

**BURDEN ON CAREGIVERS OF CHILDREN DIAGNOSED WITH CANCER AND ITS  
ASSOCIATED EFFECTS AT KENYATTA NATIONAL HOSPITAL.**

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## DECLARATION

I, Namazzi Stella declare that this dissertation is my original work and has not been presented in any other institution of higher learning or elsewhere for the award of credit.

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## CERTIFICATE OF APPROVAL

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## **DEDICATION.**

I specially dedicate this work to my dear parents Ms. Alice Stella Namazzi and Mr. Tabula Moses. You are surely God given thank you for always believing in me as your daughter and for the constant support. Every sacrifice made for my sake may God reward you a hundred fold more.

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## LIST OF ABBREVIATIONS

<b>BMA:</b>	Bone marrow aspirate
<b>ERC:</b>	Ethics and Research Committee
<b>KNH:</b>	Kenyatta National Hospital
<b>NGOs:</b>	Non-Government Organizations
<b>NHIF:</b>	National Hospital Insurance Fund
<b>QOL:</b>	Quality of life
<b>SD:</b>	Standard Deviation
<b>SPSS:</b>	Statistical Package for Social Sciences.
<b>UoN:</b>	University of Nairobi
<b>USA:</b>	United States of America.
<b>ZBI:</b>	Zarit Caregiver Interview

## OPERATIONAL DEFINITION OF TERMS

**Adaptation:** a process by which the caregiver reorganizes her/ himself both internally and externally to overcome the negative impacts of the child's illness.

**Caregivers:** the parents of children diagnosed with cancer (father or mother)

**Caregiver burden:** the extent to which caregivers of children suffering from cancer feel that their emotional, physical health, social life, and financial status have suffered as a result of caring for the ill child.

**Child:** in this study a child is one with the age of 0-12 years, diagnosed with cancer.

**Parent:** mother or father that is taking care of their child diagnosed with cancer at KNH.

**Degree of caregiver burden:** it is the measure of how the caregivers to children diagnosed with cancer at KNH feel that their child's illness has affected them psychologically, physically, socially and economically.

**Stimuli:** in this study stimuli is the cause of caregiver's burden, it can be focal stimuli (the child's illness), contextual (external or internal factors like the finance) and residual (the confounding factors like demographic characteristics).

## ABSTRACT

**Background:** Childhood cancers affect caregivers in various ways; physically, socially, psychologically and economically which lead to caregiver burden. Caregiver burden is still a challenge in the developing countries where little research has been done on the subject. Research has shown that parents of children with cancer suffer significant stress, loneliness, job loss, family conflict and reduced self-care during the time of care, in Kenyatta National Hospital approximately 1110 children aged between 0 and 12 years are diagnosed with cancer in annually. There is a great need to know how the caregivers of these children are affected.

**Objective:** The aim of the study was to determine the burden on caregivers of children diagnosed with cancer and its associated effects at Kenyatta National Hospital (KNH).

**Methodology:** In this cross sectional descriptive study a total number of 74 caregivers of children diagnosed with cancer and being hospitalized at Kenyatta National Hospital (KNH) were selected. Simple random sampling method was used to select the participants from the different pediatric wards. Caregiver burden was measured using the Zarit Caregiver Burden Interview scale/ tool (ZBI) and a semi-structured questionnaire was used to obtain data on the social demographics of the caregivers and the children, economic status/concern and the psychosocial effects that influence caregiver burden. Data was entered and analyzed using SPSS computer package, version 21. Chi square tests were used in a bi-variate analysis to assess how caregiver burden index varied among the demographic characteristics, economic and psychosocial effects. A P value less or = to 0.05 was used to indicate statistical significance. Data was presented in textual, tables, bar graphs and pie-charts.

**Results:** A total of 74 caregivers of children suffering from cancer admitted in Kenyatta National Hospital were involved in the study. Majority of the caregivers were mothers 73% (n= 54) of middle age 30-39 years. On average, the caregivers reported moderate to severe (58.6+/- 11.2 SD) caregiver burden. More than half 57% (n= 42) having severe caregiver burden and majority being women. Majority of the respondents 95% (n= 70) reporting strain in finances as they cared for their children. Psychologically insertion of intravenous cannulas influenced caregiver burden among caregivers with a P-value of 0.028

**Conclusion:** The degree of caregiver burden among the study population as measured by the ZBI Scale was moderate to severe in majority of the respondents with an average score of 58.6 which is way too high than the normal 0-20.

**Recommendation:** Using the findings of the study, health care providers need to formulate a holistic and family centered program considering the effects that increase caregiver burden.

# CHAPTER ONE: INTRODUCTION

## 1.1 Background

Cancer is a chronic, long-term illness that affects not only the child but also the family as a whole. (Elcigil and Conk, 2010), such a serious illness causes the child to undergo aggressive treatment regimen accompanied by a magnitude of burdens to the parents (Masa'Deh *et al.*, 2013). Caring for a loved one is rewarding but is also associated with caregiver burden (Hsu *et al.*, 2014). "Burden of Care" is the reflection of the undesirable events and difficulties brought about by the disease upon the members of the family (Elcigil and Conk, 2010). Globally the burden on caregivers of children diagnosed with cancer has not been established. Using the Zarit caregiver burden interview, caregivers in Nigeria had an average score of 50.8 which revealed moderate to severe caregiver burden (Oyegbile and Brysiewicz, 2017)

Studies of the child cancer impact on the Family Status are rarely found (Nagy *et al.*, 2017). Seventy eight percent of the family caregivers of cancer patients dedicate between 21 and 24 hours, which concur with increased multi-tasking among caregivers (Warner *et al.*, 2014). In one of the South African province KwaZulu Natal a qualitative study revealed that mothers were highly affected by care giving since they had to spend most of their time with the sick child and leave other older children and the fathers to operate the house hold duties. One mother exclaimed why the cancer affected her child and not her herself (Naidoo *et al.*, 2016). Generally, the care of child with cancer negatively affects the day to day life and job routine of parents, since they prioritize on the child's treatment (Kohlsdorf, Luiz and Junior, 2012)

A study examining the distress among caregivers and their patients in Germany revealed that 23% of the caregivers reported unmet psychological, emotional and even a higher percentage of 48 agreed on willingness to receive psychological support if offered (Haun *et al.*, 2014). In Mitchell, A. J. *et al.* (2013) systematic review of depression and anxiety in cancer survivors

compared to their spouses revealed 26% prevalence of depression among patients and 26% in their spouses and 28% prevalence of anxiety in patients to 40% of that in the spouses this confirms the significant anxiety among caregivers than even the patients.

In Jordan a study showed that the mothers of ill children experience significant stress (Masa'Deh *et al.*, 2013). In India Padmaja, G. *et al.*, (2016) reported that females care givers with a history of a psychiatric disorder as well as those who take a very negative view of the patient's illness, are very vulnerable to high distress of development of affective disorder.

Currently the term financial toxicity is being adopted in reference to cancer management, the treatment is so expensive that some parents have sold off their assets to be able to buy drugs and cater for diagnostic tests resulting in to financial burden (Carrera, Kantarjian and Blinder, 2018). In Columbia the financial burden registered 92% of conflicts in families in one of the study since parents go into debt and have to sell off their assets to meet medical costs of the ill child (Velandia, Instructor and De, 2018).

In Kenya, the incidence of childhood cancers is about 3000 new cases per year. Lymphoma, kidney cancer, eye tumors (retinoblastoma) and leukemia constitute about 80% of all childhood cancers in Kenya and majority respond well to treatment. Childhood cancers account for 15% of cancer admissions in Kenyatta National Hospital (KNH), only 1 out of 10 survives as compared to 7 out of 10 in developed countries (National Guidelines for Cancer Management Kenya, 2013). Mothers of ill children experience significant stress (Masa'Deh *et al.*, 2013).

A qualitative study conducted in western Kenya among palliative caregivers described the experience of seeing a loved one suffer from a chronic illness as burdensome and stressful though they reported to remain strong through the period, the major challenge was the limited resources and lack of finances throughout the caring period (Johnston, 2017).

There is an evident gap between medical intervention and the psychosocial field of oncology in the underdeveloped countries (El Malla, 2017). Health care teams are at a strategic position to identify caregivers with significant burden and can be of great assistance through directly supporting them or referring them to helpful services (Girgis *et al.*, 2013).

## **1.2 Problem Statement**

Childhood cancer is very devastating especially to the loved ones especially the immediate family. The role undertaken by parents in caring for their children with cancer is enormous and overwhelming. In most cases the outcome of the cancer cannot be predicted and in many cases, the prognosis is poor. This has a great implication on caregivers' Psychological status. The caregivers may themselves be ill. They may also have other children that optimally depend on them. The caregivers then have their roles extended to specialized care of the sick child, while at the same time need to avail psychological support to the child and other children (Kohlsdorf, Luiz and Junior, 2012). Psychological reactions start immediately from when the child is diagnosed and anecdotally in the African setting parents will have to stay in hospital so as to provide care to their admitted child (Naidoo *et al.*, 2016). The whole journey of the child's aggressive procedures and treatment is disturbing and parents must adjust to increased parental responsibilities like accompanying the child for medical appointments and hospitalization (Shiota *et al.*, 2004). The overload of responsibility may increase their likelihood of reactions for example anxiety, sleep disturbances and depression (Kazak *et al.*, 2004).

Due to the child's illness there is always role shifting in the house, the older children and the fathers take on the house hold core roles. Mothers feel that this is less than the ideal and this may increase their levels of guilt and anxiety as they are always unsure of the family they leave behind (Naidoo *et al.*, 2016).

Treatment of childhood cancer in most cases involves hospital stays, many diagnostic tests, use of chemotherapy and other pharmaceuticals. In some instances radiotherapy or surgery area needed. Once the child is discharged from the hospital, treatment entails numerous outpatient visits. All these are very costly.

Every year, approximately 1110 cases of childhood cancers are diagnosed in Kenyatta National Hospital. Understanding the psycho-social and economic burden of childhood cancer among the caregivers is essential. This may help in developing appropriate public health policy, more so on psycho-social support and on allocation of healthcare resources, for the support of schemes for caregivers of such children (KNH Statistics).

### **1.3 Justification**

A consensus was reached in Nasab, A. F. and Foroghi, M. (2016) that cancer in children impairs the mental status of parents. Another consensus was reached that the parents suffer severe financial burden (Saifan *et al.*, 2014). If attention is completely on a child it may cause the family to break up, affect communication and or self-care deficit in the of parents (Velandia, Instructor and De, 2018). There are many studies that have been done concerning burden of caregivers of patients with different cancers in Kenya. However from the review of literature a study on burden on caregivers of children diagnosed with cancer and its associated effects has never been done in Kenya.

In line with the Kenya National Cancer Control Strategy 2017-2022, objective 3.6 aims at good quality of life of those living with, recovering and dying from cancer and their families through support and rehabilitation. Health, M. O. F. (2017) 'National Cancer Control Strategy 2017-2022'

A study in KNH is suitable because it is the largest National Referral Hospital and it receives most of the referral cases of childhood cancers from all over the country so a study in KNH will expose how caregivers are affected by the child's illness this will then act as a road map on how best they can be assisted to cope and adopt to the challenge. Considering the experience to the caregivers, it is worth identifying these burdens and plan efficient solutions (Kohlsdorf, Luiz and Junior, 2012).

The findings of this study could serve as a blue print for how the caregivers are affected and how better the government policies and programs can be implemented to solve the challenges.

## **1.4 Research Questions**

- i. What are the socio-demographic characteristics that contribute to caregiving burden among caregivers of children diagnose with cancer at KNH?
- ii. What is the degree of caregiver's burden among caregivers of children diagnosed cancer at KNH?
- iii. What are economic status and concerns of caregivers of children diagnosed with cancer and its influence on the burden of care?
- iv. What psychological issues affect caregivers as they care for children diagnosed with cancer at KNH?

## **1.5 Objectives**

### **1.5.1 Broad objective**

To determine the burden on caregivers of children diagnosed with cancer and its associated effects at Kenyatta National Hospital.

### **1.5.2 Specific objectives**

- i. To identify the socio-demographic characteristics of caregivers and children diagnosed with that influence caregiving burden at KNH.
- ii. To determine the degree of caregiver's burden among the caregivers of children diagnosed with at KNH.
- iii. To determine economic status and concerns of caregivers of children diagnosed with cancer and its influence on caregiver burden.
- iv. To determine the psychological effects of caring of children diagnosed with cancer at KNH among the caregivers.

## **1.6 Hypothesis**

### **1.6.1 Null hypothesis**

There is no relationship between economic status and the degree of burden among caregivers of children diagnosed with cancer at KNH

### **1.6.2 Alternative hypothesis**

There is a relationship between the economic status and the degree of burden among parents of children diagnosed with cancer at KNH.

## **1.7 Theoretical Frame Work: Sister Calista Roy's Adaptation Model**

Roy focused on human adaptive system responses and environmental stimuli, which are dynamic.

Roy's model describes the individual as a collection of related systems; biologically, psychologically and socially. In her theory, she emphasized that an individual or a group with choice can consciously create a conducive environment which she referred to as adaptation. (Roy & Andrew, 1999). Adaptation begins when the natural adaptive systems fail to harmonize with

the environment in a way to sustain the required status of the system. The adaptation process that the caregivers of children suffering from cancer make Roy's Adaptation Model (RAM) applicable. According to the adaptation theory, human beings are adaptive systems with inputs of stimuli and output as behavior responses that serve as feedback. The systems also have control processes which are known as coping mechanisms.

### **1.8 Application of Roy's Adaptation Model**

Roy's Model has three classes of stimuli that confront the human system; the focal stimulus is referred to as the stimulus that is immediately confronting the human system. In this study the focal stimuli to the parents is the child's illness (cancer). Contextual stimuli refers to the other stimuli of the human's internal and external environments they could have a positive or negative effects on the situation. In this study the social needs (care for other siblings, marital duties), the economic needs and effects (medical bills, resigning from job, transport bills) and psychological (aggressive diagnostic procedures, fear of child's death) effects are the contextual stimuli that accompany the issue of the child's illness.

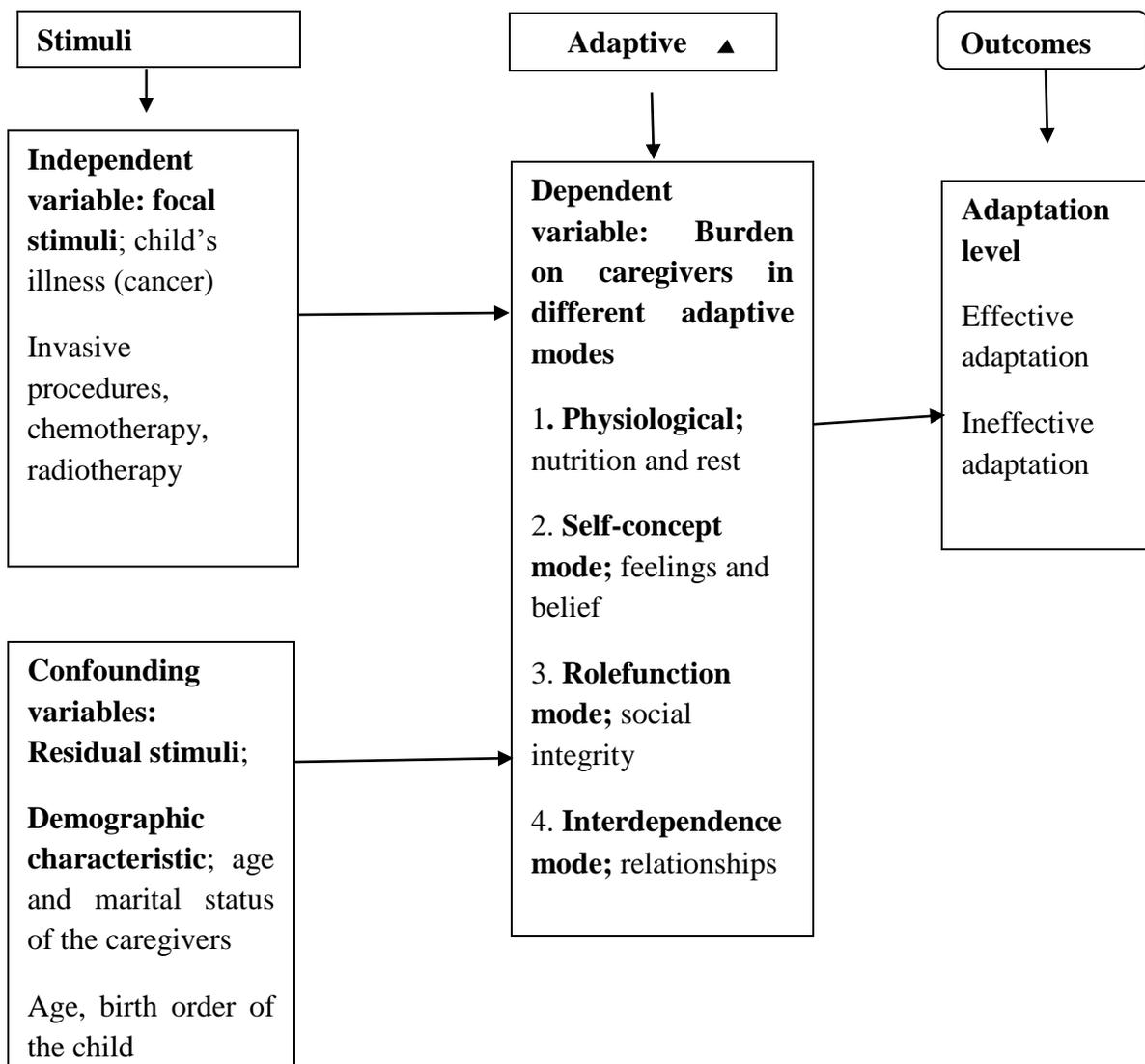
The third stimulus is the residual stimuli and it includes the external factors whose current effect is unclear also known as the confounding. These stimuli are thought to have effect on the child's illness in this study the confounders include: social-demographic characteristics of the caregivers for example age, sex, marital status, education level of the caregivers.

After the stimuli (situation) individuals adapt to these situations differently and in Roy's model she made mention of 4 adaptive modes; physiologic- physical mode where the humans interact as physical beings through activity and resting, nutrition and protection. The role function mode is the underlying need of social integrity. The self-concept mode refers to the self-esteem, hopelessness in an individual. Lastly the interdependence mode which deals with the interaction

and emotions related to giving and receiving love and care respect and values from the family and others in the community.

Adaptation finally emerge in to either positive or negative individual behavior and this is the feedback to the system (parents) and to the environment who are the significant others.

### 1.9 Theoretical Frame Work: Using Modified Roy Adaptation Model (RAM)



*Figure 1: Theoretical framework*

## 1.7 Conceptual Framework

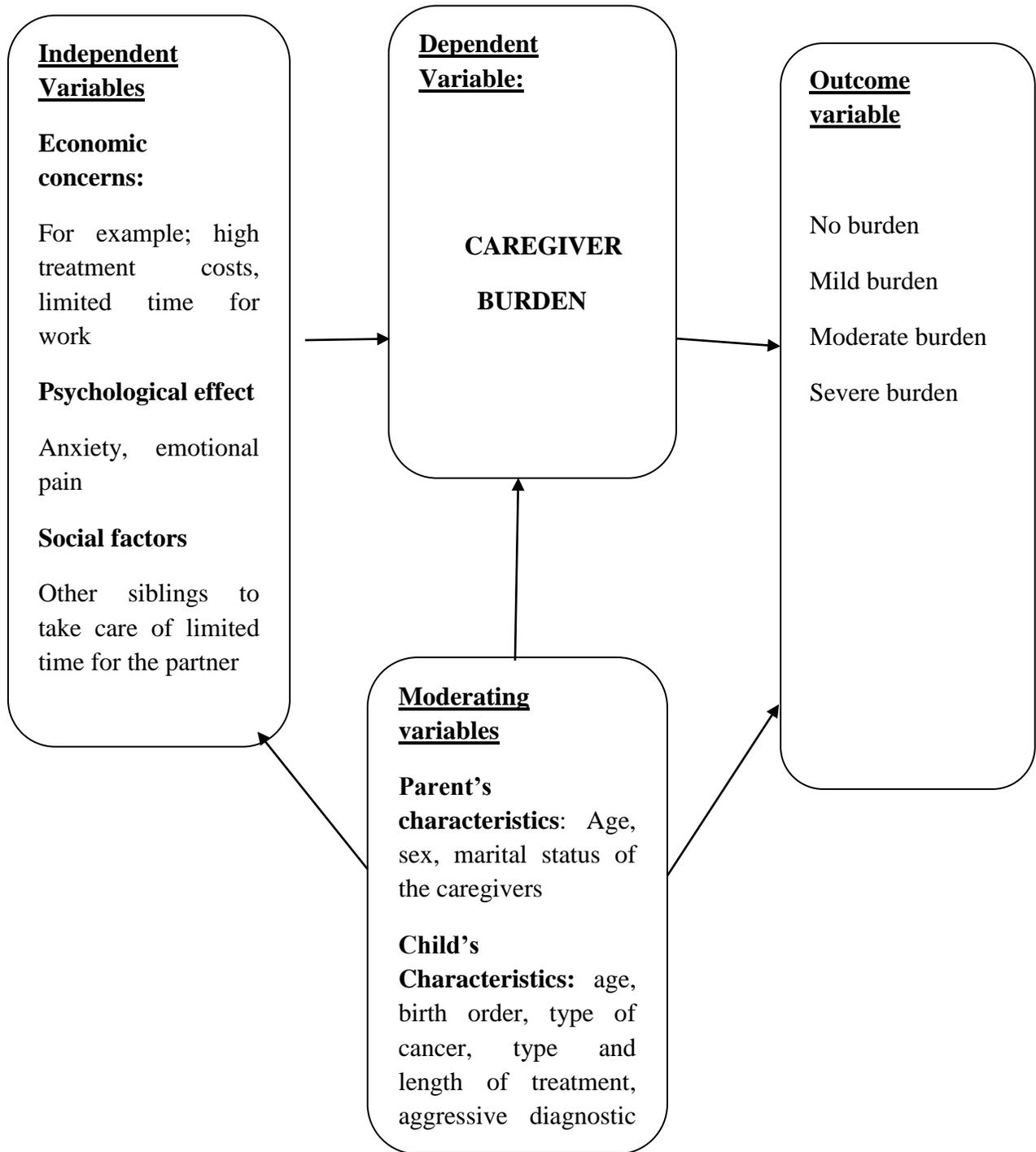


Figure 2: Conceptual framework

## **1.8 Key Variables**

### **1.8.1 Independent Variables**

Economic factors for example the high costs of cancer treatment.

Psychological factors for example fear of death of the child.

Social factors for example other siblings who could optimally need care.

### **1.8.2 Moderating Variable**

Social demographics for example the age, sex, marital status of the caregivers.

### **1.8.3 Dependent Variable**

The burden on the caregiver during the care of their child suffering from cancer

### **1.8.4 Outcome**

Economically the burden would lead to loss of job, loss of assets, family conflict.

Psychologically caregivers could end up depressed, anxious, lack sleep, lose weight lonely.

Socially caregivers could divorce and even neglect other family member or adapt to the situation.

## **CHAPTER TWO: LITERATURE REVIEW**

### **2.1. Introduction**

Childhood cancers impact families at many levels (Aung *et al.*, 2014). The literature search focused on; caregiver burden, economic effects that influence caregiver burden and the psychosocial effects that influence caregiver burden.

### **2.2 Caregiver Burden**

Caregiver burden can be explained as a level where a caregiver feels holistically drained that is economically, socially and psychologically as a result of caring. Burden of Care” is the reflection of the undesirable events and difficulties brought about by the disease upon the members of the family (Elcigil and Conk, 2010). Majority receive satisfaction from taking care of loved ones however the burden still exists (Johnston, 2017).

Kahrima and Zaybak 2015, in their study to find out the caregiver burden using the Zarit caregiver burden interview, it reflected that 50% of the care givers experienced mild care giving burden and only 7.5% experienced severe care giving burden and they related this to the Turkish culture that says that it is only natural for the relatives to provide care to the sick relative. They also found out that the levels of care burden increases with high level of dependency condition of the patient since it increases the need for assistance in even simple tasks such as eating bathing and toileting. However, there was a low perceived care burden among mothers of children with cancer which they related to the account of their motherly instincts.

Physical stability highly depends on how well an individual physically functions. Caregiving can easily cause negative health status and related behaviors through constant fatigue, sleep deprivation and reduced nutrition (Glajchen and Director, 2012a). The physical impact parents experience is in unison with the day today tasks that these parents must perform so symptoms of

caregiving burden gradually increase. The performance status of these children may greatly reduce and so parents must intervene in the activities that these children used to perform (Glajchen and Director, 2012b). Over a given duration of time, with the ill child taking the center stage the caregivers become physically wanting with expression of conditions like high blood pressure, joint pain and insomnia (Bishop *et al.*, 2007).

### **2.3 Economic Concerns among Caregivers of Children's Cancer Diagnosis that Influence Caregiver Burden.**

There are so far minimal researches that have been done on economic impact of child cancer treatment and financial stability of families (Warner *et al.*, 2014). Childhood cancers impact the family life at many levels. They still reported that factors which may adversely influence the context in which the families care for these children included the caregiver being unemployed; and the caregiver whose leave status or pay are negatively affected.

Warner, B. *et al.*, (2014) reported the need of insurance models and the need to incorporate financial assessment in to pediatrics care models. This was following their review of 24 studies that confirmed family financial burden due to childhood cancer treatment.

“Financial toxicity” has been adopted and is currently being used in reference to cancer care and treatment. The cancer drugs especially the newer classes of therapies are very costly (Carrera, Kantarjian and Blinder, 2018). Financial toxicity arises from both objective financial burden and subjective financial distress. The former burden is due to the direct costs of cancer treatment, which increase from diagnosis to end of treatment. With more time of care the house loses almost all income generating items because of treatment costs. Subjective financial discouragement is loss of assets plus increased worries over the cancer experience (Carrera, Kantarjian and Blinder, 2018).

In a survey of 71 parents of children with progressive, recurrent and non-responsive cancer at 3 pediatrics hospitals in the United States, proved that across all levels of income the parents work was disrupted, in 42% of the families at least one of the parents had to quit working. And the most affected were the poorest families with 6 (50%) of the poorest families lost more than 40% of their income as compared to the 5% lost by the wealthiest families (Bona *et al.*, 2014).

In a qualitative study carried out in the provinces of Canada with 28 caregivers of pediatric cancer patients reported that they had incredible increase in their daily expenditure, self-employed parents experienced an immediate loss of income and although none of the interviewed parents accepted withdrawing care from their children because of financial constraint there was a foresight that many parents struggled with financial hardships and these concerns imposed additional stress to the family (Miedema *et al.*, 2008).

Regarding finances in Nigeria, caregivers in a study of end stage renal disease indicated that they do not have enough money to settle medical cost. From the qualitative data, participants revealed that they sacrificed financially in order to provide care to their sick relatives. Uncertainties around sourcing for fund and prolonged payment of substantial amount for treatment increased the stress (Oyegbile and Brysiewicz, 2017).

#### **2.4 The Psychological Effects of Caring for Children Diagnosed with Cancer at KNH Among the Caregivers.**

It's almost impossible for the clinicians to treat cancer patients without the informal caregivers. Some of these caregivers provide this care for 24 hours every day yet currently there is inadequate special support offered to the same undertaking this role. Health care providers are well positioned to try and recognize caregivers that stand high chances of significant burden. Professionals can either provide support directly or refer them to the social workers for proper management (Girgis *et al.*, 2013).

The parents in KwaZulu Natal in South Africa reported that it was difficult to manage changes and interferences that arose at home in their absences because the father and other siblings had to shift household roles (Naidoo *et al.*, 2016). For the mothers the experience was disturbing and lost their motherly role. The mothers were not certain of the family's survival without her presence especially with household responsibilities. This added on their guilt and worry for the left behind family. The entire family struggled to regain stability until the ill child was well (Naidoo *et al.*, 2016). A study in Morocco that involved 49 caregivers revealed that more than 32 of these caregivers reported that they were no longer socializing and had also neglected their families (Lkhoyaali *et al.*, 2015).

A study in Iran that examined the caregivers' quality of life among cancer children in three domains of; physical, emotional and environmental status revealed significantly lower quality of life (QOL) among the care givers to these cancer patients than that of the general population; this revealed how cancer care affects the emotional domain (Sajjadi *et al.*, 2013).

Mitchell, A. J. *et al.*, (2013) reviewed depression and anxiety in long term cancer survivors compared to their spouses revealed 26% prevalence of depression among patients and 26% in their spouses and 28% prevalence of anxiety in patients to 40% of that in the spouses this confirms the significant anxiety among caregivers than that of patients. In a study that involved both the patients and their caregivers indicated that, caregiver's depression, anxiety and somatization greatly predicted depression in the cancer patients (Girgis *et al.*, 2012) the results of the study clearly showed a positive relationship between the caregiver's anxiety and patient's distress.

A study in Malaysia that included 130 caregivers revealed that the care givers who provided care for more than 20hrs a week these did not share the caregiving responsibility with other people and were more likely to develop stress (Daripada Penjagaan *et al.*, 2013).

A study carried out in Nepal that included 50 care givers of patients with cancer revealed that; 34% participants had severe level of depression, 32% respondents had moderate depression, 6% participants' had mild level of depression and 28% participants' had consider minimal range of depression (Sharma and Mehta, 2015). Aung *et al.*, (2012) evaluated for personal strain among parents and findings reported 75% of personal strain among mothers

Social support, especially family support, being a highly effective psycho-social support intervention, if caregivers' well-being is enhanced, they contribute further to the well-being of the patients.

## **2.5 Conclusion.**

There is limited literature on caregiver burden especially in Africa. Though some studies show a low caregiver burden, majority of the studies show a significant need for psychological intervention in the oncological sector.

## **CHAPTER THREE: METHODOLOGY**

### **3.1 Introduction**

This chapter discusses the methodology was used in the study of burden on caregivers of children diagnosed with cancer and its associated effects at KNH. The chapter details on the study design, the study site, population under study and the sample size the participants who fit in the study, the tools that were used to collect the data. Data collection procedure, data analysis and presentation ethical consideration among others.

### **3.2 Study Design**

A cross sectional descriptive using a quantitative method that sought to determine the burden on caregivers of children diagnosed with cancer and its associated effects Kenyatta National Hospital.

### **3.3 Study Site**

The study took place in Kenyatta National Hospital in the pediatrics wards that is ward 3A, 3B, 3C, 3D and the pediatric oncology ward 1E. KNH is the largest and oldest referral hospital in Kenya established in 1901. It is located in Nairobi 3.5km west of the business center. Due to the availability of many pediatrics specialists like the hematologists, most of the childhood cancer cases are referred to KNH and also the availability of the radiotherapy machines in Kenyatta makes it more suitable for childhood cancer treatment.

The pediatric wards are located on the third floor and are labeled as 3A, 3B, 3C and 3D. These wards admit all children from the age of 0-12 years with all medical conditions inclusive of the children suffering from cancer. Each of these wards has a bed capacity of about 70 beds and the wards are divided in to several cubicles. Each ward has a cubical dedicated to the children suffering from cancer. Each ward has 25 nurses that take care of these children and there are several medical specialists that are consulted on the different medical conditions. The caregivers

of these ill children are constantly with the children in the wards until discharge. Ward 1E located on the first floor is also a specialized ward that specially admits children with hematological aged 0-13 years and has a bed capacity of 28 beds. Unlike the pediatric wards on third floor, parents in ward 1E only come once in a while to check on how the child is fairing. This is because the ward is too small to accommodate the caregivers also.

### **3.4 Study Population**

The targeted group was caregivers of children diagnosed and were being treated for cancer at Kenyatta National Hospital.

### **3.5 Inclusion Criteria and Exclusion Criteria**

#### **3.5.1 Inclusion Criteria**

Caregivers with children diagnosed three or more month ago and were started on either chemotherapy or radiotherapy treatment within the period of their stay in hospital.

Caregivers who were the biological parents to the child suffering from cancer in KNH.

The caregivers who voluntarily consented and agreed to participate in the study.

#### **3.5.2 Exclusion Criteria**

Caregivers who could have lost their child in the course of the day of data collection.

Caregivers whose children had not started on either chemotherapy or radiotherapy

### **3.6 Sample Size Determination**

Statistical information from the health records office indicated that a total of 1110 children aged 0-12 years were admitted with cancer in KNH in the year 2018 ( January – December). Approximately averages of 92 children were diagnosed with cancer per month in 2018. The study was done in one month (a population size of 92 caregivers were considered as the number of target population at the time of the study)

The sample size was calculated using fisher's formula.

$$n = Z^2 (p) (q)/d^2$$

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

Z = is the standard normal deviation at 95% confidence interval (Z = 1.96 for 95%)

P = the proportion in the target population estimated to experience caregiving burden and its associated effects. Since no study has been done on the subject 50% on anecdotal evidence was used to determine the minimum sample size.

d = the level of precision (set at +/-5% or 0.05)

$$Q = 1 - P$$

e = Allowable Error (0.05)

Given that among the mothers 50% are experiencing caregiver burden

Substitution

$$n = 1.96 \times 1.96 \times 0.5 \times 0.5 / 0.05 \times 0.05$$

$$n = 384$$

Since the target population was less than 10,000, the following formula was used to calculate the final sample size

$$nf = n / (1 + n / N)$$

Where nf = the desired sample size when the population is less than 10,000

n = the desired population when the sample size is greater than 10,000

N = the estimate of the population

$$nf = 384 / 1 + 384 / 92$$

$$nf = 74 \text{ caregivers.}$$

To meet the required sample size, Proportionate allocation was done for each ward using the formula  $:(nI^N_2) nf$ .

Where:

$n_1$  = number of study participants per each sampled Ward

$N_2$  = Total number of participants in all sampled Wards =87

$nf$  = the minimum sample calculated number of study participants =74

A list of patients in each ward was obtained and the statistics per ward were as follows: 3A- 16,3B- 12, 3C -15, 3D- 16, 1E- 28 giving you a total of 87 patients so 87 caregivers attending to them.

**Table 3.1: Sample Size Proportions**

Ward	Number of patients in the ward	Total number of parent participants	Percentage
3A	16	$16/87 \times 74 = 14$	18.9%
3B	12	$12/87 \times 74 = 10$	13.5%
3C	15	$15/87 \times 74 = 12$	16.2%
3D	16	$16/87 \times 74 = 14$	18.9%
1E	28	$28/87 \times 74 = 24$	32.5%
Total	87	74	100

### 3.7 Sampling Technique

KNH was purposefully selected, being the largest teaching and referral hospital in Kenya. Wards 3A, 3B, 3C, 3D and 1E were purposefully selected because its where pediatric patients suffering from cancer are admitted. A list of children suffering from cancer was obtained from the senior nursing officer in-charge of each ward. Simple random sampling method was used to pick the eligible participants from each ward. "YES" was written on small pieces of paper (based on proportionate allocation for the specific ward) equal number of papers were left blank. All the pieces of papers were folded and put in a basket. The caregivers who picked a paper with "YES" were included in the study.

### **3.8 Research Tool**

Data was collected using a semi structured questionnaire (Appendix 4) and the Zarit care giver burden scale (Appendix 7) by the researcher and research assistants. The Zarit burden interview is a self-report to measure the burden on the caregiver by Zarit, Reeve-Peterson, 1980 currently it has 22 items after the review and the caregiver responds by circling any number on a 5 point scale

### **3.9 Recruitment and Training Research Assistants**

Three registered Bachelors of Science Nurses were trained as research assistants to help in identification of study participants, administration and filling questionnaire during data collection and verification of the completeness of the questionnaires.

### **3.10 Role of Project Team:**

The researcher ensured smooth planning of the project, worked hand in hand with the research assistants to make sure that the rights of the participants were protected and that the research was generally conducted according to valid research design and methods. The researcher made sure that credible data was collected and cleaned before entry and analyzed the data in consultation with the statistician.

### **3.11 Pretest, Reliability and Validity of the Tool.**

The questionnaires were pretested in ward 1F (9D) in KNH, a ward that also admits pediatric oncology patients but with ophthalmology conditions. This ward falls under the ophthalmology department not under pediatrics and is not part of the selected wards under this study. The tools were pretested on 7(10%) of the sample size. This helped in verification of the data collection tool before data was collected. It also helped identify some important questions that have been left out, some ambiguous and unnecessary questions to also establish how much time respondents were requiring to fill the questionnaire.

### **3.12 Recruitment Strategy**

The researcher introduced herself and the research assistants to the ward in-charge and produced the obtained ethical approval and also requested for a room where the participants who cannot read would be interviewed from. With the in-charge's permission, the researcher identified the caregivers of the children suffering from cancer in the ward. The researcher and the research assistants approached the identified parents, introduced themselves and informed them of the intended study in detail. Informed consent (appendix 3) was obtained after the participant had fully understood the purpose of the study and knowing that all information that would be given would remain confidential. The participant then was taken to the room on the ward after ensuring that the child was being taken care of by another nurse during the interview. At the end of the interview they thanked the participant for the opportunity availed.

### **3.13 Data Collection Process**

The data was collected using researcher administered semi structured questionnaires at any given time apart from the morning hours when the ward rounds were taking place or nursing procedures were being performed. The participants were identified and sampled from each selected wards. The researcher or research assistant approached the identified participant and introduced him or herself and informed them about the intended study. When the sampled participant agreed, she/he was explained the process and this enabled him/her to give informed consent. She/ he was asked to respond to the questions in the semi structured questionnaire. She/he would then give response to the questions in the Zarit burden interview scale (Appendix 7).

### **3.14 Data Cleaning and Entry**

The questionnaires were checked daily for completeness by the researcher and research assistants. The data was then entered in SPSS computer package version 21.0 in which also the meaningless data was left out.

### **3.15 Data Analysis and Presentation**

The data were analyzed using inferential and descriptive statistics Quantitative data were entered and analyzed using SPSS computer package, version 21.0 Chi- square test was done in a bi-variant analysis to assess how caregiver burden index varies among the economic and psychosocial factors a p value equal to or < 0.005 indicated statistical significance. Percentages were used for categorizing data and data were presented in form of pie charts, tables and bar graphs.

### **3.16 Data Storage**

The questionnaires had codes and respondents did not include their names on them, once they had been recorded they were then locked up in a safe cupboard. The laptop used in the analysis of the data had a password so that it had limited access by only authorized personnel.

### **3.17 Ethical Consideration**

The researcher obtained ethical clearance of the study from the Kenyatta National Hospital/University of Nairobi- Ethics and Research Committee (KNH/ UoN- ERC).A clearance to conduct the study was also obtained from KHN department of research. Permission was sought from KNH administration as well as from the pediatrics wards in-charges.

The participants gave informed consent after they had understood the purpose of the study. These participants were assured that all the information gathered would remain confidential, and the results obtained from the study will be shared with relevant stakeholders without disclosing

the names of the participants. The participants were informed that the study was voluntary with no monetary gains and one could decline participation any time with no penalty.

### **3.18 Study Limitations and Delimitations**

The research topic was sensitive and emotionally draining. This may have caused the participants not to reveal some information. However, the researcher provided quality time to the parents in order to obtain the required information and also remained focused on the research topic.

The researcher was not well versed with Kiswahili language this might have led to miss understanding and scanty information. The researcher employed research assistants who were well conversant with Kiswahili language.

### **3.19 Data Dissemination Plan**

The findings of the study will be presented to the staff members including doctors, nurses and social workers in the wards where the study took place during continuous professional development meetings, Presentation of the study results will be made to the panel of the nursing faculty at the University of Nairobi. The study findings will also be published in a peer reviewed journals. A copy of the report and recommendations from the study will be submitted to the Chief Executive Officer Kenyatta National hospital and University of Nairobi.

## **CHAPTER FOUR: RESULTS**

### **4.1 Introduction**

This chapter presented the findings of the study based on the study objectives. The results are presented burden on caregiver of children and its associated effects at KNH

### **4.2 Response Rate**

Caregivers who were enrolled by the end of the study were 74 from pediatric oncology wards. The respondents were enrolled based on the eligibility criteria. A questionnaire and a caregiver burden scale were used to gather the required data. All questionnaires were completely filled contributing to a response rate of 100%.

### **4.3 Social Demographic Characteristics of the Study Population.**

Most of the respondents in the study were between 30-39 and 20-29 years 33% (n=26) and 32% (n=25) respectively. Only 1% (n=1) were aged 10-19, none of the respondents were above 49 years. Majority of the respondents were females 73% (n=54) and the males were 27% (n=20). Most 77% (n=57) of the respondents were married and only 1 (1%) was divorced. More than half 54% (n=40) of the respondents were residing outside Nairobi city and the rest were from Nairobi city. Most of the caregivers 48.6% (n=36) attained education up to secondary level and only 5% (n=4) attained education to university level. The findings are presented in table 4.1 below

**Table 4.1: Demographic Characteristics of Respondents**

*N* =74

<b>Variables</b>		<b>Frequency (n)</b>	<b>Percent (%)</b>
Age	10-19	1	1.4
	20-29	25	32.1
	30-39	26	33.3
	40-49	22	28.2
	50-59	0	0
Gender	Male	20	27
	Female	54	73
Marital status	Single	14	19
	Married	<b>57</b>	<b>77</b>
	Separated	2	3
	Divorced	1	1
Residence	Nairobi	34	46
	Not from Nairobi	40	54
Level of education	None	3	4
	Primary	9	12.
	Secondary	36	48.6
	College	22	30
	University	4	5.4

Bivariate analysis was further done to determine the relationship between their caregiver's burden scores and demographic characteristics, this revealed that more females 74% (n=31) experienced severe caregiver burden than the male caregivers 26% (n=11) and most married respondents 74% (n=31) also experienced severe caregiver burden than the singles, divorced and separated. The chi square test revealed no significant relationship between the categorical ZBI

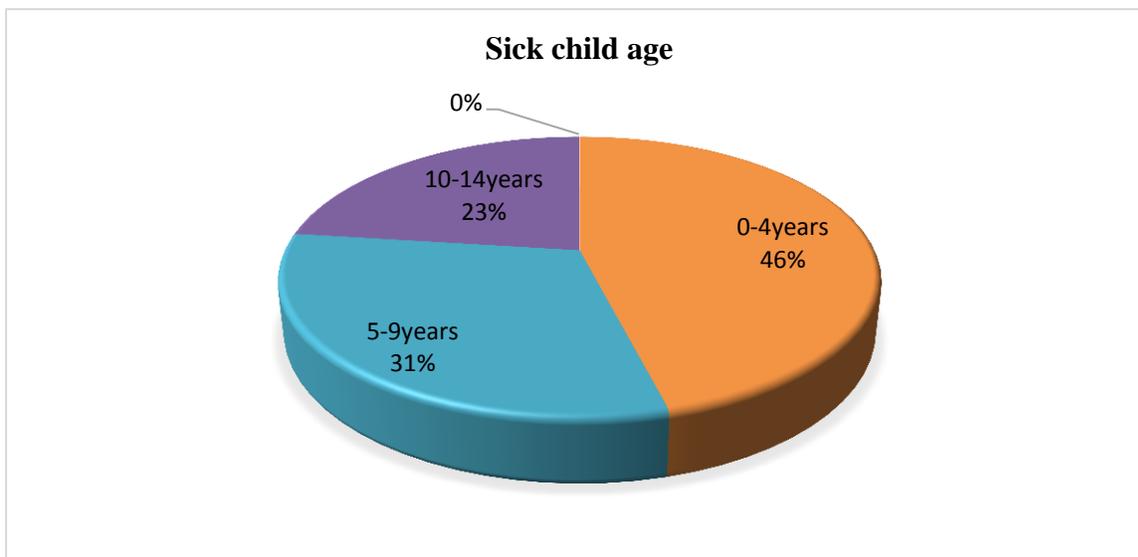
scores and demographic characteristic of the parents. The results are presented in table 4.2 below.

**Table 4.2: Correlation between the caregivers' Demographic characteristics and the ZBI Scores**

Variables		Burden score category				p- value
		Mild	Moderate	Severe	Total	
Ages of caregivers	10-19	0	0	1		0.979
	20-29	2	10	13	25	
	30-39	2	9	15	26	
	40-59	2	7	13	22	
caregiver's gender	Male	3	6	11	20	0.629
	Female	3	20	31	54	
Marital status	Single	1	5	8	14	0.837
	Married	5	20	31	57	
	Divorced	0	1	0	1	
	Separated	0	0	2	2	

**4.3.1 The Children's age**

Majority of the children 46% (n=34) were of age between 0 and 4 years. The results are presented on figure 4.1 below.



**Figure 4.1: Children's Ages**

**4.3.2 The Sick Children's Birth Order**

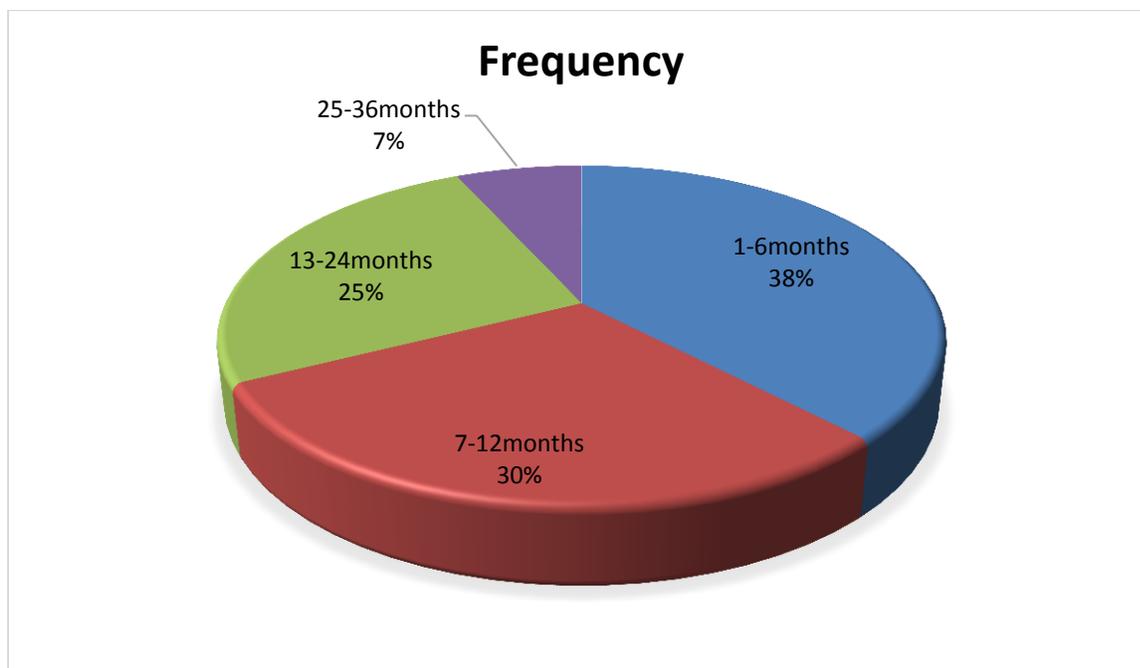
Most of the children 43% (n=32) were the first borns to their parents, 30% (n=22) were second borns and only 1% (n=) was the fifth born. Results were presented in table 4.3 below.

**Table 1.3: Child's Birth Order**

Birth order	Frequency(n)	Percentage (%)
1st born	32	43
2nd born	22	30
3rd born	14	19
4th born	5	7
5th born	1	1
Total	74	100

**4.3.3 Number of Months since Child's Diagnosis**

The study revealed that most participants had children diagnosed with cancer for a period of 0-6 months 37.8% (n=28) and only 6.8% (n=5) have had the cancer between 25-36 months. The findings are presented on figure 4.2.



*Figure 4.2: Duration of Diagnosis*

**4.3.4 Parent's Views on Treatment Outcomes**

Forty two percent (n=31) respondents graded the treatment outcome of their children as good and only 12% (n=9) reported poor prognosis. The findings are in table 4.4 below.

*Table 4.4: Treatment Outcomes*

<b>Treatment Outcome</b>	<b>Frequency (n)</b>	<b>Percent (%)</b>
Excellent	17	23
Very good	17	23
Good	31	42
Poor	9	12
Total	74	100

Bivariate analysis was further done to determine the relationship between caregiver's burden and children's characteristics, it revealed that more than half of the caregivers 52% (n=22) with children aged between 0 and 4 years reported severe caregiver burden. The chi square test did not reveal any statistical significance between the two variables. Results were presented in table 4.5.

**Table 4.5: Association of the ZBI Scores and Children's Characteristics**

Variables		Burden score category (N=74)				P values
		Mild	Moderate	Severe	Total	
Age of children	0-4	2	10	22	34	0.441
	5-9	1	10	12	23	
	9-14	3	6	8	17	
Birth order	First	3	11	18	33	0.959
	Second	2	7	13	22	
	Third	1	5	8	14	
	Forth	0	2	3	5	
	Fifth	0	1	0	1	
Duration of cancer diagnosis	0-6months	2	9	17	28	0.752
	7-12months	1	8	13	22	
	13-24months	3	6	10	19	
	25-23 months	0	3	2	5	

#### 4.3.5 Social Concerns of the Caregivers

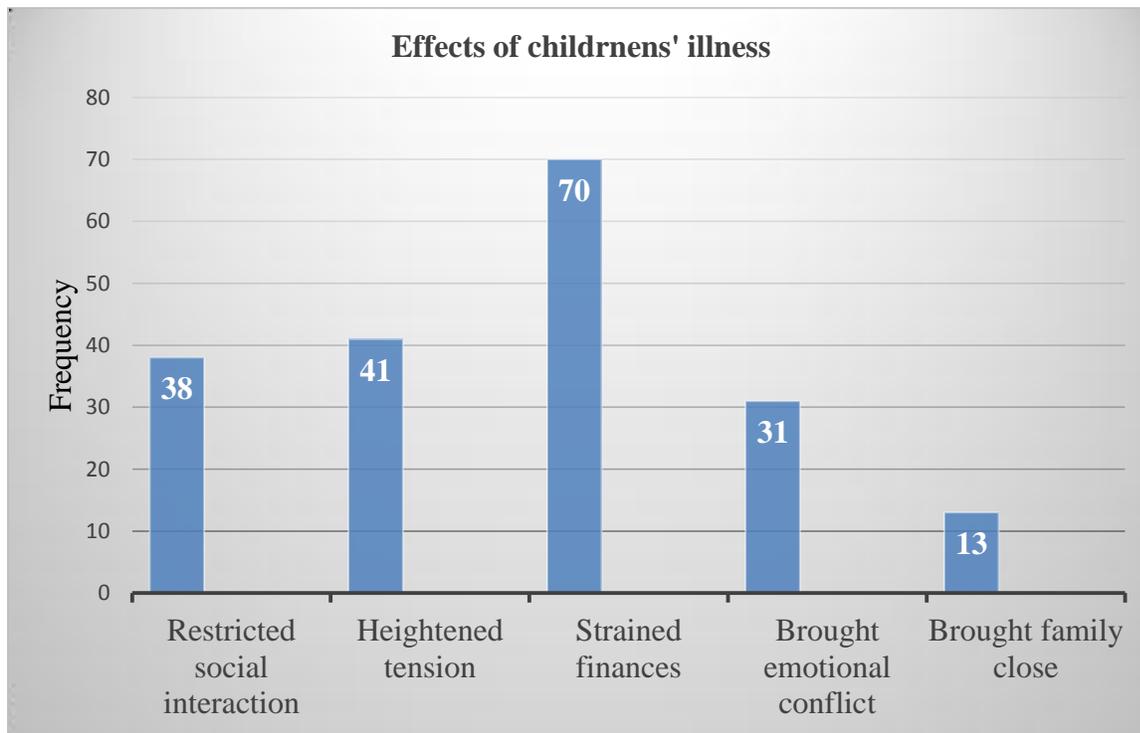
Most of the respondents 35% (n=26) had two children and only 4% (n=3) had 5 children. Most of the caregivers 74% (n=55) had children who optimally depended on them. More than half 54% (n=40) of the caregivers reported to have spent more than a month in hospital as they cared for the sick child. The above results have been shown in table 4.6 below.

**Table 4.6: Caregiver's Social status N=74**

Variables		Frequency (n)	Percentage %
Number of children	1	16	22
	2	26	35
	3	14	19
	4	15	20
	5	3	4
Time spent in the hospital	0-7days	2	3
	1week	7	9
	2weeks	6	8
	3weeks	3	4
	1month	16	22
	More than a month	40	54

#### 4.3.6 Effects of the Child's Illness on the Family Unit

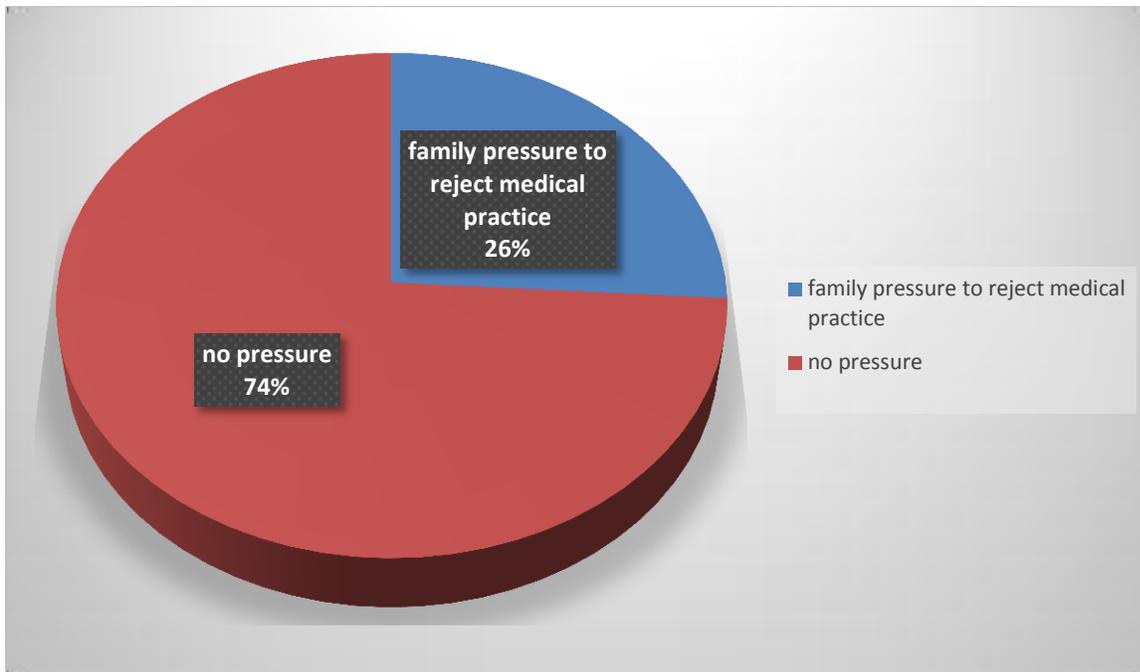
Majority of the respondents 95% (n=70) reported that the child's illness caused a strain in finances, more than half 55% (n=41), 51% (n=38) reported increased tension and restriction on their social interaction respectively. The results are presented in figure 4.3 below.



*Figure 4.3: Effects of the child's illness on the Family Unit*

#### 4.3.7 Family Pressure to Reject Medicine

Figure 4.4 shows the respondents who received pressure from family members to reject therapeutic practices and they were 26% (n=19)



*Figure 3.4: Family Pressure to Reject Medical Practices*

#### **4.4 Caregiver Burden among the caregivers of Children Diagnosed with Cancer at KNH.**

##### **4.4.1 Zarit Burden Interview Score Categories**

The ZBI score is a scale used to determine caregivers' burden through a score that is rated. The range between 0-88, with scales of 0-20 indicating no burden, 21-40 for mild burden, 41-60 for moderate to severe burden and finally 61-80 for severe burden. In this particular study, the minimum ZBI score was 28 and the maximum was 79, the average score (mean) was 58.6 which revealed moderate to severe caregiver burden. The standard deviation was 11.25 and median of 61. Findings are presented in table 4.7 below.

**Table 4.7: Statistics of the ZBI Scores**

	<b>Statistics (N=74)</b>	<b>Value</b>
<b>Measure of central tendency</b>	Mean	58.675
	Median	61.000
	Mode	61.00
<b>Measure of dispersion</b>	Standard deviation	11.258
	Variance	126.743
	Range	51.00
	Minimum score	28.00
	Maximum score	79.00

#### **4.4.2 The Respondent’s Categorical Scores of the ZBI.**

Majority of the respondents 74% (n=42) reported severe caregiver burden, 35% (n=26) reported moderate burden, 8% (n=6) experienced mild burden and none of the respondents reported no burden at all. The above results are represented in table 4.8 below.

**Table 4.8: Respondents’ Categorical Scores of the ZBI.**

<b>Burden</b>	<b>Frequency (n)</b>	<b>Percentage (%)</b>
None	0	0
Mild	6	8.1
Moderate-severe	26	35.1
Severe	42	58.6
Total	74	100

## 4.5 Economic Status and concerns of Caregivers that Influence Caregiver Burden.

### 4.5.1 Employment status of the Respondents

Majority of the respondents 93% (n=69) were casually employed, though more than half 70% (n=52) abandoned their work since the child started on cancer treatment and only 7% (n=5) continued to work. More than half of the respondents earned between 0-5000 Kenyan shillings (Ksh). The results are represented in table 4.9 below.

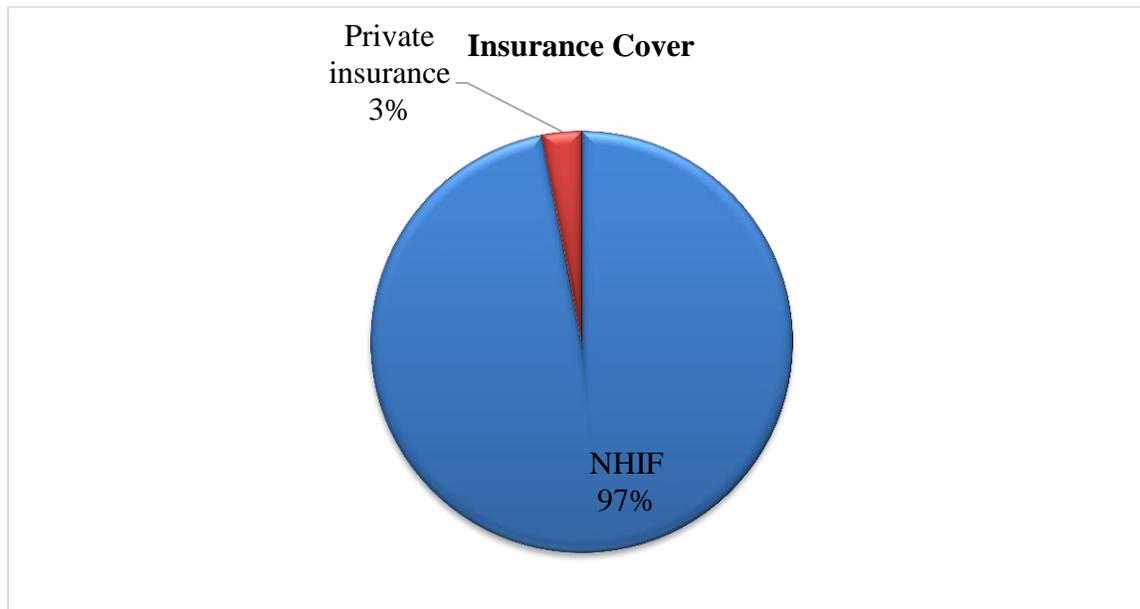
**Table 4.9: Economic Status of the Caregivers**

Variables		Frequency (n)	Percentage (%)
Employment	Regular/permanent	5	7
	Causal employment	69	93
Status of the job	Continue to work	7	9.5
	Paid leave	4	5.5
	Unpaid leave	11	14.8
	Abandoned work	52	70.2
	Total	74	100
	Monthly income	0-5000 Ksh	38
5001-10000Ksh		12	16
10001-15000Ksh		10	14
15001-20000Ksh		4	5
20001-25000Ksh		5	8
25001-30000Ksh		3	4
Above 30000Ksh		2	2
Total		74	100

### 4.5.2 Insurance Coverage

The insured respondents were 89% (n=65), 97% (n=63) of these were insured with NHIF and 3% (n=2) had private insurance. Those who reported complete payments of the hospital bills by the insurance company were only 3% (n=2). Despite many being insured with the National

Hospital Insurance Fund (NHIF), majority 86% (n=64) reported failure to pay the child's hospital bills and only 14% (n=10) reported ability to pay all hospital bills. The findings are represented on figure 4.5 below.



**Figure 4.5: Insurance Coverage**

Bivariate analysis was further done to determine the relationship between caregiver's burden the economic status of the respondents. This revealed that most 69% (n=29) of those who had abandoned their work suffered severe caregiver burden. The chi square test did not reveal a significant relationship between caregiver burden and economic status of the caregivers. The findings are presented in table 4.10.

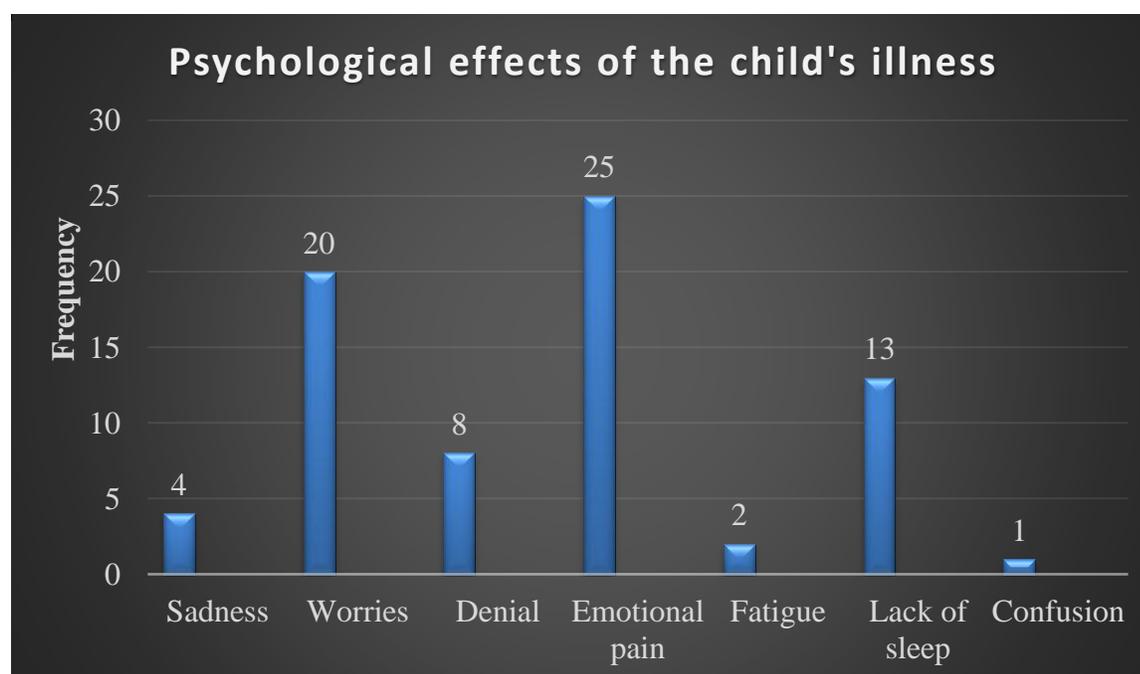
**Table 4.10: Association of the ZBI Score and the Parent's Economic Status**

Variables		Burden score category (N=74)				
		Mild	Moderate	Severe	Total	p-value
Employment	Regular/permanent	0	0	1	1	0.979
	Causal employment	2	10	13	25	
Status of job	Continue to work	2	0	5	7	0.297
	Paid leave	0	1	3	4	
	Unpaid leave	0	6	5	11	
	Abandoned work	5	18	29	52	
Covered with health insurance	Yes	6	22	37	65	0.72
	No	0	4	5	9	

#### **4.6 Psychological Effects of Caring of Children Diagnosed with Cancer at KNH among the Caregivers.**

##### **4.6.1 Psychological Effects of the Child's Illness on the Caregivers**

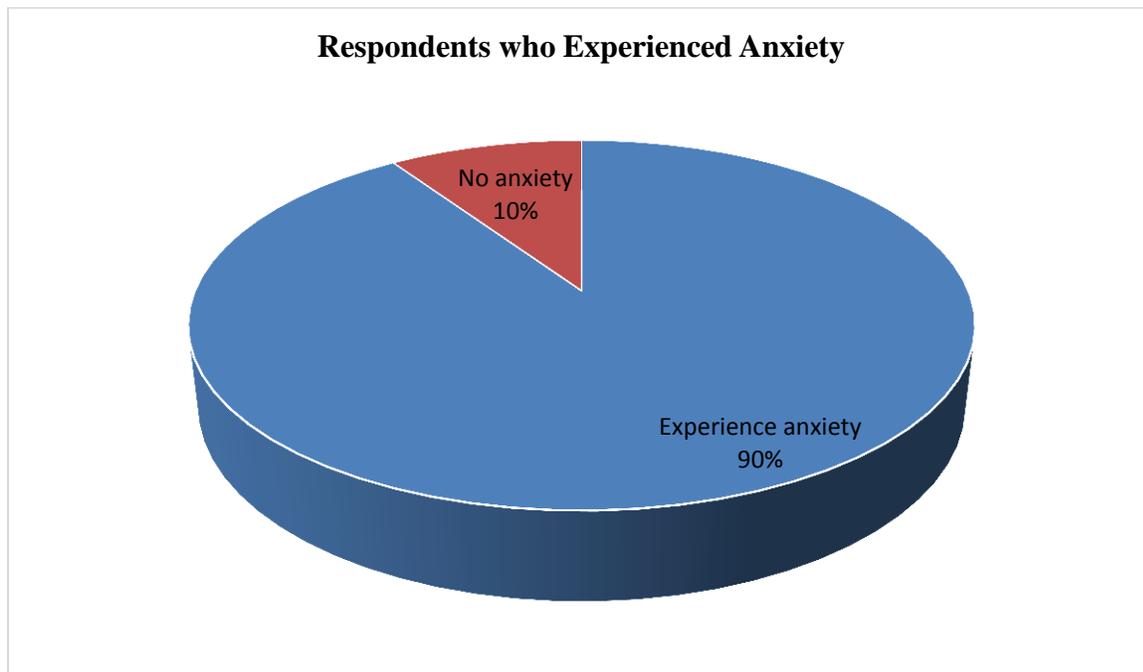
The child's illness psychologically affected the respondents in many ways; sadness, worries, denial, emotional pain, fatigue, lack of sleep, and if also caused confusion. The findings are summarized in figure 4.6 below.



**Figure 4.6: Psychological Effects of the Child's Illness on the Caregivers.**

#### **4.6.2 Caregiver's Report on Anxiety**

Majority of the respondents 90.5% (n=67) experienced anxiety due to their child's illness and this manifested in different ways. Only 9.5% (n=7) did not report anxiety due to the child's illness. The results were presented on figure 4.7 below.

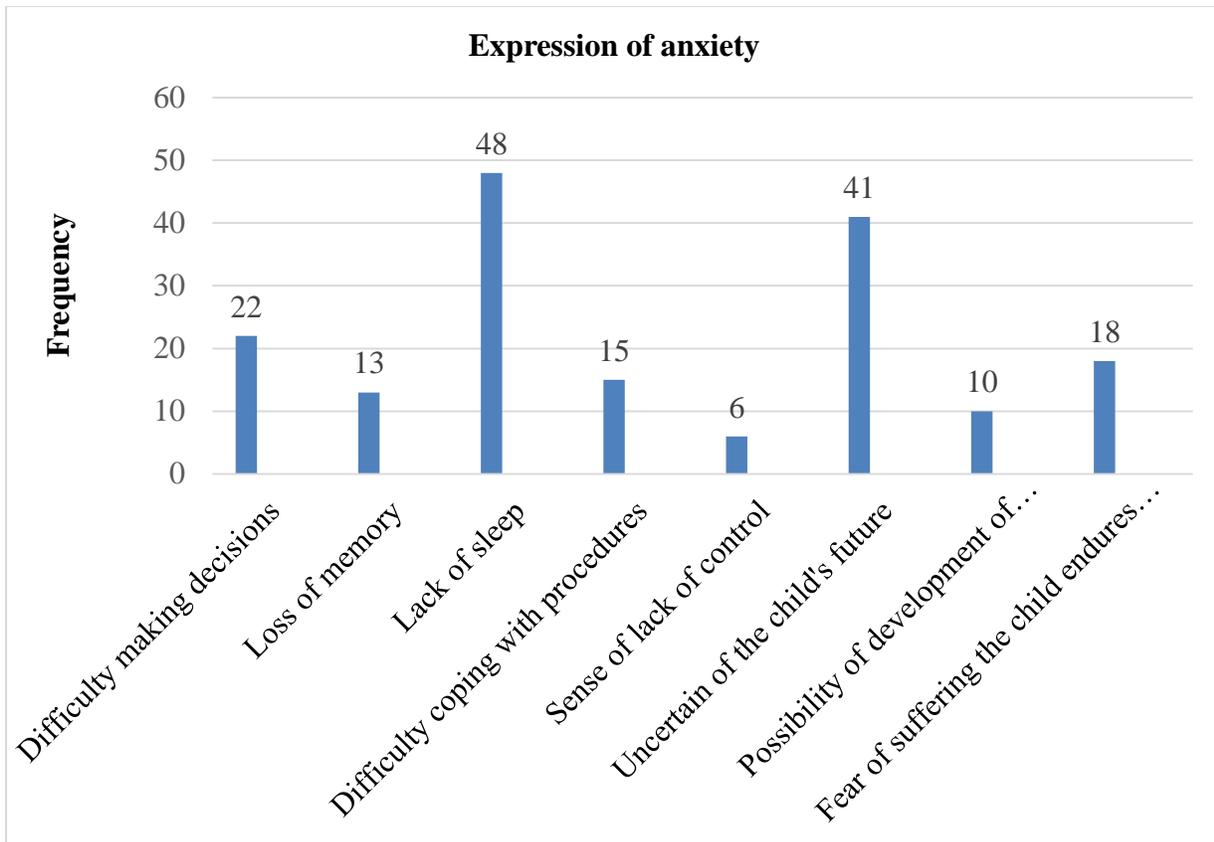


**Figure 4.7: Caregivers who Reported Anxiety**

#### **4.6.3 Factors Associated to caregiver's Anxiety**

Most of the respondents 65% (n=48) reported lack of sleep due to the child's illness. More than half 55% (n=41) were uncertain of their child's and only 8% (n=6) reported lack of sense of control brought about by the child's illness.

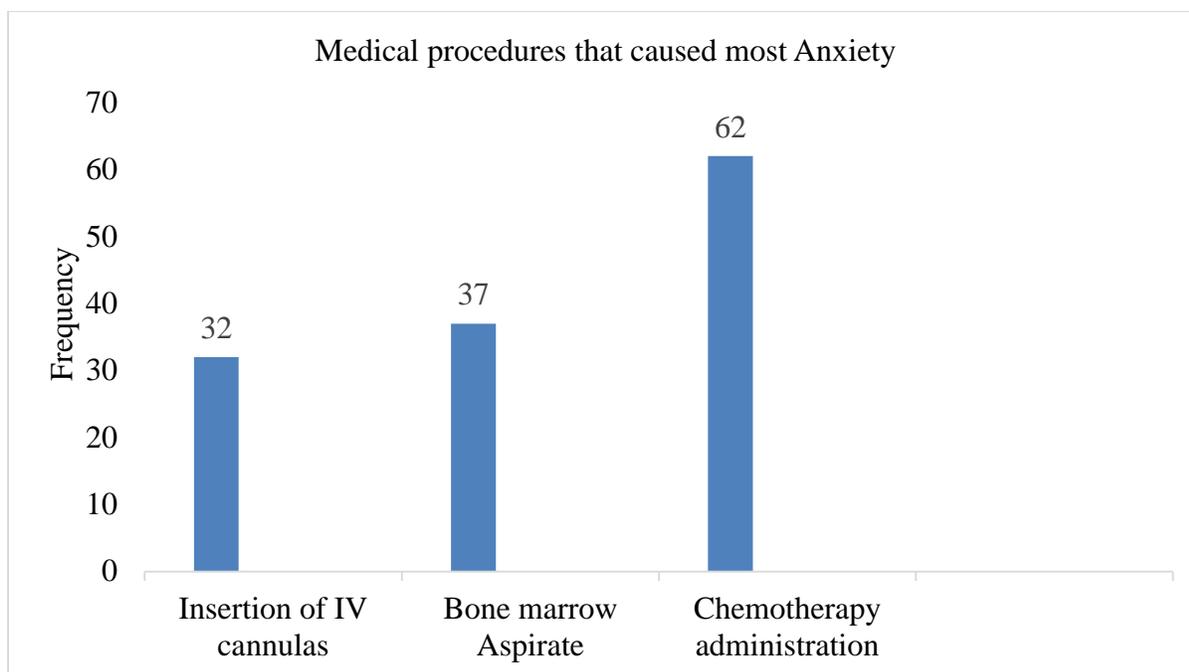
The results were presented in figure 4.8 below.



**Figure 4.8: Expression of Anxiety by the Caregivers**

**4.6.4 Medical Procedures that caused most anxiety to the Caregivers.**

Majority of the respondents 84% (n=62) reported that they were always anxious when their children were receiving chemotherapy. Half of the respondents 50% (n=37) were distressed by bone marrow aspiration. The results are presented in figure 4.9 below.



**Figure 4.9: Medical Procedures that caused most anxiety among caregivers**

Bivariate analysis was further done to show the relationship between the caregiver’s burden and the procedure performed and this revealed that chemotherapy administration caused severe caregiver burden to most of the caregivers though the chi-square test didn’t reveal a significant relationship. The results showed that there was a significant relationship between the caregiver burden and insertion on intravenous cannulas at a p-value of 0.028. Results are presented in table 4.11 below.

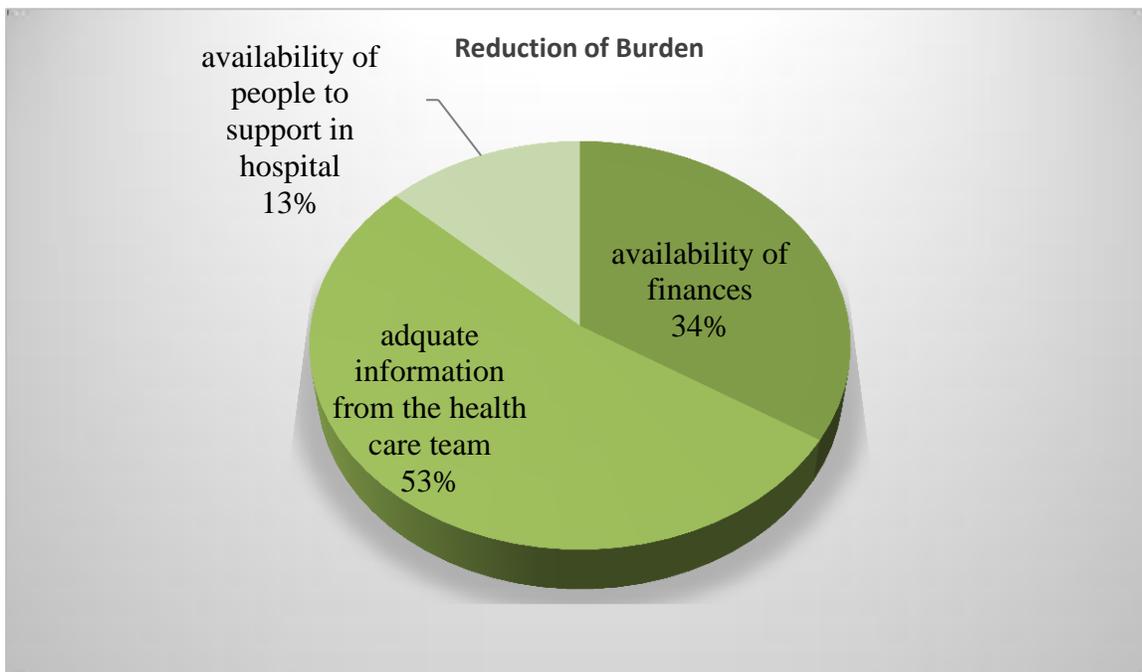
**Table 4.11: Association between the ZBI Scores and the Performed Procedures.**

PROCEDURE		Burden score category ( )			P values
		Mild	Moderate	Severe	
Putting IV cannula	Yes	1	16	15	0.028
	No	6	6	26	
Bone marrow aspirate	Yes	3	14	20	0.677
	No	4	10	21	
Chemotherapy administration	Yes	5	21	35	0.968
	No	1	4	6	

#### 4.6.5 Caregiver Suggestions on how to Reduce Burden

More than half 53% (n=39) of the respondents reported that adequate information from the health care team would help reduce the burden. Results are presented on figure 4.10 below.

*Figure 4.10 Caregivers Suggestions on Burden Reduction*



#### 4.7 Hypothesis Testing

The which stated that “There was no relationship between economic status and the degree of burden among caregivers of children diagnosed with cancer at KNH” was accepted since the p values from the statistical association of the variables was greater than 0.05 as shown in table 4.12 below.

**Table 4.12: Hypothesis Testing ‘Association of the ZBI Score and the Caregiver’s Economic Effects’**

Variable		Burden score category				
		Mild	Moderate	Severe	Total	p-value
Status of job	Continue to work	2	0	5	7	0.297
	Paid leave	0	1	3	4	
	Unpaid leave	0	6	5	11	
	Abandoned work	5	18	29	52	
	<b>Total</b>	<b>7</b>	<b>25</b>	<b>42</b>	<b>74</b>	

# CHAPTER FIVE: DISCUSSION, CONCLUSION AND RECOMMENDATION

## 5.1 Introduction

This chapter discusses the findings of the assessment on caregiver burden and its associated factors among parents of children suffering from cancer in KNH. The discussion goes as follows: social-demographic characteristics of the caregivers and the children, caregiver burden, the economic concerns of caring on the caregivers and psychological effects that influence caregiver burden.

## 5.2 Discussion

### 5.2.1 Social Demographic Characteristics of the Study Population

In this study majority 73% of the caregivers were females and mostly middle aged. These findings were consistent with Naidoo *et al*, (2016) that mothers contribute more to the family caring role and varied with Nguyen, 2015 were majority of the cancer caregivers were males. The results further revealed that the females in this age range still suffered more severe caregiver burden, this could probably be due to the great emotional attachment of mother and child. Further consistent with Motlagh *et al*, (2019) who reported that younger caregivers have scanty of experiences to help them use supportive resources and not financially stable which contribute to a higher level of care burden.

Most 46% of the children with cancer in this study were aged between 0 and 4 years this was consistence with the past reports from the United States of America (USA); Siegel *et al.*, (2018), US Cancer Statistics (2017) and Ward *et al.*, (2014) were pediatric cancers were diagnosed at the same age and lesser in those aged between 5 to 9 years. The findings varied with Enobong *et al.*, (2015), were the prevalence of cancer in Nigerian children was more in children aged between 5-

10 years. Most 37.8% of children were diagnosed with the cancer within a period of six months, this could probably be a reason for the increased care burden as Wang *et al.*,(2017) also reported that there exists a higher care burden in the caregivers of children who are newly diagnosed with cancer.

More than half 57% of the respondents were married and had other children who also optimally depended on them, these were left either with their fathers or grandparents as the mothers had to attend to the child in hospital for more than a month. This could also have contributed to the increased caregiver burden as mothers have to coordinate even the home affairs as in line with Naidoo *et al.*, (2016) study that was conducted in Nigeria. More than half 51% of the respondents also reported restricted social interactions for a long period of time, this concurred with a study that was done in Morocco where 65% of the caregivers were no longer socializing and they had neglected their families (Lkhoyaali *et al.*, 2015). Deniz H, & Inci 2015, in their study of burden of care and quality of life in leukemic children they found out that the less care time the parents had the lower the care burden. In this study caregivers provided 24 hours care more than a month which contributes to a higher caregiver burden.

The lack of significance between the socio-demographic characteristics and caregiver burden in this study could be attributed to the parental attachment and consistence of the study population. The caregivers of children with cancer suffer a great magnitude of care burden and there is need for the health care professionals to critically examine and provide educational sessions to reduce the burden.

### **5.2.2 Degree of Caregiver's Burden among Caregivers of Children Diagnosed with Cancer at KNH**

The degree of burden among the study population on average was moderate to severe (ZBI Score 58.3) with majority 74% scoring severe caregiver burden. This was far beyond the normal levels

according to Wang *et al.*,(2017) who reported only 12% of caregivers had severe care burden and Kahrima and Zaybak (2015) where 50% of the care givers had mild burden and only 7.5% reported severe caregiver burden, the latter related these low burden scores to the Turkish culture that it's only natural for the relative to assist care for their sick relative and due to the motherly instincts the mothers of children with cancer don't suffer severe caregiver burden.

The findings of this study were in line with the results from Nigeria where the caregivers had an average score of 50.8 which revealed moderate to severe caregiver burden (Oyegbile and Brysiewicz, 2017) and consistent also with Nguyen, 2015 from Vietnam where the average burden score indicated moderate to severe caregiver burden, the females were most affected and none of the respondent reported no caregiver burden at all. A study in Iraq also revealed that 89% of the caregivers had moderate to severe care burden and the level of education had significant effect on the lower caregiver burden. They recommended health care providers to pay some more attention to these parents and engage them in educational programs (Motlagh *et al.*, 2019).

In this study the high care giver burden could possibly be due to the low education level which contributes to lack of employment which compromises the finances, majority of the children being young and optimally depend on their parent for everything. The caregivers were also uncertain of the children's future and what to do for them thus increasing the anxiety. Majority 84% of the caregivers were also burdened with the procedures performed in hospital especially cytotoxic drug administration this increased stress.

### **5.2.3 Economic Effects of Caring for a Child Diagnosed With Cancer at KNH.**

Majority 93% of the respondents had casual employment were they earned approximately between 0- 5000 Kenyan shillings per month and had abandoned work in order to attend to the sick child in hospital who would be admitted for more than a month. This was in line Carrera *et*

*al.*, (2018) who mentioned that cancer care causes financial toxicity both objective and subjective. A study in the United States of America also reported that across all levels of income the caregivers' work status was interrupted, in 42% of families at least one of the parents had to quit work and the most affected were the majority and the poorest (Bona *et al.*, 2014). Motlagh *et al.*, (2019) reported that caregivers with good income have lower caregiver burden reason being that they can better support their families and also avail excellent treatment for the ill child.

The low income state of the respondents in this study could have caused significant caregiver burden among the respondents. These caregivers must travel, feed and also provide for the family left at home and yet the cancer care is also way very expensive.

Majority 97% of the respondents reported to be insured with the National Hospital Insurance Fund although the treatment costs are more than what the insurance offers so the treatment bills are not fully catered for and thus not solving the financial burden that the parents experience during the care of their children. Following a review of 24 studies that confirmed family financial burden due to childhood cancer treatment, Warner *et al.*, (2014) reported the need of insurance models and the need to incorporate financial assessment in to pediatrics care models as this could contribute to better management of cancer in children. From the results of this study may be there is need for the policy maker to consider complete funding of childhood cancer treatment.

#### **5.2.4 Psychological Effects of Caring for Children Diagnosed with Cancer at KNH among the Caregivers.**

In this study, the respondents reported several emotional challenges; the most 65% reported lack of sleep which they had never experienced before their child's illness. Similar to Kazak *et al.*, (2004), their study reported that the excessive responsibilities parents undertake during caregiving process increases the chances of reactions like: anxiety, sleep disturbances and

depression. This also coincided with a study in Malaysia where the caregivers provided care for more than 20hrs per week and these were likely to develop significant stress (Daripada Penjagaan *et al.*, 2013). The reported psychological effects in this study could be probably because the caregivers did not share the caregiving responsibility with any other person in hospital and fear of their children's future. All the respondents reported to be anxious and this was still expressed by lack of sleep. The findings were also in line with the study findings in Jordan which revealed that mothers of ill children experience significant stress which makes them fail to sleep (Masa'Deh *et al.*, 2013). The respondents in this study reported to overcome the anxiety by praying and talking to church elders and friend who came to visit in the hospital.

The caregivers reported difficulty in coping with procedures done in hospital this was in line with Shiota *et al.*, (2004) that whole journey of aggressive procedures and treatment is irritating to the caregivers which increases the care burden, these procedures included: insertion of intravenous cannulas, blood transfusion and bone marrow aspiration among others. Of these there was a significant statistical relationship (p- value 0.028) between caregiver burden and insertion of intravenous cannulas. The caregivers watch the children being pricked several times in a week while taking off blood samples, giving antibiotics, for chemotherapy drugs and for parenteral feeds for those who are malnourished. This procedure is emotionally draining since it causes the children to bitterly cry and almost a daily procedure.

### **5.3 Conclusion**

Based on the findings of the study the following conclusions are drawn.

1. The participants were young with secondary level of education and low socio-economic status. Most of their sick children were aged between 0 and 4 years. All these intertwined could be the reason for the high caregiver burden.

2. The degree of caregiver's burden among the study population as measured with the ZBI scale was moderate to severe 58.3 which is way too high than the normal 0-20.
3. Strained finances which was linked to the low socio-economic status highly contributed to the caregiver burden
4. Psychologically the procedures performed on the children caused anxiety to all the respondents and there was statistical significance (P-value of 0.028) between Insertion of Intravenous into the sick children and caregiver burden.

## **5.4 Recommendation**

Using the findings of the study, health care providers can formulate a holistic and family centered program considering the factors that increase caregiver burden.

Need to strengthen the existing psychological support in KNH through family and group counseling to reduce on the burden experienced.

Policy makers need to consider full financing of pediatric cancer management through the universal health coverage.

There is need for the health care team to provide adequate education concerning diagnosis, treatment, procedures to be performed during cancer management to the care givers so as to promote cooperation and help reduce emotional distress and reduce caregiver burden.

## **5.5 Further Studies**

A qualitative study on the caregiver burden and its associated factors will clearly express the emotions that caregivers could not express on paper.

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## APPENDICE

### APPENDIX 1: APPROVAL LETTER FROM ETHICS AND RESEARCH COMMITTEE



UNIVERSITY OF NAIROBI  
COLLEGE OF HEALTH SCIENCES  
P O BOX 19676 Code 00202  
Telegrams: varsity  
Tel:(254-020) 2726300 Ext 44355

Ref: KNH-ERC/A/207

Stella Namazzi  
Reg. No. H56/8639/2017  
School of Nursing Sciences  
College of Health Sciences  
University of Nairobi

Dear Stella,

**RESEARCH PROPOSAL: BURDEN ON CAREGIVERS OF CHILDREN AND ITS ASSOCIATED FACTORS AMONG PATIENTS OF CHILDREN WITH CANCER IN KENYATTA NATIONAL HOSPITAL (P98/02/2019)**

This is to inform you that the KNH- UoN Ethics & Research Committee (KNH- UoN ERC) has reviewed and approved your above research proposal. The approval period is 31<sup>st</sup> May 2019 – 30<sup>th</sup> May 2020.

This approval is subject to compliance with the following requirements:

- a. Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
- b. All changes (amendments, deviations, violations etc.) are submitted for review and approval by KNH-UoN ERC before implementation.
- c. Death and life threatening problems and serious adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH-UoN ERC within 72 hours of notification.
- d. Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH- UoN ERC within 72 hours.
- e. Clearance for export of biological specimens must be obtained from KNH- UoN ERC for each batch of shipment.
- f. Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (*Attach a comprehensive progress report to support the renewal*).
- g. Submission of an *executive summary* report within 90 days upon completion of the study. This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/ or plagiarism.

Protect to discover



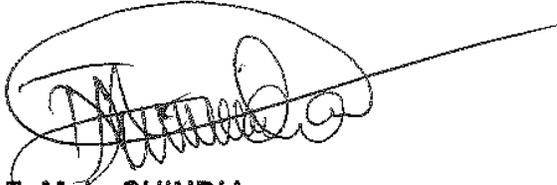
KENYATTA NATIONAL HOSPITAL  
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Tel: 726300-9  
Fax: 725272  
Telegrams: MEDSUP, Nairobi

31<sup>st</sup> May, 2019



For more details consult the KNH- UoN ERC website <http://www.erc.uonbi.ac.ke>

Yours sincerely,

A handwritten signature in black ink, appearing to read 'M. L. Chindia', is written over a horizontal line. The signature is enclosed in a hand-drawn oval.

**PROF. M. L. CHINDIA**  
**SECRETARY, KNH-UoN ERC**

c.c.      The Principal, College of Health Sciences, UoN  
            The Director, CS, KNH  
            The Chairperson, KNH- UoN ERC  
            The Assistant Director, Health Information, KNH  
            The Director, School of Nursing Sciences, UoN  
            Supervisors: Dr. Margaret Chege (UoN), Dr. Joyce Jebet (UoN)

# APPENDIX 2: LETTER OF APPROVAL FROM KNH

KNH/R&P/FORM/01



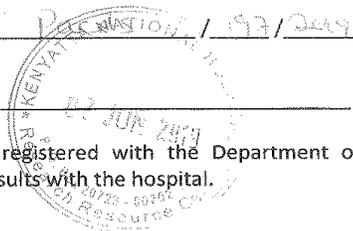
**KENYATTA NATIONAL HOSPITAL**  
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Research & Programs: Ext. 44705  
Fax: 2725272  
Email: [knhresearch@gmail.com](mailto:knhresearch@gmail.com)

## Study Registration Certificate

1. Name of the Principal Investigator/Researcher  
NAMAZZI STELLA
2. Email address: murungirichait@gmail.com Tel No. 0740869986
3. Contact person (if different from PI).....
4. Email address: ..... Tel No. ....
5. Study Title  
BURDEN ON CAREGIVERS OF CHILDREN AND ITS ASSOCIATED FACTORS AMONG PARENTS OF CHILDREN WITH CANCER IN KNH
6. Department where the study will be conducted PEDIATRICS  
(Please attach copy of Abstract)
7. Endorsed by Research Coordinator of the KNH Department where the study will be conducted.  
Name: ..... Signature ..... Date .....
8. Endorsed by KNH Head of Department where study will be conducted.  
Name: Makau Signature DMN Date 6/6/19
9. KNH UoN Ethics Research Committee approved study number P98/02/2019  
(Please attach copy of ERC approval)
10. I NAMAZZI STELLA commit to submit a report of my study findings to the Department where the study will be conducted and to the Department of Research and Programs.  
Signature..... [Signature] Date 02 June 2019
11. Study Registration number (Dept/Number/Year) PEDIATRICS / 97 / 2019  
(To be completed by Research and Programs Department)
12. Research and Program Stamp \_\_\_\_\_

All studies conducted at Kenyatta National Hospital **must** be registered with the Department of Research and Programs and investigators **must commit** to share results with the hospital.



## **APPENDIX 3: ENGLISH INFORMATION DOCUMENT**

**Title of the study:** Burden on caregivers of children and its associated factors among parents of children suffering from cancer in Kenyatta National

**Researcher:** Namazzi Stella (Master of Science in Nursing student, Year II)

**Institution of Study:** University of Nairobi

**Study sponsor:** Uganda Cancer Institute

### **I. Introduction to the study**

You are invited to fill in the questionnaire as a part of a research study, carried out by Namazzi Stella who is a student pursuing Master of Science in Nursing (Oncology) “cancer”, at the University of Nairobi. The research will be carried at the children’s wards, in KNH in the month of May 2019. The purpose of this research study is to assess the burden on caregivers of children and its associate factors among parents of children suffering from cancer in KNH

The study will shed light on the different experiences and help create strategies to alleviate any negative effect of the child’s illness on the parent.

You are being invited to take part because your child is suffering from cancer you may be having experiences that can guide in acquiring the information that is relevant.

Approximately 74 parents will participate in the study.

This consent form gives you information about the study, the risks and benefits, and the process will be explained to you. Once you understand the study, and if you agree to take part, you will be asked to sign your name or use your thumb finger to put a mark (thumbprint) on the consent form.

### **II. Study Objective**

The study objective is to determine the burden on caregivers of children and its associated factors among parents of children suffering from cancer at Kenyatta National Hospital. The specific areas of study include: To explore the caregiver burden, demographic characteristics of the parents and the ill child, economic and psychosocial factors that influence caregiving burden

### **III. Benefits of the study**

Regarding benefits, there may not be any direct benefits for participants. The parents who will express severe burden and psychological distress during the study will be referred for psychological counselling services at ward 1E in KNH. Group therapy or one on one therapy with a counsellor will be recommended

The information collected will help shed light on caregiver burden that is emotional, financial and physical. These results could be used to come up with strategies to improve the negative effects of caregiving. The findings of the study could be used for planning and designing appropriate interventions by the Ministry of Health, Non-Governmental Organizations and other stakeholders.

### **IV. Risks**

There are minimal risks to you for participating in this study. One potential risk is psychological distress

### **V. Procedures**

If you agree to participate in this, study know that there is only one approach:

Filling in the questionnaire which has sections.

#### **i) Questionnaire**

You shall be asked to read and understand all the questions before answering them. The questionnaires will be numbered (coded) thus you will not be required to give any personal information like writing your name. The questionnaire will contain both open and close ended

questions. You may also be guided by the researcher or the assistant to respond to the questions appropriately. Filling in a questionnaire will take between 30-40 minutes. The questionnaire will be divided into different sections to gather information on socio-economic history, social concerns, psychological factors, demographic data of parents and some information on child characteristics and degree of caregiver burden

## **VI. Compensation**

There shall be no monetary rewards for the participants in this study.

## **VII. Voluntary Participation and Withdrawal**

Please, your participation is entirely voluntary. Should you change your mind, you have the right to drop out at any time without facing any consequences. You may skip questions or stop participating at any time.

## **VIII. Sharing the results**

The results of this study may be presented during scientific and academic forums and may be published in scientific journals and academic papers

## **IX. Confidentiality**

You will not be required to write your name or to give any personal identification in the questionnaire there will be no way to identify individual participants. There shall not be use of any information that would make it possible for anyone to identify you in any presentations or written reports about this.

## **X. Contact Persons**

Name and role	Institution	Contact
Namazzi Stella(researcher)	University of Nairobi Nursing school	Tel: 0740-869986, Email- <a href="mailto:murungi4christ@gmail.com">murungi4christ@gmail.com</a>
DR. Margret Chege (Lead supervisor)	University of Nairobi Nursing school	Email- <a href="mailto:margret.chege@gmail.com">margret.chege@gmail.com</a>
Dr. Joyce Jebet (second supervisor)	University of Nairobi Nursing school	Email- <a href="mailto:jjcheptum@gmail.com">jjcheptum@gmail.com</a>
Prof. M.L Chindia (Secretary)	KNH-UON Ethics and Research Committee	<a href="mailto:uonknh_erc@uonbi.ac.ke">uonknh_erc@uonbi.ac.ke</a>

**English Consent confirmation form**

I have read the consent explanation and understood its content. I have been given the opportunity to discuss all my concerns with the researcher. I have had my questions answered in language that I understand. The risks and benefits have been explained to me. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I understand that all efforts will be made to keep information regarding my personal identity confidential.

I understand that by signing this consent form, I have not given up any of the legal rights that I have as a participant in a research study.

**I agree to participate in this research study: Yes No**

I agree to fill in the questionnaire Yes No

**Participant signature/ Thumb stamp ----- Date-----**

**Participants' printed name ----- Date -----**

**Researcher's statement**

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

Researchers Name: -----Signature ----- Date -----

Role in the study-----

Witness Name -----Signature----- Date: -----

Witness contact: Tel Number: ----- P. O Box ----- Email -----

## **APPENDIX 4: MAELEZO YA UKUZAJI**

**Kichwa cha utafiti:** Mzigo juu ya walezi wa watoto na sababu zake zinazohusiana kati ya wazazi wa watoto wanaosumbuliwa na kansa katika hospitali ya Taifa ya Kenyatta.

**Mtafiti:** Namazzi Stella (Mwanafunzi wa shahada ya pili ya Uuguzi, Mwaka wa II)

**Taasisi ya Utafiti:** Chuo Kikuu cha Nairobi

**Mdhamini wa utafiti:** Taasisi ya Kansa ya Uganda

### **I. Utangulizi wa utafiti**

Unakaribishwa kujaza dodoso kama sehemu ya utafiti unaofanywa na Namazzi Stella ambaye ni mwanafunzi wa shahada ya pili katika Uuguzi (Oncology) "kansa", katika Chuo Kikuu cha Nairobi. Utafiti utafanyika katika kata za watoto, katika hospitali ya Taifa ya Kenyatta (KNH) mwezi wa Mei 2019. Kusudi la utafiti huu ni kuchunguza mzigo juu ya walezi wa watoto na mambo yanayohusiana nao kati ya wazazi wa watoto wanaosumbuliwa na kansa huku KNH.

Utafiti utaelekeza juu ya uzoefu tofauti na kusaidia kujenga mikakati ya kupunguza athari yoyote ya ugonjwa wa mtoto kwa mzazi.

Unakaribishwa kushiriki kwa sababu mtoto wako anaishi na saratani na unaweza kuwa na uzoefu ambao unaweza kuongoza katika kupata taarifa inayofaa.

Takribani wazazi 74 watahiriki katika utafiti.

Fomu hii ya idhini inakupa taarifa kuhusu utafiti, hatari na faida, na mchakato utaelezewa kwako. Mara tu unapoelewa kujifunza, na ikiwa unakubali kushiriki, utaulizwa kusaini jina lako au kutumia kidole chako kuweka alama kwenye fomu ya kibali

### **II. Lengo la utafiti**

Lengo la utafiti ni kuamua mzigo juu ya walezi wa watoto na mambo yanayohusishwa kati ya wazazi wa watoto wanaosumbuliwa na kansa katika Hospitali ya Taifa ya Kenyatta. Maeneo maalum ya utafiti ni pamoja na: Kuchunguza mzigo wa mlezi, tabia za idadi ya watu ya wazazi na mtoto mgonjwa, mambo ya kiuchumi na ya kisaikolojia ambayo huathiri mzigo wa kujitunza.

### **III. Faida za utafiti**

Wazazi ambao wataeleza mzigo mzito na dhiki ya kisaikologia wakati wa utafiti watatumwa kwa huduma za ushauri wa kisaikologia. Taarifa zitakazokusanywa zitatumiwa kuweka mikakati ya kupunguza madhara mabaya yanayo tokana na huduma. Matokeo ya utafiti inaweza kutumika kwa ajili ya kupanga na kubuni mipango sahihi na Wizara ya Afya, mashirika yasiyo ya Serikali na wadau wengine.

#### **IV. Hatari**

Kuna hatari ndogo kwako kwa kushiriki katika utafiti huu. Hatari moja ya dhiki ya kisaikolojia.

#### **V. Utaratibu**

Ikiwa unakubali kushiriki katika huu utafiti, jua kwamba kuna njia moja tu:

Kujaza katika dodoso ambayo ina sehemu kadhaa.

##### **i) Swala la Maswali**

Utaombwa kuisoma na kuelewa maswali yote kabla ya kujibu. Maswali haya yatahesabiwa na namba maalum hivyo hautahitajika kutoa taarifa yoyote ya kibinafsi kama kuandika jina lako. Jarida hilo litakuwa na maswali mawili yaliyo wazi na ya karibu. Unaweza pia kuongozwa na mtafiti au msaidizi kujibu maswali kwa usahihi. Kujaza katika dodoso itachukua kati ya dakika 30-40. Jarida hilo litagawanywa katika sehemu tofauti ili kukusanya taarifa juu ya historia ya kijamii na kiuchumi, wasiwasi wa kijamii, sababu za kisaikolojia, data ya idadi ya wazazi na habari fulani juu ya tabia za watoto na mzigo wa mlezi.

#### **VI. Fidia**

Hakutakuwa na malipo ya fedha kwa washiriki katika utafiti huu.

#### **VII. Kushiriki kwa hiari na Kuondolewa**

Ushiriki wako ni kwa hiari. Kama utabadilisha mawazo yako, una haki ya kuacha wakati wowote bila kukabiliana na matokeo yoyote. Unaweza kuruka maswali au kuacha kushiriki wakati wowote.

#### **VIII. Kushiriki matokeo**

Matokeo ya utafiti huu yanaweza kutolewa wakati wa vikao vya kisayansi na vya kitaaluma na inaweza kuchapishwa katika majarida ya kisayansi na karatasi za kitaaluma.

## IX. Usiri

Hautahitajika kuandika jina lako au kutoa kitambulisho chochote cha kibinafsi katika swala la maswali. Haitatumia habari yoyote ambayo inawezekukutambulisha kama mshirika wa utafiti..

## X. Watu wa Mawasiliano

Jina na jukumu	Taasisi	Wasiliana
Namazzi Stella (mtafiti)	Chuo Kikuu cha Nairobi Shule ya uuguzi Simu: 0740-869986,	Barua pepe- <a href="mailto:murungi4christ@gmail.com">murungi4christ@gmail.com</a>
DR. Margret Chege (Msimamizi Mkuu)	Chuo Kikuu cha Nairobi Shule ya uuguzi	Barua pepe- <a href="mailto:margret.chege@gmail.com">margret.chege@gmail.com</a>
Dr Joyce Jebet (msimamizi wa pili)	Chuo Kikuu cha Nairobi Shule ya uuguzi	Barua pepe- <a href="mailto:jjcheptum@gmail.com">jjcheptum@gmail.com</a>
Prof. M. Chindia (Katibu)	Kamati ya Maadili na Utafiti wa KNH-UON	Barua pepe- <a href="mailto:uonknh_erc@uonbi.ac.ke">uonknh_erc@uonbi.ac.ke</a>

## Fomu ya uthibitisho

Nimesoma maelezo ya ridhaa na kuelewa maudhui yake. Nimepewa fursa ya kujadili wasiwasi wangu wote na mtafiti. Nimekuwa na maswali yangu akajibu kwa lugha ambayo ninaelewa. Hatari na faida zimeelezwa kwangu. Ninaelewa kwamba ushiriki wangu katika utafiti huu ni hiari na ninaweza kujiondoa wakati wowote. Ninaelewa kwamba jitihada zote zitafanywa kuweka taarifa kuhusu utambulisho wangu binafsi.

Ninaelewa kuwa kwa kusaini fomu hii ya kibali, sijaacha haki yoyote ya kisheria ambayo ninayo kama mshiriki katika utafiti huu.

**Nakubali kushiriki katika utafiti huu: Ndiyo Hapana**

**Nakubali kujaza maswali ya utafiti huu: Ndio Hapana**

**Sahihi**-----

**Tarehe** -----

-

**Jina la kuchapishwa kwa washiriki** ----- **Tarehe** -----

**Taarifa ya Mtafiti**

Mimi kama mtafiti mkuu nimeelezea kikamilifu maelezo muhimu ya utafiti huu kwa mshiriki aliyechaguliwa hapo juu na kuamini kwamba mshiriki ameelewa na ametoa kwa hiari ridhaa yake.

Jina la mtafiti: ----- Saini ----- Tarehe -----

Jukumu katika utafiti -----

Jina la Shahidi ----- Saini ----- Tarehe: -----

Nambari ya simu ya shahidi ----- P. O Box ----- Barua pepe -----

## APPENDIX 5: ENGLISH QUESTIONNAIRE

### Directions for completing the questionnaire

- Before filling in this questionnaire, we are requesting you to read, understand and sign the attached consent for Please do not write your name in any of the pages of the questionnaire.
- Please read carefully the instructions at the beginning of each section of the questionnaire before answering the questions in that section
- Please answer all the questions in each section if possible

### Demographic data (Choose one response only)

Questionnaire code number

1. What is your Age in years?  
a) 10-19 [ ]   b) 20-29 [ ]   c) 30-39 [ ]   d) 40-49 [ ]  
e) 50-59 [ ]   f) Over 60 years [ ]
2. What is your gender?  
Male [ ]                      Female [ ]
3. Marital Status?  
Single [ ]  
Married [ ]  
Divorced [ ]  
Separated [ ]
4. Where do you live?  
Nairobi [ ]  
Others, please explain.....
5. Do you incur transport costs to bring the child to hospital?  
Yes [ ]      No [ ]  
If yes approximately how much per month?  
.....

### Child's Characteristics

6. What is your sick child's age in years?

Please specify .....

7. How many children do you have?

Please specify.....

8. If you have more than one child, please tell me this sick child's birth order in the family /

.....

9. Is it the first time the child is diagnosed with cancer?

YES [ ]                      NO [ ]

If No, please specify if relapse

Relapse once [ ]

Relapse more than once [ ]

10. What is the length of time in months since the child was diagnose with cancer?

1-6 months [ ]

7-12 months [ ]

13- 24 months [ ]

25- 36 months [ ]

More than 36 months [ ]

11. In your view what is the outcome of your child treatment? ( choose the most appropriate)

Excellent [ ]

Very good [ ]

Good [ ]

Fair [ ]

Poor [ ]

### **Social Concerns**

12. Do you have other children who optimally depend on you?

Yes [ ]                      No [ ]

If yes who helps you take care of other children while you come to hospital?

.....

13. How has the illness of your child affected the family unit?

**(Choose all that apply)**

a) It has restricted social interaction [ ]

b) It has heightened tension [ ]

c) Strained finances [ ]

d) Brought emotional conflict [ ]

e) Brought the family close [ ]

f) Others

Specify

.....

14. Have you had family pressures to reject medical practices?

YES [ ]

NO [ ]

If yes how did you respond?

.....

**Economic history (For the questions with multiple responses, choose only one)**

15. What is your highest level of formal education?

None [ ]

Primary [ ]

Secondary [ ]

College [ ]

University [ ]

16. Please tell me your occupation/ source of income?

.....

17. If employed, what is the type of engagement?

Regular/permanent employment [ ]

Casual employment [ ]

18. Kindly tell me about your job since the child's illness

Continue to work [ ]

Paid leave [ ]

Unpaid leave [ ]

Abandoned work [ ]

Others please explain.....

19. Who is the main bread winner in the sick child's house-hold?

Father [ ]

Mother [ ]

Sibling [ ]

Grandparent [ ]

Other specify .....

20. What is the family's estimated monthly income in Kenyan Shillings? Specify  
 .....
21. How many people live in the household on a regular basis?  
 .....
22. How much percentage of income is used on the child's treatment and care per month?  
 .....
23. Do you have health Insurance?  
 YES [ ]                      NO [ ]
- If yes which one?  
 NHIF [ ]  
 Private insurance scheme [ ]  
 Others \_\_\_\_\_ specify
24. Does the insurance meet all the illness cost of treatment?  
 YES [ ]                      NO [ ]
25. Do you experience episodes of inability to get prescription medication or pay hospital bills? /  
 YES [ ]                      NO [ ]  
 c) Others specify.....
26. If you do not have health insurance how do you meet the treatment cost? (Please explain)  
 .....

**Psychological factors that affect caregiver burden**

27. How has the child's diagnosis affected you? (Choose the most significant for You) it has caused:
- Sadness [ ]  
 Shock /Denial [ ]  
 Emotional pain [ ]  
 Hopelessness [ ]  
 Reduced energy [ ]  
 Fatigue [ ]  
 Lack of sleep [ ]  
 Anger [ ]

Confusion [ ]

Worries [ ]

Fear of recurrence [ ]

Concern about the child's image [ ]

Feelings of loss of control (helplessness) [ ]

Others, specify

.....

28. Have you previously experienced the above issue before this child's cancer illness?

YES [ ]

NO [ ]

If yes, which one of the above did you experience prior to this child's illness?

.....

29. What was the cause?

.....

30. Has the child's cancer illness worsened the experience?

YES [ ]

NO [ ]

31. Do you experience high levels of anxiety?

a) YES [ ]

b) NO [ ]

If yes how does the anxiety manifest? (**Choose all that apply**)

a) Difficulty making decisions [ ]

b) Loss of memory [ ]

c) Difficulty concentrating [ ]

d) Lack of sleep [ ]

e) Treatment avoidance [ ]

f) Difficulty coping with necessary procedures performed on the child [ ]

g) Sense of lack of control [ ]

h) Negative impact on professional routines [ ]

i) Uncertainty of the child's future [ ]

j) Possibility of developing a second cancer [ ]

k) Fear of suffering the child will endure through treatment? [ ]

Others, specify

.....

32. What have you done about the above issues experienced?

.....  
.....  
33. Have you experienced similar levels of anxiety before?

YES [ ] NO [ ]

If yes, what was the cause (Please explain)

.....  
34. Is there relationship between the previous anxieties with the current child's illness?

YES [ ] NO [ ]

35. Do you get difficulty coping with procedures performed on the child?

YES [ ] NO [ ]

If yes which procedures distress you most? (**Choose all that apply**)

- a) Putting intravenous cannula into the vein [ ]
- b) Bone marrow aspiration [ ]
- c) Blood transfusion [ ]
- d) Intravenous fluids administration [ ]
- e) Phlebotomy procedure [ ]
- f) Radiological Procedure e.g. ultrasound and X-Rays [ ]
- g) Chemotherapy administration [ ]
- h) Others specify / .....

36. What have you done about the above issues?

.....  
37. Do you have people who help in contributing to the sick child's wellbeing in one way or the other?

YES [ ] NO [ ]

If yes who are they?

- a) Aunts [ ]
- b) Uncles [ ]
- c) Grandparents [ ]
- d) Neighbors [ ]
- e) Friends [ ]
- f) Church groups [ ]

g) Others,  
specify.....

38. In your opinion, what would help reduce the burden of caring for the child who has cancer (**Choose the most helpful?**)

- a) Availability of finances [  ]
- b) Adequate information from the health care team [  ]
- c) Availability of people who support in the care of the child [  ]
- d) Prospect [  ]

39. On average how much time do you spend in hospital when you bring the child for treatment?

- |                              |                              |                              |                              |                              |                              |
|------------------------------|------------------------------|------------------------------|------------------------------|------------------------------|------------------------------|
| 0-7 days                     | 1 week,                      | 2 weeks,                     | 3 weeks                      | 1 month                      | > month                      |
| [ <input type="checkbox"/> ] |

## APPENDIX 6: KISWAHILI QUESTIONNAIRE

- Kabla ya kujaza dodoso hii, tunakuomba usome, uelewe na kusaini fomu ya idhini
- Tafadhali usiandike jina lako katika kurasa yoyote ya dodoso.
- Tafadhali soma kwa makini maelekezo katika mwanzo wa kila sehemu ya dodoso kabla ya kujibu maswali katika sehemu hiyo
- Tafadhali jibu maswali yote katika kila sehemu ya dodoso

### Demographic data

Nambari ya dodoso \_\_\_\_\_

1. Umri wako ni miaka mingapi?  
10-19 [ ] b) 20-29 [ ] c) 30-39 [ ]  
d) 40-49 [ ] e) 50-59 [ ] f) Zaidi ya miaka 60
2. Je, jinsia yako ni ipi?  
Kiume [ ] Kike [ ]
3. Hali yako ya ndoa ni ipi?  
sijaolewa [ ]  
Nimeolewa [ ]  
Nimetalaki [ ]  
tumetengana [ ]
4. Je, unaishi wapi?  
Nairobi [ ]  
Nje ya Nairobi, (tafadhali eleza).....
5. Je, unapata gharama yoyote ya usafiri kumleta mtoto hospitalini?  
Ndio [ ] La [ ]  
Ikiwa ndio, takriban kiasi gani kwa mwezi?  
.....

### Sifa za mtoto

6. Mtoto wako mgonjwa ana umri gani.....
7. Je, una watoto wangapi? .....
8. Kama una zaidi ya mtoto mmoja, tafadhali niambie mtoto huyu mgonjwa ni mzaliwa wa ngapi katika familia.....

9. Je, ni mara ya kwanza mtoto huyu mgonjwa kupatikana na Saratani

Ndio [ ] La [ ]

Kama la, tafadhali eleza kama imerudi tena mara ngapi

mara moja [ ]

zaidi mara moja [ ]

10. Je, ni muda gani kwa miezi tangu mtoto alipoanza kuugua ugonjwa wa saratani?

Miezi 0-6 [ ]

Miezi 7-12 [ ]

Miezi 13- 24 [ ]

Miezi 25- 36 [ ]

Miezi > 36 [ ]

11. Je kwa maoni yako, matokeo ya matibabu ya mtoto wako ni yapi?.

(Chagua moja ambalo linafaa Zaidi kati ya yatuatayo)

Mazuri zaidi [ ]

Mazuri sana [ ]

Mazuri [ ]

Wastani [ ]

Mabaya [ ]

12. Je, una watoto wengine ambao hukutegemea wewe?

Ndio [ ] La [ ]

Ikiwa ndio ni nani ambaye husaidia kuwatunza wakati wewe uko hospitali?

.....

### **Maswala ya kijamii**

13. ugonjwa wa saratani kwa mtoto umebadilisha familia kwa njia gani? (chagua majibu yote yote yanayo kuhusu)

a) Una vikwazo kwa mahusiano ya kijamii [ ]

b) Umeiweka mvuta [ ]

c) Uhaba wa fedha [ ]

d) Kuleta migogoro ya hisia [ ]

e) Kuleta familia karibu [ ]

f) Mengine, (eleza).....

14. Je, umepata shinikizo ya familia kukubali au kukataa mazoea matibabu?

Ndio [ ]

La [ ]

Kama ndiyo, ni jinsi gani uliweza kuwajibu

.....  
**Sababu za kiuchumi zinazoathiri mzigo wa mlezi (chagua moja)**

15. Ngazi yako ya juu ya elimu rasmi ni gani?

Sikuenda shule [ ]

Shule ya msingi [ ]

Sekondari [ ]

College [ ]

Chuo Kikuu [ ]

16. Tafadhali niambie Kazi yako/ chanzo cha mapato ni nini?

.....  
17. Kama katika ajira, ni ajira ya aina gani?

Ajira ya kudumu [ ]

Ajira ya muda [ ]

18. Tafadhali niambie tangu mtoto alipoanza kuwa mgonjwa ulifanya nini

niliendelea kufanya kazi [ ]

nilipata likizo ya kulipwa [ ]

nilipata Likizo bila malipo [ ]

niliacha Kazi [ ]

Mengine (tafadhali eleza).....

19. Ni nani hugharamia matumizi ya nyumbani?

Baba [ ]

Mama [ ]

Ndugu [ ]

Babu/Nyanya [ ]

Wengine,( tafadhali eleza).....

20. Ukikadiria, mapato ya familia ya kila mwezi ni kama shilingi ngapi za Kenya?

.....  
21. Ni watu wangapi huishi katika nyumba yenu?

.....  
22. Ni asilimia gani ya mapato inatumika katika matibabu ya mtoto kwa mwezi

.....  
23. Je, una bima ya afya

Ndio [ ]

La [ ]

Kama ndiyo, ni gani?

NHIF /Bima ya taifa ya hospitali [ ]

Bima ya kibinafsi [ ]

zingine,( tafadhali eleza).....

24. Je, bima hutosheleza gharama zote za matibabu?

Ndio [ ]

La [ ]

25. Je umeshawahi kukosa uwezo wa kupata dawa au kulipa gharama ya hospitali?

Ndio [ ]

La [ ]

26. Kama huna bima ya afya ni jinsi gani unaweza kugharamia matibabu? (Tafadhali eleza)

.....

**Wasiwasi wa kisaikolojia** (chagua muhimu zaidi)

27. Je, utambuzi wa mtoto ulikuathiri aje?

**Imesababisha:**

Huzuni [ ]

Mshtuko [ ]

Maumivu ya kihisia [ ]

Kukata tamaa [ ]

Upungufu wa nguvu ya kufanya kazi [ ]

Uchovu [ ]

Ukosefu wa usingizi [ ]

Ukali [ ]

Utata [ ]

Wasiwasi [ ]

Hofu ya marudio ya tukio [ ]

Wasiwasi kuhusu sura ya mtoto [ ]

Hisia za kupoteza udhibiti [ ]

Mengine,eleza.....

28. Je, tukio kama hili mbeleni kabla mtoto kuugua saratani?

Ndio [ ]

La [ ]

Kama ndiyo, ni tukio gani ulipata kabla ya matibabu ya saratani ya

damu ya mtotohuyu?.....

29. Nini ilikuwa sababu

.....

30. Je, mtoto kuugua saratani kumezidisha adhari ya tukio hilo?.....

Ndio [ ]

La [ ]

31. Je, una wasiwasi kupita kiasi?

Ndio [ ]

La [ ]

Kama ndiyo ni jinsi gani wasiwasi umedhihirika? (chagua yote yanayokuhusu)

a) Ugumu kufanya maamuzi [ ]

b) Kupoteza kumbukumbu [ ]

c) Ugumu wa kuzingatia [ ]

d) Ukosefu wa usingizi [ ]

e) Kuepusha matibabu [ ]

f) Ugumu kukabiliana na taratibu muhimu waliomfanyia mtoto [ ]

g) Hisia ya ukosefu wa udhibiti [ ]

h) Athari juu ya utaratibu wa kitaalamu [ ]

i) Kutokuwa na uhakika wa hali ya baadaye ya mtoto [ ]

j) Uwezekano wa kupatwa na saratani ya pili

k) Hofu ya mateso kwa mtoto kwa ajili ya matibabu

32. Je, umefanya nini kuhusu maswala haya ya juu ulioshuhudia

.....

33. Je, umewahi kuwa na wasiwasi kupita kiasi hapo awali?

Ndio [ ]

La [ ]

Kama ndio, ni nini ilisabababisha (tafadhali fafanua)

.....

34. Je, kuna uhusiano kati ya wasiwasi za awali na ugonjwa ya sasa?

Ndio [ ]

La [ ]

35. Je, unapata ugumu kukabiliana na utaratibu wa kazi juu ya mtoto?

Ndio [ ]

La [ ]

Kama ndio ni taratibu gani za matibabu zinakusumbua zaidi? (**Chagua**

**Yoteyanayokuhusu)**

a) Kurekebisha branular

b) Kutoa mafuta ya mfupa

- c) Kuongezewa damu
- d) Tiba ya kuweka maji mwilini
- e) Utaratibu wa kuchukua damu
- f) Picha k.m..X-Rays
- g) Tiba ya radiotherapy
- h) Mengine,( eleza).....

36. Umefanya nini kuhusu masuala haya ya juu

.....

37. Je, una watu wanaosaidia katika kuchangia ustawi wa mtoto mgonjwa katika njia moja auningine?

Ndio [ ]

La [ ]

Kama ndiyo ni nani hao?

- a) Shangazi [ ]
- b) wajomba [ ]
- c) Babu/Nyanya [ ]
- d) Majirani [ ]
- e) Marafiki
- f) Makundi ya kanisa
- g) Wengine, (eleza).....

38. Kwa maoni yako, nini ingesaidia kupunguza mzigo wa kutunza mtoto na saratani

(chagua moja yenye munufaa zaidi)

- a) Upatikanaji wa fedha
- b) Taarifa za kutosha kutoka kwa timuya huduma ya afya
- c) Upatikanaji wa watuambao wanaunga mkono huduma ya mtoto
- d) kila sehemu kama inawezekana

39. Kwa wastani unatumia muda gani katika hospitali unapoleta mtoto hospitalini

Siku0-7

wiki1

wiki2,

wiki3mwezi1> mwezi 1

[ ]

[ ]

[ ]

[ ]

[ ]

[ ]

## APPENDIX 7: CAREGIVER BURDEN SCALE

Adopted from: Zarit et al. (1980), *Gerontologist*, 20(6), 649-55

Instructions: Read each statement and rate it on a scale from 0 (never) to 4 (nearly always) /

Maagizo: soma kila kauli na uipime kwa kiwango kwa 0-4

In general, how often do you feel? /Kwa ujumla, unalisikiaje?

	0	1	2	3	4
There is not enough time for yourself /Hakuna wakati wa kutosha kwa ajili yako mwenyewe					
Overtaxed with responsibilities/ Kuzidiwa na majukumu					
Like you've lost control over your life/ Ni Kama umepoteza udhibiti juu ya maisha yako					
In regard to the relative for whom you are caring, how often do you feel: / Kuhusu jamaa unayemwangalia, ni mara ngapi unajisikia:					
Uncertain about what to do for your relative/ Hauna Uhakika kuhusu nini cha kufanya kwa jamaa yako					
Like you should do more for your relative/ Kama unapaswa kufanya zaidi kwa jamaa yako					
Like you could do a better job of caring/ Kama unaweza kufanya kazi bora Zaidi ya kumwangalia					
When you are with the relative for whom you are caring, how often do you feel:/ Unapokuwa na jamaa unayemwangalia, ni mara ngapi unajisikia:					
A sense of strain /Unajikaza Zaidi					
Anger/ Hasira					
Embarrassment/ aibu					

Uncomfortable about having friends over/ Kusumbuka kuhusu kuwa na marafiki Zaidi					
How often do you feel that your relationship with the relative for whom You're caring negatively impacts:/ Ni mara ngapi unahisi kuwa uhusiano wako na jamaa unayemwangalia kunaadhiri					
Your social life Maisha yako ya kijamii					
Other relationships with family and friends/ Mahusiano mengine na familia na marafiki					
Your health /Afya yako					
Your privacy/ Faragha yako					
How often do you: / Ni mara ngapi wewe:					
Feel you receive excessive help requests /Jisikia upokea maombi mengi kupita kiasi ya usaidizi					
Feel all the responsibility falls on one caregiver/ UnaJisikie wajibu wote unaanguka kwa mlezi mmoja					
Fear the future regarding your relative /Hofu ya baadaye kuhusu jamaa yako					
Fear not having enough money to care for your relative /Unaogopa kutokuwa na fedha za kutosha ili kumtunza jamaa yako					
Fear not being able to continue caring for your relative/ Unaogopa kuto kuwa na uwezo wa kuendelea kutunza jamaa yako					
Wish to leave the care of your relative to someone else/ Unataka kumwachia jamaa yako mtu mwingine					
How much does your spouse/loved one depend on you as the caregiver? Je! Mke wako / mpendwa wako hutegemea wewe					

kama mlezi kwa kiwango gani?					
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(0)No burden at all, Hakuna mzigo (1) mild burden, mzigo mwepesi (2) moderate burden mzigo mzito kiasi, (3) severe burden mzigo mzito mno, (4)extreme burden mzigo mzito zaidi

**Interpretation (ufafanuzi)**

Level of burden (kiwango cha mzigo)	Total scores(Jumla ya alama)
No or minimal burden (Hakuna au mzigo mdogo)	0-20
Mild to moderate burden (Mzigo mwepesi au wa wastani)	21-40
Moderate to severe burden (Kiwango cha mzigo mkubwa)	41-60
Severe burden (Mzigo mzito zaidi)	61-88

## APPENDIX 8: A MAP OF KENYATTA NATIONAL HOSPITAL.

