroring trends observed in other developing countries.

The demographic and clinical factors, such as the age of the caregiver, relationship with the children, and financial strain, number of hospital admissions significantly impact the level of burden experienced by caregivers. However, variables such as the age of children, sex, education level, and employment, stage of diseases, duration of caring for the children were not significant predictors of burden in the multivariate analysis, suggesting a complex interplay of factors influencing caregiver burden.

The study also highlighted the crucial role of healthcare systems in either alleviating or exacerbating caregiver burden. While caregivers generally felt informed about patient care and had positive communication experiences with healthcare professionals, these factors alone were insufficient to mitigate the overall burden.

6.2 RECOMMENDATION

Based on this study, and particularly considering the prevalence of caregiver burden, economic and social challenges, and factors associated with the burden, here is a recommended comprehensive care support plan tailored to the identified needs."

Assessment of Caregiver Burden

Regular assessments using validated tools like the Zarit Burden Interview (ZBI) should be conducted to monitor caregiver burden levels and identify those at risk. This will include

evaluating economic and social needs to ensure targeted interventions are provided to those in needs.

Economic Support

To alleviate financial strain, the program should offer subsidized healthcare costs, financial counseling, and access to income-generating initiatives. Skill development programs and microfinance support will empower caregivers to enhance their financial stability while managing caregiving responsibilities.

Social Support Enhancement

The program should strengthen family and community support by offering family counseling and establishing local support groups. Volunteer networks and respite care services will provide caregivers with much-needed breaks and assistance in daily tasks, reducing the burden and preventing burnout.

Educational and Psychological Support

Caregiver education workshops should provide vital knowledge about leukemia and caregiving techniques, while stress management training will equip caregivers with tools to manage the emotional challenges they face. Access to psychological counseling and peer support groups will offer ongoing emotional support.

Hospital-Based Support Services

Interdisciplinary care coordination teams should ensure seamless communication between healthcare providers, while hospital navigators and information desks will help caregivers access necessary services. Logistical support during hospital admissions will ease the stress of managing hospital visits.

Long-Term Care and Follow-Up

The program should offer post-treatment support and bereavement services to help caregivers cope with the long-term effects of caregiving. Longitudinal studies will track the impact of caregiving over time, guiding continuous improvement of the support provided.

Advocacy and Policy Development

Advocacy efforts should focus on securing caregiver rights, including financial aid and workplace accommodations. Partnerships with NGOs and government agencies will be established to mobilize resources and expand the program's reach, ensuring sustained support for caregivers.

Gaps for future research:

Further Mixed-Methods Longitudinal Study is needed to explore the Nature and long term impacts of Caregiver Burden in leukemia Pediatric Oncology.

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APPENDICES

Appendix I: Questionnaire

Participant Unique Identification Number: _____

Date: _____

Part1. Social Demographic information and factors associated with the caregiver burden

Please **circle** the response that best describes how you feel.

Caregiver's characteristics

1. Indicate your age:……..
2. Identify your gender: (a) Male (b) Female
3. Indicate your current marital status: (a) Married (b) Unmarried
4. What is your highest level of education:
   (a) Standard seven (b) Secondary education (c) college/university
5. Indicate your employment status
   (a) Unemployed (b) Not employed
6. What is Your relationship to the pediatric cancer patient you are caring for (a)Parent (b) Sibling (c) guardian
7. How long you have been caring for a pediatric cancer patient?
   (a) 1 month – 6 month (b) 7 months to 1 year (c) More than 1 year
8. What is the primary method of payment for hospital costs?
   (a) Cash payment (b) Health insurance

Patient characteristics

9. Please indicate the age of the pediatric cancer patient you are caring for:

   ……..

10. Please indicate the number of Hospitalizations up to now:

(a) 1 time (b) 2 times (c) 3 times or more

11. Are you aware about the stage of the pediatric cancer patient's disease?

(a) I know (b) I don't know

Part 2: Estimating the caregiver burden (ZBI scale with 22 items)

Please **circle** the response that best describes how you feel.

- **Score descriptions**

0: Never, 1: rarely, 2: sometimes, 3: quite frequently, 4: nearly always

Item and List of statements	**0: Never**	**1: Rarely**	**2: Sometimes**	**3:Quite frequently**	**4:Nearly always**
1. Do you feel that your relative asks for more help than he or she needs?	0	1	2	3	4
2. Do you feel that, because of the time you spend with your relatives, you don't have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed about your relative's behavior?	0	1	2	3	4
5. Do you feel angry when you are around your relatives?	0	1	2	3	4
6. Do you feel that your relative currently affects your relationship with other family members?	0	1	2	3	4
7. Are you afraid about what the future holds for your relative?	0	1	2	3	4
8. Do you feel that your relative is dependent upon you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4
10. Do you feel that your health has suffered because of your involvement with your relative?	0	1	2	3	4
11. Do you feel that you don't have as much privacy as you would like, because of your relative?	0	1	2	3	4

12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
13. Do you feel uncomfortable having your friends over because of your relative?	0	1	2	3	4
14. Do you feel that your relative seems to expect you to take care of him or her as if you were the only one, he or she could depend on?	0	1	2	3	4
15. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you were unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel that you have lost control of your life since your relative's death?	0	1	2	3	4
18. Do you wish that you could just leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel that you should be doing more for your relative?	0	1	2	3	4
21. Do you feel that you could do a better job in caring for your relative?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

Part 3: Nature of burden caregiver's experience during caring the children with leukemia.

Please **circle** the response that best describes how you feel.

Social Aspect:

1. How do you perceive the social support (emotional, advice, financial, time spent with you) you receive from family, friends, or the community as a caregiver of a child with leukemia? (a) Good (b) Average (c) Poor

2. How often do you feel isolated or lonely in your caregiving role?
   (a) Always (b) Occasionally (c) Rarely

3. To what extent do caregiving responsibilities disrupt your social life?
   (a) Significantly (b) Moderately (c) Slightly

4. Which of the following are primary sources of social support for you in managing the caregiver burden? (Select all that apply)
   (a) Family members (b) Friends (c) Support groups
   (d) Healthcare professionals (e.g., doctors, nurses, social workers) (e) none

Economic Aspects:

5. To what extent have caregiving roles affected your employment or income?
   (a) Significantly (b) Moderately (c) Slightly

6. Do you experience financial strain as a result of caring for a child with leukemia?
   (a) Frequently (b) Occasionally (c) Rarely (d) Never

7. Which of the following are the main financial challenges you face as a caregiver? (Select all that apply)
   (a) Medical bills (b) Transportation expenses (c) Foods (d) None

8. How often do you face challenges in affording treatments and medications for your child's leukemia treatment?
   (a) Frequently (b) Occasionally (c) Rarely

9. How do you manage unexpected expenses related to your child's leukemia treatment? (Select all that apply)
   (a) Use savings (b) Borrow money (c) Seek financial assistance programs
   (d) Rely on insurance coverage

10. Do you feel adequately supported in managing the financial aspects of caregiving for your child with leukemia?
   (a) Yes, fully supported (b) Yes, somewhat supported (c) No, not supported

Healthcare Setting Aspects:

11. What are the main barriers you face in accessing healthcare services for your child with leukemia? (Select all that apply)
   (a) Long waiting times (b) Financial constraints (c) Transportation issues
   (d) Lack of information about available services

12. How adequately informed and educated do you feel about your child's condition and treatment options?

(a) Well informed (b) Somewhat informed (c) Not very informed

13. How do you perceive the level of communication between you and healthcare professionals? (a) Good (b) Average (c) Poor

14. Are there any recreational facilities or activities available for caregivers at Muhimbili National Hospital Oncology Unit (a) Yes (b) No

15. If yes, how satisfied are you with the quality and accessibility of these recreational facilities or activities? (a) Satisfied (b) Dissatisfied

Kiambatanisho II: Dodoso

Nambari ya Utambulisho wa Mshiri: _____

Tarehe: _____

SEHEMU YA 1:

Taarifa za kidemographia za kijamii na sababu yanayohusiana na mzigo wa mlezi wa mtoto mwenye saratani ya damu.

Tafadhali zungusha duara jibu linaloelezea vizuri hisia zako

Wasifu wa mlezi wa mtoto

1. Ainisha umri wako ……..
2. Ainisha jinsia yako
   (a) mwanaume (b) mwanamke
3. Ainisha hali yako ya ndoa kwa sasa
   (a) Nimeoa/Nimeolewa (b) sijaolewa/sijaoa
4. Ainisha kiwango chako cha elimu
   (a) Darasa la saba (b) Elimu ya sekondari (c) Elimu ya juu
5. Ainisha hali yako ya ajira
   (a) Sina kazi (b) Nina kazi
6. Ainisha uhusiano wako na mgojwa wa saratani ya damu unayemhudumia?
   (a) Mzazi (b) Ndugu (c) mlezi
7. Umekuwa ukimhudumia mgonjwa wa saratani hii ya damu kwa muda gani sasa? (a) Mwezi 1 – Miezi 6 (b)Miezi 7 hadi mwaka 1 (c) Zaidi ya mwaka 1
8. Ipi njia kuu ya malipo ya gharama za hospitali?
   (a) Malipo ya pesa taslimu (b) Bima ya afya

Wasifu wa mgojwa

9. Tafadhali ainisha umri wa mgonjwa wa saratani ya damu unaye muhudumia

   …….

10. Tafadhali ainisha idadi ya kulazwa hospitali hadi sasa:

    (a) Mara 1 (b) Mara 2 (c) Mara 3 au zaidi

11. Je unajua hatua (stage) ya ugonjwa ya mtoto mwenye saratani ya damu?

(a) Ndio, Najua (b) Hapana, Sijui

SEHEMU YA 2: Kukadiria kiwango cha mzigo/changamoto za malezi ya mtoto mwenye saratani ya damu (kipimo cha ZBI chenye vipengele 22)

Tafadhali zungusha duara jibu linaloelezea vizuri hisia zako

- **Maelezo ya alama**

0: Kamwe, 1: Mara chache, 2: Wakati mwingine, 4: Mara kwa Mara, 5: Karibu kila wakati

Kipengere na Orodha ya taarifa	**Hapana**	**Mara chache**	**Wakati mwingine**	**Mara kwa mara**	**Karibu kila wakati**
1. Unajisikia mgonjwa wako anakuomba msaada mwingi zaidi kuliko anavyohitaji?	0	1	2	3	4
2. Unajisikia kwamba, kwa sababu ya muda unaotumia na mgonjwa wako, huna muda wa kutosha kwako mwenyewe?	0	1	2	3	4
3. Unapata changamoto kati ya kumtunza/kumhudumia mgonjwa wako na kujaribu kutimiza majukumu mengine kwa familia yako au kazi?	0	1	2	3	4
4. Je, unaona aibu kuhusu tabia za mgonjwa wako?	0	1	2	3	4
5. Je, unasikia hasira unapakuwa karibu na mgonjwa wako?	0	1	2	3	4
6. Unajisikia kwamba mgonjwa wako kwa sasa anaathiri uhusiano wako na wanafamilia wengine?	0	1	2	3	4
7. Unaogopa chochote kuhusu maendeleo ya mgonjwa wako siku za usoni?	0	1	2	3	4
8. Je unahisi kwamba mgonjwa wako anakutegemea zaidi?	0	1	2	3	4
9. Je, unajisikia msongo wa mawazo unapokuwa karibu na jamaa yako?	0	1	2	3	4
10. Unajisikia kwamba afya yako imedhoofika kutokana kuhusika kwako na mgonjwa wako?	0	1	2	3	4
11. Unajisikia kwamba huna faragha ya kutosha , sababu ya mgonjwa wako?	0	1	2	3	4

12. Unajisikia kwamba maisha yako ya kijamii yamedhoofika kwa sababu ya kuuguza mgonjwa wako?	0	1	2	3	4
13. Unasita kuwaalika/ kukaa na marafiki zako kwa sababu ya hali ya mgonjwa wako ?	0	1	2	3	4
14. Unajisikia kwamba mgonjwa wako anatarajia umtunze/umhudumie, kana kwamba wewe ndiye pekee tu anaye kutegemea?	0	1	2	3	4
15. Unajisikia kwamba huna pesa za kutosha kumtunza/kumhudumia mgonjwa wako, pamoja na matumizi yako mengine?	0	1	2	3	4
16. Unajisikia kwamba utakuwa huna uwezo wa kumtunza mgonjwa wako kwa muda mrefu zaidi?	0	1	2	3	4
17. Unajisikia umepoteza udhibiti/mwelekeo wa maisha yako tangu kuugua kwa motto huyu?	0	1	2	3	4
18. Unatamani ungeweza kumwachia mtu mwingine jukumu la kumuuguza mgonjwa wako?	0	1	2	3	4
19. Unahisi hujui la kufanya kuhusu mgonjwa wako?	0	1	2	3	4
20. Unajisikia kwamba unapaswa kujitolea zaidi kwa ajili ya mgonjwa wako?	0	1	2	3	4
21. Unahisi kwamba unapaswa kufanya mengi zaidi kwa ajili ya mgonjwa wako?	0	1	2	3	4
22. Kwa ujumla, unajisikia mzigo/changamoto kiasi gani katika kumtunza/kumuuguza mgonjwa wako?	0	1	2	3	4

Sehemu ya 3: Asili ya Changamoto za mlaezi wakati wa kumuhudumia mtoto wenye saratani ya damu.

Tafadhali zungusha duara jibu linaloelezea vizuri hisia zako

Changamoto za ki jamii

1. Unauonaje msaada wa kijamii (kihisia, ushauri, fedha, muda wa kukaa na wewe) unaopata kutoka kwa familia, marafiki au jamii kwako kama muuguzi wa mtoto mwenye leukemia? (a) Nzuri (b) kawaida (dcMbaya
2. Mara ngapi unajisikia kutengwa au upweke katika jukumu lako la kuuguza? (a) Mara kwa mara (b) Mara chache (c) Kamwe

3. Majukumu ya kuuguza yanasumbua maisha yako ya kijamii kwa kiwango gani? (a) kwa kiasi kikubwa (b) Kwa kiasi fulani (c) Kidogo

4. Ni yapi kati ya yafuatayo ndiyo vyanzo vikuu vya msaada wa kijamii kwako katika kushughulikia changamoto za kuuguza? (Chagua vyote vinavyofaa) (a) Wanafamilia (b) Marafiki (c) Vikundi vya Msaada (d) wahudumu wa afya na maafisa jamii (e) Hakuna

Changamoto za kiuchumi

5. Kuuguza kumeathiri kwa kiwango kipi ajira au kipato chako? (a) kiasi kikubwa (b) kiasi kidogo (c) Hakuna athari

6. Je, unakabiliwa na changamoto za kifedha kutokana kuuguza mtoto wako? (a) Mara kwa mara (b) Mara chache (c) Hapana

7. Ni yapi kati ya yafuatayo ndiyo changamoto kuu za kifedha unazokabiliana nazo kama muuguzi/mlezi? (Chagua vyote vinavyofaa) (a) Gharama za matibabu (b) Gharama za usafiri (c) Chakula (d) Hakuna

8. Mara ngapi unakabiliwa na changamoto katika kumudu matibabu na dawa za matibabu ya mtoto wako wa leukemia? (a) Mara kwa mara (b) Mara chache (c) Hakuna

9. Jinsi gani unashughulikia gharama zisizotarajiwa zinazohusiana na matibabu ya mtoto wako wa leukemia? (Chagua vyote vinavyofaa) (a) Kutumia akiba (b) Kukopa pesa (c) Kutafuta programu za msaada wa kifedha (d) Kutegemea bima

10. Je, unaungwa mkono vyema katika kushughulikia masuala ya kifedha ya uuguzi kwa mtoto wako mwenye leukemia? (a) Ndio, ninaungwa mkono kikamilifu (b) Ndio, ninaungwa mkono kidogo (c) Hapana, siungwi mkono

Changamoto za Mfumo/Mazingira ya Huduma ya Afya

11. Ni vikwazo vipi vikuu unavyokabiliana navyo katika kupata huduma za afya kwa mtoto wako mwenye leukemia? (Chagua vyote vinavyofaa) (a) Muda mrefu wa kusubiri (b) Vikwazo vya kifedha (c) Matatizo ya usafiri (d) Ukosefu wa habari kuhusu huduma zinazopatikana

12. Unajisikia umejulishwa na kuelimishwa vyema kuhusu hali ya mtoto wako na chaguo za matibabu kwa kiwango gani? (a) Nimejulishwa vya kutosha (b) Nimejulishwa kidogo (c) Sijaeleimishwa vizuri

13. Unakionaje kiwango cha mawasiliano kati yako na wataalamu wa afya? (a) Bora sana (b) bora (c) kawaida

14. Je, kuna vifaa vya burudani au shughuli za burudani zozote zinazopatikana kwa wewe unae uguza mtoto katika Kitengo cha Saratani cha Hospitali ya Taifa ya Muhimbili? (a) Ndio (b) Hapana

15. Ikiwa ndio, unaridhika vipi na ubora na upatikanaji wa vifaa hivi vya burudani au shughuli za burudani? (a) Nimeridhika (b)Sijaridhika

Appendix III. Consent form (English version)

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES

DIRECTORATE OF RESEARCH AND PUBLICATION

ID NO

Consent form for participating in a Research study.

Greetings, my name is Romanus Mapunda a postgraduate student; pursuing a Master of Science in Oncology Nursing at Muhimbili University of Science and Allied Sciences (MUHAS) in the School of Nursing. I am researching the "estimating the caregiver burden and its nature among caregivers of children with leukemia at the MNH oncology unit

The aim of the study: This study aims to estimate the caregiver burden and its nature among caregivers of children with leukemia at the MNH oncology unit.

The results of this research will offer valuable information that can enhance health outcomes and the quality of life for caregivers of children with leukemia at MNH and other healthcare facilities.

Procedure

I would like you to take part in this study as the primary caregiver of children undergoing cancer treatment for over a month. If you decide to join, you will receive a questionnaire to read and complete, which takes approximately 15-20 minutes.

Confidentiality

All responses were kept confidential. Your responses will solely be utilized for research purposes and shared with MUHAS as needed. I will ensure that any information in my report does not reveal your identity as the participant. Throughout the data collection and reporting of findings, no names were disclosed.

Right to refuse or withdraw

It is your choice to participate in this study. Also, you don't have to answer anything you don't want and you may stop the questionnaire at any time for any reason without repercussions. However, I encourage you to participate because your experience is very important in this study.

Benefits

Participating in this study may not benefit you personally, but it might provide useful information that will fit the healthcare system and other caregivers by improving their well-being.

Risks

There was no harm to you as a result of participation in this study although some questions may be personal.

Whom to Contact

In case of any inquiry please contact the researcher, Romanus Mapunda, from MUHAS, P.O. BOX 65001, Dar-es-Salaam, mobile number 0768403171 or via email romanusmapunda5@gmail.com If you ever have questions about your rights as a participant, you may contact the Director of Research and Publications, at MUHAS P.O. BOX 65001, Dar-Es- Salaam-Tanzania.

Signature

Do you agree to participate? Put a tick in the appropriate box

Participant agrees ☐ participant does NOT agree ☐

I ……... have read the contents of this form and understand.

My questions have been answered; I agree to participate in this study.

Signature of participant……Date……

Signature of researcher…….Date……

Appendix IV. Fomu ya ridhaa (kwa kiswahili)

CHUO KIKUU CHA AFYA NA SAYANSI SHIRIKISHI MUHIMBILI

KURUGENZI YA UTAFITI NA MACHAPISHO

Namba ya utambulisho

Fomu ya Ridhaa ya Kushiriki Katika Utafiti

Habari, naitwa Romanus Mapunda mwanafunzi wa shahada ya uzamili, katika fani ya Uuguzi wa magonjwa ya saratani katika Chuo Kikuu cha Afya na Sayansi Shirikishi Muhimbili (MUHAS) katika shule ya Uuguzi. Ninatafiti kadirio la mzigo wa malezi na chanzo chake miongoni mwa walezi wa watoto wenye saratani y katika kitengo cha Saratani cha Hospitali ya Taifa ya Muhimbili.

Lengo la Utafiti

Utafiti huu unalenga kutafiti kadirio la mzigo wa malezi na chanzo chake miongoni mwa walezi wa watoto wenye saratani ya damu katika kitengo cha Saratani cha Hospitali ya Taifa ya Muhimbili. Matokeo ya utafiti huu yatatoa taarifa muhimu inayoweza kuboresha huduma ya afya na ubora wa maisha kwa wauguzi wa watoto wenye saratani ya damu katika Hospitali ya taifa ya Muhimbili na vituo vingine vya afya.

Mchakato

Ningependa uchukue sehemu katika utafiti huu kama mwuguzi mkuu wa Mtoto anayepata matibabu ya kansa kwa zaidi ya mwezi mmoja. Ikiwa utachagua kushiriki, utapokea maswali ya kujibu ambayo utasoma na kuyajibu, na hii itachukua takriban dakika 15-20.

Usiri

Majibu yote yatahifadhiwa kwa siri. Majibu yako yatatumiwa tu kwa madhumuni ya utafiti na kushirikishwa na MUHAS kama inavyohitajika. Nitahakikisha kuwa taarifa yoyote katika ripoti yangu haifichui utambulisho wako kama mshiriki. Katika ukusanyaji wa data na taarifa ya matokeo, hakuna majina yatakayofichuliwa.

Haki ya Kukataa au Kujitoa

Ni chaguo lako kushiriki katika utafiti huu. Pia, huna wajibu wa kutoa majibu kwa chochote usichotaka, na unaweza kusitisha kujaza maswali wakati wowote kwa sababu yoyote bila kusababisha madhara. Hata hivyo, nakuhimiza kushiriki kwa kuwa uzoefu wako ni muhimu sana katika utafiti huu.

Faida

Kushiriki katika utafiti huu huenda isilete manufaa kwako binafsi, lakini inaweza kutoa taarifa muhimu ambayo itasaidia mfumo wa huduma za afya na wauguzi wengine kwa kuboresha ustawi wao.

Hatari

Hakutakuwa na madhara kwako kutokana na ushiriki katika utafiti huu ingawa baadhi ya maswali yanaweza kuwa ya kibinafsi.

Nani wa Kuwasiliana Naye

Kwa maswali yoyote, tafadhali wasiliana na mtafiti, Romanus Mapunda, kutoka MUHAS, P.O. BOX 65001, Dar-es-Salaam, namba ya simu 0768403171 au kupitia barua pepe romanusmapunda5@gmail.com. Ikiwa una maswali kuhusu haki zako kama mshiriki, unaweza kuwasiliana na Mkurugenzi wa Utafiti na Machapisho, MUHAS P.O. BOX 65001, Dar-es-Salaam, Tanzania.

Sahihi

Je, Unakubali kushiriki? Weka alama ya tiki (√) katika kisanduku husika.

Ndiyo  Hapana 

Mimi…….....……nimesoma fomu hii ya ridhaa na nimeielewa. Maswali yangu yamejibiwa. Nakubali kushiriki katika utafiti huu.

Saini ya mshiriki…… ……Tarehe……

Saini ya mtafiti …… ……..Tarehe……

Appendix V: Ethical clearance

UNITED REPUBLIC OF TANZANIA

MINISTRY OF EDUCATION, SCIENCE AND TECHNOLOGY

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES

OFFICE OF THE DIRECTOR – RESEARCH, PUBLICATIONS AND INNOVATIONS

Ref. No.DA.282/298/01.C/2175 Date: 22/04/2024

MUHAS-REC-04-2024-2175
ROMANUS MAPUNDA
SHOOL OF NURSING
MUHAS

RE: APPROVAL FOR ETHICAL CLEARANCE FOR A STUDY TITLED: ESTIMATING THE CAREGIVER BURDEN AND ITS NATURE AMONG CAREGIVERS OF CHILDREN WITH LEUKEMIA AT MUHIMBILI NATIONAL HOSPITAL ONCOLOGY UNIT IN DAR-ES-SALAAM.

Reference is made to the above heading,

I am pleased to inform you that the Chairperson 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: 22/04/2024
EXPIRATION DATE OF APPROVAL: 22/04/2025

STUDY DESCRIPTION:
Purpose:
The purpose of this study is to ESTIMATE THE CAREGIVER BURDEN AND ITS NATURE AMONG CAREGIVERS OF CHILDREN WITH LEUKEMIA AT MUHIMBILI NATIONAL HOSPITAL ONCOLOGY UNIT IN DAR-ES-SALAAM.

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-%2015409.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/.



Dr. Nahya Salim Masoud,
Chairperson, MUHAS Research and Ethics Committee

Appendix VII. Introduction letter

UNITED REPUBLIC OF TANZANIA

MINISTRY OF EDUCATION, SCIENCE AND TECHNOLOGY

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES

OFFICE OF THE DIRECTOR – POSTGRADUATE STUDIES

In reply quote;
Ref. No. HD/MUH/T.494/2022

03rd May, 2024

The Executive Director,
Muhimbili National Hospital,
P.O. Box 65000,
DAR ES SALAAM

RE: INTRODUCTION LETTER OF ROMANUS MAPUNDA

We would like to inform you that the carrier of this letter is Romanus Mapunda with registration number HD/MUH/T.494/2022 a student at Muhimbili University of Health and Allied Science (MUHAS), pursuing MSc. Oncology Nursing.

As part of his studies, he will be doing an elective research titled **"Estimating The Caregiver Burden And Its Nature Among Caregivers Of Children With Leukemia At Muhimbili National Hospital Oncology Unit In Dar-Es-Salaam.** he is being supervised by Dr. Khadija Malima from MUHAS and Nazahed Richard from MNH.

The Ethical Clearance for doing the said research has been given by the University.

Kindly request your assistance and cooperation to our student.

Yours Sincerely,

Mr. Sebe Mohamed
For: DIRECTOR, POSTGRADUATE STUDIES

cc: Romanus Mapunda

9 United Nations Road; Upanga West; P.O. Box 65001, Dar Es Salaam: Tel. G/Line: +255-22-2150302/6; Ext. 1015; Direct Line:+255-22-2151378;Telefax:+255-22-2150465;E-mail:dpgs@muhas.ac.tz;Web:

Appendix VIII. Permission letter

THE UNITED REPUBLIC OF TANZANIA

MINISTRY OF HEALTH

MUHIMBILI NATIONAL HOSPITAL

In reply please quote:

Ref. No.: MNH/CRTCU/Perm/2024/204 Date: 08th May, 2024

Block Manager,
NPC – II
Muhimbili National Hospital

RE: PERMISSION TO COLLECT DATA AT MNH

Name of PI	**Romanus Mapunda**
Title	**"Estimating the Caregivers Burden an dits Nature Among Caregivers of Children with Leukemia at Muhimbili National Hospital Oncology Unit – Dar es Salaam"**
Institution	Muhimbili University of Health and Allied Sciences
Supervisor	Dr. Khadija Malima (MUHAS)
Co – Investigators	Nazahed Richard (MNH) Kibwana Athuman
Period	08th May 2024 to 30th June, 2024

Approval has been granted to the above principal investigators to collect data at MNH. Dissemination of study findings at MNH shall be overseen by **Nazahed Richard (**MNH) supervisor.

Kindly ensure the named principal investigator abide to the ethical principles and other conditions of the research approval.

Sincerely,

Dr. Sima Rugarabamu
For: Head of Clinical Research, Training and Consultancy Unit

c.c DNS
c.c Dr. Nazahed Richard
c.c **Romanus Mapunda**

HEAD OF TRAINING, RESEARCH & CONSULTANCY UNIT * P.O. Box 65000 DAR-ES-SALAAM * MUHIMBILI NATIONAL HOSPITAL *

Upanga West, Kalenga Street, Plot No. 10480/3, P.O. BOX 65000, Dar es Salaam, Tanzania.
Telephone: +255-22-2151367-9, Telephone: +255-22-2151351-2
Email: info@mnh.or.tz, Website: www.mnh.or.tz

Appendix IX. Plagiarism certificates

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