PSYCHOSOCIAL CHALLENGES EXPERIENCED BY CAREGIVERS WITH CHILDREN UNDERGOING CHEMOTHERAPY AT THE PEDIATRIC UNIT OF KENYATTA NATIONAL HOSPITAL

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DECEMBER, 202

DECLARATION

This research project is my original work and has not been presented in any other institution for award of credit or examination purposes.

Signature .... Date 09/12/2020

Celine Sein Kilanya

Reg. no: H56/12467/2018

CERTIFICATE OF APPROVAL

This research proposal has been submitted for examination with our approval as the University supervisors.

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DEDICATION

This work is dedicated to my wonderful son Leteipan and my parents, Mr. and Mrs. Ole Perrio for their love, support and encouragement throughout the entire period. May the Almighty God bless you all.

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I wish to take this opportunity to thank all those who made this study a success. My special gratitude goes to my supervisors, Dr. Irene Mageto and Dr. Samuel Kimani, who through their consistent support, guidance, expert advise and follow up of this research work led to its successful completion. I also wish to acknowledge the caregivers of pediatric cancer patients who participated in this study for their invaluable input. I am also thankful to Kenyatta National Hospital for allowing me to carry out the study in the facility. My regards also go to my family, friends and colleagues for their moral support and encouragement throughout my studies.

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ABBREVIATIONS AND ACRONYMS

EBV	**:**	Epstein Bar Virus
HepB	**:**	Hepatitis B VIRUS
HepC	**:**	Hepatitis C Virus
HIV	**:**	Human Immunodeficiency Virus
HPV	**:**	Human Papilloma virus
IMCI	**:**	Integrated Management of Childhood Illnesses
PTSD	**:**	Post Traumatic Stress Disorder
SDG’s	**:**	Sustainable Development Goals
WHO	**:**	World health Organization

OPERATIONAL DEFINITION OF TERMS

Anxiety- Refers to strong fears experienced by caregivers of children undergoing chemotherapy in relation to cancer care, treatment and patient overall outcome.

Cancer -Refers to abnormal growth and spread of cells in children which later invade the organs which requires treatment through chemotherapy among other methods

Chemotherapy- Involves use of drugs that target cancer cells to treat cancer in children

Coping strategies- refers to specific actions taken by caregivers of children undergoing chemotherapy to solve or manage their stressful situation resulting from cancer treatment.

Depression-refers to extreme feelings of sadness and hopelessness experienced by caregivers related to cancer care, treatment and overall patient outcome

Health related stigma- A feeling of rejection by the caregivers due to the condition and the treatment of their children

Psychological aspects: Refers to thoughts, feelings, behavior and body reactions in relation to cancer diagnosis and treatment.

Self Esteem- refers to the parents' view of themselves in relation to their child condition and their competence in caring for the child with Cancer.

Social support- refers to persons to whom caregivers of children undergoing cancer chemotherapy can reach out to in times of crisis, specifically spouses, family members, friends and religious persons.

Sociological aspects- refers to aspects of society pertaining to cancer care, which includes relationships and interactions between the patient, parent/caregiver, healthcare system, income, occupation, education, transportation and social support.

Stressor-is an agent that causes tension or strain or discomfort to caregivers of children undergoing cancer chemotherapy.

ABSTRACT

Background: The diagnosis of childhood cancer is a critical life event that impacts the psychological status of children and their parents. Due to this, caregivers of children with cancer experience considerable psychological burdens despite the high probability of cure and considerable advances of treatment protocols. There was need to evaluate psychosocial challenges experienced by caregivers of pediatric cancer patients as it is an area that remained grossly under-researched locally.

Broad objective: To determine the psychosocial challenges faced by caregivers of children undergoing chemotherapy at Kenyatta National Hospital's Pediatric Unit.

Methodology: This was a hospital based descriptive cross-sectional study. The study was conducted in the Pediatric Unit oncology rooms (Dayroom) in all four pediatric wards (3A,3B,3C,3D) and in Pediatric oncology ward 1E of KNH. The study population was 128 caregivers of children aged below 12 years 11 months undergoing chemotherapy in KNH. The study sample comprised of 96 caregivers selected using stratified and simple random sampling methods. A validated researcher administered questionnaire was used to collect data. In data analysis, quantitative data was analyzed through descriptive statistics using the Statistical Package for Social Science (SPSS, version 23) and presented in percentages and frequencies while qualitative data was analyzed thematically using content analysis. The study results were presented in tables, graphs and charts and later disseminated in the form of the final research project report to University of Nairobi and through publication in a peer reviewed journal. Authority to conduct the study was sought from KNH/UoN Ethics and Research Committee and from Kenyatta National Hospital. Ethical principles of respondents' consent, voluntary participation, confidentiality of information obtained and anonymity in processing study data were observed.

Results: The psychological challenges faced by caregivers with children undergoing chemotherapy in KNH included feelings of anxiety and mental distress (100%); hopeless and helpless (88.6%); sadness, shock and disbelief (100%); sleeping and eating disorders (95.7%); being irritated easily (84.3%) and being overwhelmed (90%) in light of their children's medical condition and therapy. The sociological challenges faced by caregivers with children undergoing chemotherapy in KNH included feelings of inadequate emotional and material support (91.4%); isolation and being neglected (88.6%); restricted social life (100%), financial difficulties (100%); fear of losing one's work/job (87.1%); social stigmatization from community members (80%) and disruption of their daily routine (100%) in light of their children's medical condition and therapy. Learning more about the disease and its treatment; seeking support from close family members and friends; joining forces with people with similar experiences and seeking divine intervention for their child's healing were the caregivers' main coping mechanisms.

Conclusions: The study concluded that caregivers of children undergoing chemotherapy at KNH did experience a wide range of psychosocial challenges in light of their children's medical condition and treatment therapy that their children were receiving.

Recommendations: KNH's administration should institute regular counselling services for the caregivers of pediatric cancer patients. In addition, KNH's administration should develop social support systems for caregivers of pediatric cancer patients admitted in the hospital.

CHAPTER ONE: INTRODUCTION

This chapter presents background of the study, statement of the problem, justification of the study, significance of the study, research questions as well as objectives of the study.

1.1 Background of the Study

Globally, cancer causes significant mortality and morbidity. Seventy percent (70%) of the global cancer burden is in the low- and middle-income countries especially in Africa (WHO, 2012). Of all the cancers irrespective of whether in adults or children, 30% are curable if detected early; 30% are treatable with prolonged survival if detected early, while 30% of cancer patients can be provided with adequate symptoms management and palliative care (WHO, 2012). In Kenya, cancer is the 3rd highest cause of morbidity causing 7% of all deaths per year, after infectious and cardiovascular diseases. It’s estimated that 39, 000 new cases of cancer occur each year in Kenya with more than 27,000 deaths per year (MoH, 2013).

Da Silva et al. (2010) indicated that the diagnosis of childhood cancer and its stressful treatment, not only adversely impact the physical and psychological health of the affected children, but also impose heavy psychological burden on their parents. According to Silva-Rodrigues et al. (2016) the uncertainty of relapse, the possibility of serious infection, and the adverse effects of medications used negatively affect the psychological status of patients and their parents. Studies about the psychological impact of chemotherapy on patients and their parents in cultures outside North America and Europe are limited and they are especially rare in the African context (Kamala, 2015).

Treatment of cancer requires long course chemotherapy and other treatment modalities which leads to prolonged hospitalizations and interrupted schooling (Long & Marsland, 2011). Parents are greatly affected and they must cope with anxieties, fears, and frustration brought about by taking care of the sick child (Silva-Rodrigues et al., 2016). Parent psychological distress can impact the well-being of childhood cancer patients and the family at large. Recognizing and alleviating factors of parent distress may improve overall family survivorship experiences following childhood cancer (Weiner et al., 2017)

Parents of children with cancer must cope with multiple challenges over time, however, parental coping has been found to be a challenge in most parts of the world especially in cases where the child is not progressing well due to chemotherapy (Van Schoor et al., 2017). As most research on parental coping had been conducted in Western countries, little information was available on the parental experience of coping in Kenya. In addition, the association of particular coping patterns with parents' report of psychosocial adjustment needed to be investigated. The assessment of the psychosocial profile of caregivers to pediatric cancer patients undergoing chemotherapy availed information that could be used to improve patient care and overall patient outcome. This could also lead to addressing psychological and sociological challenges, to both parents and patients and lead to better adaptation and coping to the rigors of the disease.

1.2 Statement of the Problem

Globally, parents have a special attachment to their young children, and when such children are separated from them through admission to receive chemotherapy, this no doubt significantly alters their quality of life (Van Schoors et al., 2017). Such admissions, observed Axia et al. (2006), were likely to evoke serious psychosocial challenges among the parents and close family members. Seeing a once healthy child being in a critical condition due to an illness such as cancer is very devastating to many of the parents (Gerhardt et al., 2007).

A study by Bayat et al. (2008) reported elevated levels of depression, stress, anxiety and hopelessness among parents of children with cancer compared to the control group. Similar observations were made in the studies of Kars et al. (2008) and Wiener et al. (2017) who reported higher levels of psychological and social distress among parents of children under chemotherapy. The studies called for higher levels of psychosocial support for these caregivers. Studies by Long, and Marsland (2011) and Kazak et al. (2005) also reported that parents of children diagnosed with cancer exhibited a wide range of post-traumatic stress symptoms including fear, anxiety, depression, feelings of being overwhelmed and helpless as well as irritability. In addition, stigma, financial strain and discrimination were also cited as eminent challenges. These studies offered evidence that parents/caregivers of children diagnosed with cancer experienced a wide range of psychosocial challenges associated with caring for their sick child. These studies were however carried out in other countries whose health care settings differed with the local setting, hence the need to validate these findings in the local context.

In Kenya, a research done at Kenyatta National Hospital identified that Leukemia diagnosis and treatment posed psychological distress which manifested in the form of shock, anxiety, worries, anger, sadness, and fatigue. There were increased levels of tension in the family as a result of leukemia diagnosis and treatment (Okumu et al. 2017). According to KNH pediatrics clinical audit (2018/2019) showed that, prior to initiation of chemotherapy, more than three quarters of parents and caregivers were eager to have their children started on chemotherapy treatment, however, once the treatment had been commenced, majority of parents tended to be reluctant to have their children continue with the treatment. Unpublished hospital reports indicated that parents felt that chemotherapy made their children sicker among many undetermined reasons. As a result, more than one third of parents failed to continue with chemotherapy courses or dropped out from follow up clinics once their children were started on chemotherapy and the effects of the same manifest. Further, high proportion of parents became emotionally disturbed as the chemotherapy continued. This clearly showed that parents or caregivers with children undergoing chemotherapy had psycho-social challenges among others that needed to be determined and addressed, hence the basis of this study.

1.3 Justification of the Study

Pediatric cancer treatment centers put more efforts on cancer treatment (Chemotherapy) while doing very little to address the needs and challenges of the caregivers of children undergoing chemotherapy during this period. This has made care givers to become hopeless, to an extent that they no longer wish to continue with the treatment any more. A diagnosis of childhood cancer represents challenges for patients and family members both regionally and globally. Evaluation of such psychological challenges of the caregivers was therefore critical in ensuring that all the necessary evidence-based interventions were taken care of to prevent any such incidences which had the potential to increase the child morbidity and mortality and to reduce parental quality of life for having a child undergoing chemotherapy.

Further, carrying out this study helped determine the psychosocial challenges and coping mechanisms of caregivers and supporting factors utilized. Most research on psychosocial experiences of parents whose children were undergoing cancer treatment had been conducted in Western countries; hence little information was available on the parental experiences in non-Western countries. In Africa, specifically in Kenya, little was known about the psychosocial challenges experienced by parents whose children were undergoing chemotherapy treatment, which presented a knowledge gap in our healthcare setting, thus the results may influence healthcare policy formulation on management of psychosocial challenges experienced by caregivers, support efficient psychosocial interventions and minimize the psychosocial costs experienced by pediatric cancer patients' caregivers.

1.4 Research Questions

1. What were the psychological challenges faced by caregivers with children undergoing chemotherapy in Kenyatta National Hospital?
2. What were the sociological challenges faced by caregivers with children undergoing chemotherapy in Kenyatta National Hospital?
3. In which ways did the caregivers address/cope with the challenges?

1.5 Objectives of the Study

1.5.1 General Objective

To determine the psychosocial challenges faced by caregivers of children undergoing chemotherapy at Kenyatta National Hospital's Pediatric Unit.

1.5.2 Specific Objectives

1. To assess the psychological challenges faced by caregivers with children undergoing chemotherapy in Kenyatta National Hospital.
2. To evaluate the sociological challenges faced by caregivers with children undergoing chemotherapy in Kenyatta National Hospital.
3. To determine how the caregivers address/cope with the challenges.

1.6 Significance of the Study

The findings of this study are beneficial to various parties as herein described;

To the caregivers of children undergoing chemotherapy, this study helps highlight the psychosocial challenges that they faced in the care of children diagnosed with cancer and undergoing chemotherapy. The study provides suggestions of possible measures that could be adopted to help address these challenges, hence alleviating or reducing the suffering of the caregivers while also helping to enhance their care giving experience.

To the health care workers and the hospital administration, the findings of this study may inform development of novel hospital based training programs and practice guidelines for nurses and doctors on better/effective management of psychosocial challenges faced by caregivers of pediatric oncology patients. This would ensure that healthcare workers have adequate knowledge and skills to enable them offer support and counselling to the caregivers of these patients through appropriate interventions.

The findings of this study may also be helpful to policy makers in the health sector as they may inform review of existing policies or development of new policies regarding management of psychosocial challenges faced by caregivers of children undergoing chemotherapy in Kenya’s hospitals.

To other scholars and academicians, this study acts as a literature source and reference point for those who may plan to undertake further research on this research subject.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

This chapter presents a review of literature as guided by the study objectives. The chapter contains an empirical review on psychological challenges faced by parents with children on chemotherapy. The chapter also contains an empirical review on sociological challenges experienced by parents with children on chemotherapy. The chapter also contains a highlight of the research gaps in the literature reviewed. The chapter also contains the theoretical and conceptual frameworks of the study.

2.2 Psychological Challenges Faced by Caregivers of Children Undergoing Chemotherapy

2.2.1 Role Strain

Cancer treatment demand that family adapts to long hospitalizations, aggressive therapy, many losses, and changes in family relationships and routines that may hinder the caregivers from performing daily tasks or responsibilities (Da Silva et a.,2010). Further, many caregivers become so preoccupied with the condition and the treatment of their child that other duties are completely ignore or not given much attention (Lavee, & Mey-Dan, 2013).

The fact that the children undergoing cancer chemotherapy needs to deal with invasive procedures, side effects, the interruption of school and social routines, the suspension of leisure activities, changes in diet, in self-image and self-conception, uncertainty of how the treatment outcome, doubts, periodical hospitalization, physical pain, separation from family members and familiar places, losses that harm socialization and interfere in personal relationships (Gomes et al., 2004; McGrath et al., 2005; Shiota et al., 2004; G. M. Silva, Teles, & Valle, 2005).

Studies have shown that majority of the caregivers have to be at the hospital attending to the admitted child while at the same time attending to other siblings who are at home, while again on the other hand has to go to work (Van Schoors, et al., 2017). According to Klassen et al., (2007) such increased roles causes strain on the caregivers which affects the caregiver’s ability to perform his or her roles amicably.

Apart from accompanying the painful process of a child undergoing treatment, parents also have to deal with increased parental responsibilities and administer the treatment requirements, provide the emotional support to the patient and siblings, moderate their own emotions, establish satisfactory communication within the medical-hospital context, adapt to family routines, deal with potential relapses, deal with expectations, care for the child's wellbeing, and pay attention to medication, handle intercurrences and side effects, establish protective care, and accompany the child on medical consultations, hospitalizations and for invasive exams (Clarke & Fletcher, 2003; Holmbeck, Bruno &Jandasek, 2006; Kars, Duijnstee, Pool, Delden, &Grypdonck, 2008; Keegan-Wells et al., 2002; McGrath et al., 2005; Shiota et al., 2004; S. Silva, Pires, Gonçalves, & Moura, 2002).

2.2.2 A Feeling of Helplessness

Long and Marsland, (2011) established that majority of caregivers become helpless especially when their children are not responding well to treatment against their earlier expectations. Similarly, Weiner et al., (2017) indicated that prior to treatment, majority of the caregivers are very optimist however, once one or two session begins, this completely changes especially when the child condition deteriorates as a result of chemotherapy

Further, Silva-Rodrigues et al,(2017) established that chemotherapy caregivers main challenges as the treatment progress are mainly include fear of relapse, anxiety, the need to accept and adjust to information received, care provided to healthy children, attempts to adapt to the new health condition, provide care in the event of side effects, among other situations, which harm the family's stability and quality of life . This fear, of the relapse makes them feel completely helpless

2.2.3 Anxiety

The experience of cancer influences the emotional response of parents in relation to their child's needs, the ability of the child to deal with adverse situations is related to the parents' ability to manage situations of crisis. The parents' quality of life in childhood cancer and the patient's quality of life during treatment are interconnected (Vance, Morse, Jenney, &Eiser, 2001; Wegner & Pedro, 2009). This relationship shows the importance of understanding the psychosocial impact of childhood cancer on parents (Hoekstra-Weebers et al., 2001; Robinson, Gerhardt, Vannatta, & Noll, 2007; Santacroce, 2002; Streisand, Kazak, &Tercyak, 2003). For parents already struggling to cope or with pre-existing mental health problems, a child's diagnosis of cancer can be overwhelming

The responsibilities falling on parents may be overwhelming and increase the probability of anxiety, depression, guilt, sleep disorders, somatic symptoms, risk behavior (smoking and alcoholism), changes in diet, perception of physical and emotional overload, events that put one’s health at risk, harm to professional and social life, and worsening of one’s quality of life, consequences that remain after the diagnosis (Gedaly-Duff, Lee, Nail, Nicholson, & Johnson, 2006; James et al., 2002; Kazak et al., 2004; Moreira &Ângelo, 2008; S. Silva et al., 2002; Young et al., 2002

Studies addressing anxiety indicate that manifestations frequently occur at the time when a diagnosis is disclosed and usually decline to normal levels, though remain higher than levels experienced by parents of healthy children (Bayat et al., 2008; Gerhardt et al., 2007)

Mothers tend to report higher levels of anxiety than fathers, whether at the time the diagnosis is disclosed or in other stages of the disease, though these manifestations can be a result of how gender roles are constructed or the way parental caregivers split responsibilities; the primary caregiver role is usually attributed to mothers (Beck & Lopes, 2007) Parents reporting high levels of anxiety at the diagnosis usually continue to experience significant manifestations even after the treatment ends (Vrijmoet-Wiersma et al.). High levels of anxiety may be correlated with post traumatic stress, difficulties making decisions, loss of memory, difficulty concentrating, insomnia and treatment avoidance (Best, Streisand, Catania, & Kazak, 2001; Santacroce, 2002).

2.2.4 Depression

The parents may respond to the diagnosis with behavior indicative of depression, such as persistent sadness, pessimism, hopelessness, guilt, helplessness, decreased energy, difficulty concentrating or making decisions, fatigue, insomnia or sleepiness, which may last for several months, especially with initial levels of moderate or severe depression (Bayat, Erdem, &Kuzucu, 2008).

About half of parents report moderate to intense levels of posttraumatic stress, including intrusive thoughts, treatment avoidance, physiological responses, flashbacks and psychological agitation (Vrijmoet-Wiersma et al., 2008). On the other hand, the work of Jurbergs, Long, Ticona e Phipps (2009) does not report significant differences in posttraumatic stress symptoms between parents of children undergoing treatment and symptoms in parents of healthy children.

Dolgin et al. (2007) found different patterns of the manifestation of symptoms six months after treatment: (1) high levels of symptoms at the time of the diagnosis, which declined over time, (2) moderate symptomatology over a period of six months, and (3) low levels that remain from the time of the diagnosis. The level of symptoms may indicate posttraumatic stress disorder in 35% of parents, according to Axia, Tremolada, Pillon, Zanesco and Carli (2006). Stoppelbein and Greening (2007), in turn, reported that only 7% of the sample presented levels that indicated such a disorder.

Emotional and physical impact of cancer in childrenis observed in parents and is characterized by depression, lack of control, anxiety, insomnia, post-traumatic stress symptoms, feeling of being overloaded, sadness, confusion, tension, loss of control, harmed self-esteem (Boman, Lindahl, &Björk, 2003; Steele et al., 2004; Steele, Long, Reddy, Luhr, & Phipps, 2003; Stehl et al., 2009). Nonetheless, even if the perception concerning symptoms diminishes, the sources of distress remain, indicating psychosocial interventions are needed (Steele et al., 2003, 2004; Stehl et al., 2009).

Parents also present high levels of symptoms immediately after the diagnosis when compared to control groups. Such symptoms decline over the first 18 months (Boman et al., 2003; Pai et al., 2007;) Variations in the duration and persistence of psychological disturbances have been reported in the literature and such levels are higher among mothers (Sahler et al., 2005; Svavarsdottir, 2005b).

2.3 Sociological Challenges Faced by Caregivers of Children Undergoing Chemotherapy

2.3.1 Isolation

At community level, some parents complained of being neglected or isolated once their child was diagnosed with cancer. The feeling of lack of support was common among widows, widowers, divorcees, and single parents. They felt that having a spouse to help nurse the child with cancer would lighten the burden. (Walubita, M., Sikateyo, B. & Zulu, J.M.2018)

2.3.2 Stigma

The negative consequences of perceived stigmatization can persist and cause severe psychosomatic symptoms, the consequences of cancer-related stigmatization on both patient and parent/caregiver and family, are even more distressing than the illness itself. In combination with social isolation and severe psychological and compliance problems, stigmatization finally results in a loss of quality of life. Therefore, investigation of stigmatization and its consequences among cancer patients and their parents/caregivers is of great clinical importance.

The studies also indicate that Eastern families have fewer social support resources available and tend to become isolated (Leavitt et al., 1999; Martinson et al., 1999).

2.3.3 Financial Constraints

Generally, Cancer treatment includes financial costs that result from the distance between home and hospital, leading to expenditures on transportation, accommodations, meals and phone calls. Losing one’s job or changes in one’s professional routine is a common occurrence (Cohn, Goodenough, Foreman, &Suneson, 2003; Dockerty, Skegg, &Williams, 2003; James et al., 2002; Lähteenmäki et al., 2004; McGrath et al., 2005; Rocha-García et al., 2002).

The treatment of childhood cancer negatively impacts the social and professional routines of parents, often requiring them to leave their jobs and give priority to treatment (Björk et al., 2005; Earle, Clarke, Eiser, & Sheppard, 2006). Attention totally focused on a child may lead to marital conflict, impair communication and/or the self-care of parents (Costa & Lima, 2002; James et al., 2002; Steffen &Castoldi, 2006).

Parents also face conflict between working and staying in the hospital, in addition to the demand to provide emotional support to the family (McGrath, 2001; Svavarsdottir, 2005a). Cultural gender roles may influence the manifestation of feelings, fears, and expectations between parents (Brody & Simmons, 2007).

2.3.4 Poor Marital and Social Support

Based on changes in parental roles required by treatment, parents may experience changes in their marital relationships, as well. Studies addressing satisfaction in marital relationships over the course of treatment have reported different results. Some couples do not report changes in their marital relationships (Dahlquist et al., 1996) while others report more positive attitudes toward the spouse, that their relationships were strengthened, they became more cohesive, and trust improved (Beltrão, Vasconcelos, Pontes, & Albuquerque, 2007; Kylmä&Juvakka, 2007; Lavee&Mey-Dan, 2003; Sloper, 2006). Reports that the parents’ relationship weakened and marital satisfaction decreased were also observed (Lavee&Mey-Dan, 2003; Pai et al., 2007).

The availability of social support from family members, friends, co-workers, and neighborhoods is also extremely important (Bayat et al., 2008). Higher levels of social support are generally available at the time the diagnosis is disclosed and decline over the treatment period, while mothers tend to receive more support than fathers (Hoekstra-Weebers et al., 2001; Holm, Patterson, & Gurney, 2003; Iobst et al., 2009; Wijnberg-Williams et al., 2006).

Changes in the usual house routine, and also in the family and professional spheres, along with somatic symptoms are responses common (Wong & Chan, 2006; Yeh, 2002). Some elements such as social support and seeking out information are commonly valued (Han, 2003; Ow, 2003; Wong & Chan, 2006). The care system also usually changes regardless of the cultural context, including overprotective behavior, changes in the imposition of limits, and in family relationships (Chao, Chen, Wang, Wu, & Yeh, 2003)

Both parents face distinct demands and tend to deal differently with challenges. Mothers usually assume the role of primary caregiver and become emotionally involved while most in most cases, the fathers act as providers and tend to distance themselves emotionally from the situation (F. A. C. Silva, Andrade, Barbosa, Hoffmann, & Macedo, 2009; Svavarsdottir, 2005a). The challenges faced by mothers can be related to working, for professional mothers, decision-making, administration of medication, promotion of comfort and support, planning of family activities, handling the children's behavioral problems and supervising routine responsibilities (McGrath, 2001; Svavarsdottir, 2005a; Yeh, 2002).

Details in studies involve access to the healthcare system, satisfaction with the health service, promoting healthful aspects, and the repertoire of self-care behavior. Such elements are essential to understanding how circumstantial differences may influence the impact of psychological disturbances or protect against them (Boman et al., 2003; Holmbeck et al., 2006; Vrijmoet-Wiersma et al., 2008).

2.4 Research Gap(s)

The identified research gaps from the literature were as summarized in Table 2.1.

Table 0.1 Research gaps summary

Author(s) & Year	**Study Objective**	**Findings**	**Gap identified**
Silva-Rodrigues et al. (2016)	The study evaluated the impact of childhood cancer on parents' marital dynamics	Childhood cancer was found to have significant impact on parents' marital dynamics	The study did not focus on the psychosocial dimension of challenges experienced by the parents, a gap the current study addressed
Da Silva et al. (2010)	Investigated how childhood cancer impacted on parents' relationships	Found that childhood cancer contributed to strain in parental relationships	Current study expounded on the scope by looking at other psychosocial

			challenges that such parents experienced
Dockerty et al. (2003)	The study investigated the economic effects of childhood cancer on families	The study observed that childhood cancer significantly impacted in an adverse way families' economic situations	The study did not focus on psychosocial challenges faced by the caregivers of children with cancer, which was the focus of the current study
Long & Marsland (2011)	The study investigated family adjustment to childhood cancer	The study established that childhood cancer was disruptive to normal family functioning and required adjustments on various domains of family life	While this study adopted a longitudinal study design, the current study used a descriptive cross-sectional research design
Dahlquist, L. M., Czyzewski, D. I., & Jones, C. L. (1996)	The study investigated levels of emotional distress, coping style, and marital adjustment among parents of children with cancer	The study found that parents of children with cancer experienced coping difficulties and severe emotional distress due to their children's health condition	The study was longitudinal in nature while the current study was cross-sectional in nature.
Holm et al. (2003)	The study focused on parental involvement and family-centered care in the diagnostic and treatment phases of childhood cancer	The study established that there were gaps in parental involvement and family-centered care practices in management of childhood cancer	This study utilized a qualitative approach while the current study utilized both qualitative and quantitative approaches

2.5 Theoretical Framework

This study was guided by the Psychosocial Oncology Framework, which is a theoretical model that acts to guide provision of high-quality psychosocial care services for cancer patients. This theoretical model was adopted from the 2008 U.S. Institute of Medicine standard - *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*. This theoretical model advocates for a multidisciplinary approach to cancer care in response to the distress experienced by cancer patients and their families, and it encourages cancer programs to develop, review, and revise psychosocial support services offered to cancer patients and their families/caregivers. The theoretical model emphasizes that identifying psychosocial health needs in both patient and caregiver/family is the essential precursor to meeting health needs of the patient (Macdonald et al., 2012).

The theoretical model contains several domains, which include;

Domain A - Raising Awareness: Understanding and Defining Psychosocial Care

Psychosocial care should be considered an integral and standardized part of cancer care for patients and their families at all stages of the illness trajectory. Strategies to promote awareness of the significance of psychosocial health care needs and uptake of psychosocial health services should be encouraged.

Domain B - Standard of Care

Comprehensive cancer care should ensure the provision of appropriate psychosocial health services by facilitating effective communication between patients, their families, and care providers; identifying psychosocial health needs of patients and families; designing and implementing a plan that links the patient and family with needed psychosocial health care services, coordinates biomedical and psychosocial health care and engages and supports patients and families in managing their illness and health; and systematically monitoring, evaluating, and readjusting plans.

Domain C - Health Care Providers

All cancer care providers have a responsibility to ensure that cancer patients and their families receive the psychosocial standard of care.

Domain D - Patient and Family Education

Cancer patients and their families should be educated to expect, and to request when necessary, cancer care that meets psychosocial health care needs.

Domain E - Quality Oversight and Monitoring Progress

Oversight mechanisms should be created that can be used to measure and report on the quality of psychosocial health care.

Domain F - Workforce Competencies

Professional competencies in the delivery of psychosocial health care should meet the requirements of educational institutions and accrediting organizations, licensing bodies, and professional societies.

Educational bodies should examine their standards and licensing and certification criteria with an eye to identifying competencies in delivering psychosocial health care and developing those competencies as fully as possible in accordance with a model that integrates biomedical and psychosocial care.

Domain G - Standardized Nomenclature

There is a need to develop a standardized trans-disciplinary taxonomy and nomenclature for psychosocial health services.

Domain H - Psychosocial Research

There is a need for continued research on psychosocial health services.

This theoretical model was relevant to the current study as it aims to help health care providers meet the psychosocial health care needs of cancer patients and their families/caregivers at both the provider and system levels.

2.6 Conceptual Framework

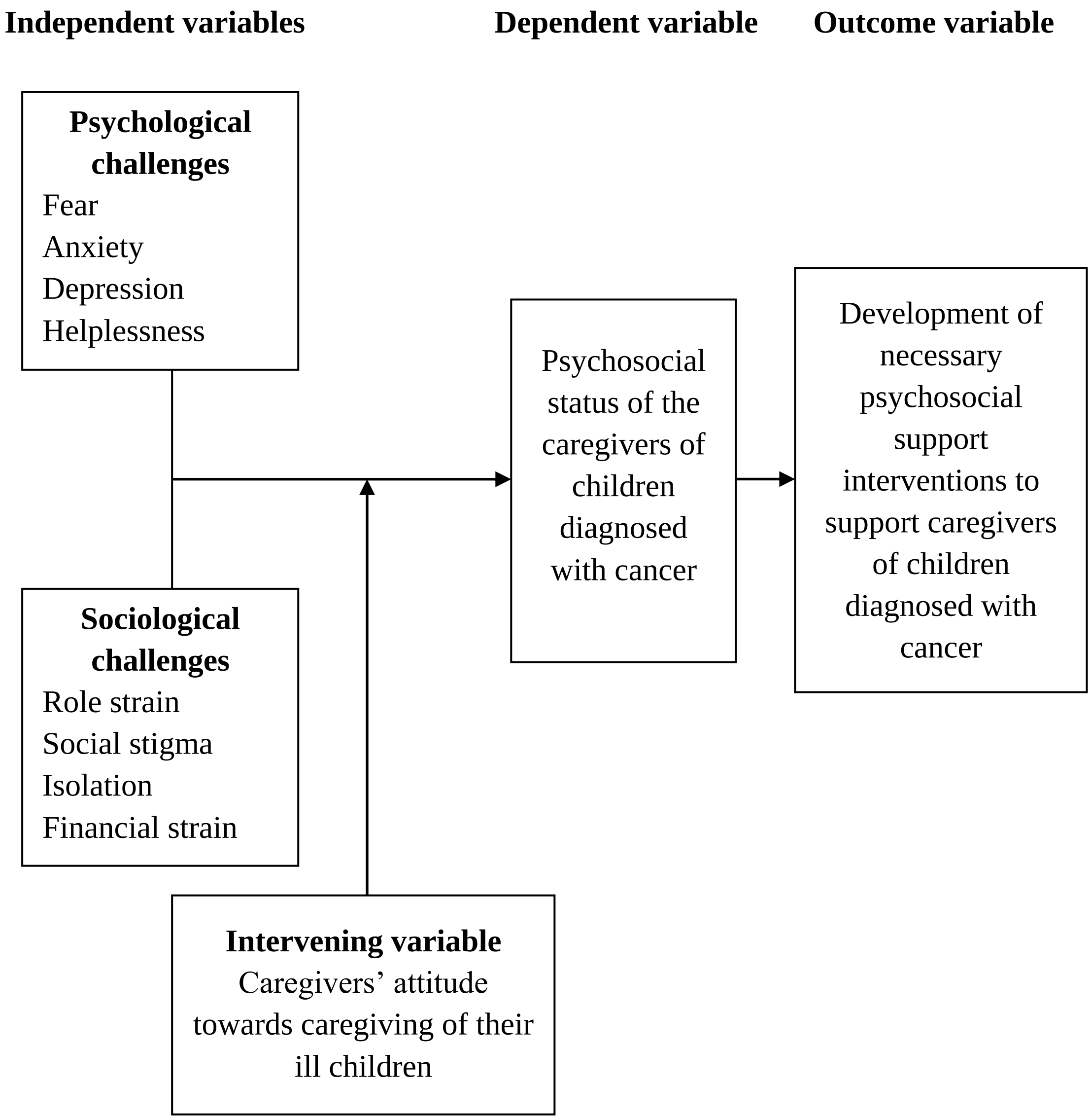

Figure 0.1 Conceptual framework

CHAPTER THREE: RESEARCH METHODOLOGY

3.1 Introduction

This chapter provides a framework of the methodology that was used in the study. It outlines the study design, study area, target population, sample size and sampling technique, inclusion and exclusion criteria, data collection instruments and procedures, pilot testing, validity and reliability of research instrument, data analysis and ethical considerations

3.2 Research Design

This was a hospital based descriptive cross-sectional study. This research design presents facts concerning variables being investigated as they exist at the time of study as well as emerging trends. This design ensured complete and accurate description of the situation under study, ensuring that there was minimum bias in the collection of data as argued by Kothari (2004).

3.3 Study Area

The study was conducted in the Pediatric Unit of Kenyatta National Hospital. Kenyatta National Hospital (KNH) is the largest public hospital in Kenya and is located about four kilometers from the Nairobi city center, off Ngong road on Hospital road. The current bed capacity of the hospital is about 2,000. The hospital offers various in and out-patient health care services in its several specialized clinics. In addition to its primary mandate to provide specialized health-care services to patients on referral basis, the hospital also facilitates medical training and research and participates in national health-care planning.

The KNH Pediatric Unit is located on the third floor and has a bed capacity of 230. The Unit admits pediatric oncology patients in all 4 KNH pediatric wards (3A, 3B, 3C, 3D) as well as referrals from other facilities across the country. Pediatric cancer patients in KNH are hospitalized in these Units, alongside Oncology Wards 1E, hence its choice as the study area. In addition, being the leading referral public hospital in the country meant that KNH handled many cancer cases among children. This setting provided a good platform for studying the psychological and sociological challenges experienced by caregivers of pediatric cancer patients undergoing chemotherapy in the facility. However, to safeguard the privacy and confidentiality of the participants, the interviews were held in the Counselling Room of the Pediatric Unit.

3.4 Study Population

The study population was caregivers of children aged below 12 years 11 months admitted with cancer and undergoing chemotherapy in Kenyatta National Hospital's Pediatric Unit. Based on the latest statistics from KNH's Pediatrics Department, the average number of peadiatric patients on chemotherapy per month in the department was 128 (HIS, KNH, 2019/2020). Hence, the study population comprised of 128 caregivers of children aged below 12 years 11 months undergoing chemotherapy in Kenyatta National Hospital.

3.5 Inclusion and Exclusion Criteria

3.5.1 Inclusion Criteria

The study included all caregivers of children aged below 12 years 11 months ailing with cancer and undergoing chemotherapy in KNH, during the study period, and who consented to participate in the study.

3.5.2 Exclusion Criteria

The study excluded caregivers of children with cancer who were critically ill. The study also excluded caregivers of children under study who declined to consent to take part in the study.

3.6 Sample Size Determination

The study sample size was calculated using the Fisher's *et al*. (1998) formula as follows:

$n = [z^2pq/d^2]$

Where;

n =desired sample size (if the population was greater than 10,000).

Z = Standard normal deviation at the required confidence interval, 95%. In this case, it was 1.96

p = the proportion of the population with desired characteristics set at 0.5.

$q = (1-p) = 1 - 0.5 = 0.5$

d = the level of significance, set as 0.05.

Hence, $n = (1.96^2 \times 0.5 \times 0.5) / 0.05^2$

$n = 384$

Given that the population for the study, that is, the average number of peadiatric patients on chemotherapy per month in KNH's pediatrics Unit of 128 was less than 10,000, the sample size was moderated for using the Finite Population Correction formula as recommended by Fisher *et al*. (1998) as follows;

$n_f = n / [1 + n/N]$ (Yamane, 1967)

Where:

n_f = desired sample size when the total population was less than 10,000

n = estimated sample size when the total population (N) was greater or equal to 10,000

N = estimated total population

Therefore, $384 / (1 + [384/128]) = 384/4 = 96$

Hence, the study sample size comprised of 96 caregivers of children aged below 12years 11 months with cancer undergoing chemotherapy at KNH's Pediatric Unit.

3.7 Sampling Technique

Both stratified and simple random sampling methods were used to recruit the study participants. Stratified sampling method was used to group the respondents on the basis of the pediatric wards. As such, each pediatric ward acted as a stratum. The proportionate number of participants per ward was calculated by dividing the number of pediatric patients in each ward by the total number of pediatric patients in the five pediatric wards of the hospital and then multiplying that with the study sample size. This was as illustrated in Table 3.1.

Table 0.1 Sample size distribution per peadiatric ward

Ward (stratum)	**Total number of patients**	**Sample size**
Ward 3A	28	28/128*96 = 21
Ward 3B	24	24/128*96 = 18
Ward 3C	24	24/128*96 = 18
Ward 3D	26	26/128*96 = 20
Ward 1E	26	26/128*96 = 20
Total	**128**	**96**

Simple random sampling method was then used to recruit the specific participants in each stratum as it eliminated biasness in sample selection given that it accords each member of the targeted population an equal chance of being chosen to form part of the sample.

3.8 Data Collection Instruments

A validated researcher-administered questionnaire was used to collect the study data. The questionnaire had 5 parts, which included: Section A - captured information on the socio-demographic data of the caregivers; Section B – captured information on the socio-demographic characteristics of the children; Section C- captured information on psychological challenges experienced by the caregivers; Section D - captured information on social challenges experienced by the caregivers and Section E - captured information on the caregivers' coping mechanisms. The reason for choosing the questionnaire as the data collection instrument for this study was primarily due to its practicability, applicability to the research problem and the size of the population. It was also cost effective (Denscombe, 2014).

3.9 Data Collection Procedures

The researcher-administered questionnaires were administered to the caregivers of the children under study. The questionnaire was administered to the respondents by the principal researcher after providing an explanation to them on the purpose of the study and after obtaining their informed consent. The data collection exercise entailed the researcher asking the respondents the questions as contained in the research tool and noting down their responses.

In light of the prevailing Covid 19 pandemic in the country and to help limit the risk of Covid 19 transmission, the researcher strictly adhered to Ministry of Health's issued Covid 19 prevention guidelines during the data collection exercise which included; the researcher donning a face mask; ensuring that both the researcher and the participants adequately sanitized through hand washing with soap or using a sanitizer prior to and after the interviews; avoiding hand shaking with the participants during the interview process; adhering to recommended social distancing rule during the interviews and providing masks to the participant(s) if they did not have.

During the data collection exercise, the researcher guided the respondents during the answering of the questions without unduly interfering with their responses. Once the study participants responded to the questionnaires, the researcher scrutinized the questionnaires for completeness before receiving them. The filled-in questionnaires were then stored safely under lock and key in readiness for data entry and analysis. The data collection exercise took two weeks.

3.10 Pretesting of the Research Tool

Pretesting of the questionnaire was carried out in Ward 1 E of Kenyatta National Hospital, where 10 questionnaires (representing 10% of the study sample size) were used. The caregivers who participated in the pretesting exercise did not form part of the main study to avoid contamination of the study's main findings. Pretesting was carried out to refine the research tool. Upon pretesting, the data collection instrument was adjusted where necessary and a final validated form of the study instrument was made.

3.11 Validity and Reliability of the Research Instrument

Validity indicates the degree to which an instrument measures what it is supposed to measure (Kothari, 2010) or the degree to which results obtained from the analysis of the data actually represent the phenomena under study (Denscombe, 2014). The research instrument was availed to the supervising lecturers and peers who helped establish its content and construct validity to ensure that the items were adequately representative of the study subject.

Reliability is a measure of the degree to which a research instrument yields consistent results after repeated trials (Nsubuga, 2006). Using data from the pilot study, the reliability of the research instrument was estimated using the Cronbach’s Alpha Coefficient. A Cronbach’s Alpha Coefficient of at least 0.70 was accepted. In case a low coefficient level was observed, the researcher would have made the needed changes to improve on the reliability of the research instrument.

3.12 Data Analysis

The filled questionnaires were coded and checked for completeness and consistency at the end of each day before storage. The quantitative data generated from the closed ended questions was analyzed through descriptive statistics using the Statistical Package for Social Science (SPSS, version 23) and presented through percentages and frequencies. The qualitative data generated from the open-ended questions was analyzed using content analysis. The study results were presented in tables, graphs and charts, as appropriate.

3.13 Dissemination of Study Findings

The study results shall be disseminated through forwarding a copy of the final research project report to the UoN Library, publication in a peer reviewed journal and presentation in organized seminars and conferences.

3.14 Ethical Considerations

The authority to conduct the study was sought from the KNH/UoN Ethics and Research Committee and from the management of Kenyatta National Hospital. Respondents’ consent was sought individually before their participation in the study.

Confidentiality was maintained for all information obtained from the study respondents. In addition, anonymity was observed by coding the questionnaires. No names or any other form of personal identification was written on the questionnaires and all information given was used strictly for research purposes only. Any emerging issues were only cited anonymously. Participation in the study was voluntary and the respondents were free to withdraw from the study at any time without victimization. No inducements or rewards were given to participants to join the study. However, if found to be experiencing (or to be suffering from) emotional distress or any other psychological condition, the respondent was referred to a counselor / psychology specialist, within the facility, for help/support. There were no associated risks to the study respondents from their participation in this study. All filled questionnaires were kept safely under lock and key in readiness for data analysis and presentation.

CHAPTER FOUR: RESULTS

4.1 Introduction

This chapter presents the study results as set out in the research methodology. The results were presented on the psychosocial challenges experienced by caregivers of children diagnosed with cancer and undergoing chemotherapy at Kenyatta National Hospital's pediatric wards. The chapter begins with highlighting the response rate and then provides results on the socio-demographic characteristics of the caregivers and the children before outlining the findings based on the research objectives. The study's specific objectives were;

1. To assess the psychological challenges faced by caregivers with children undergoing chemotherapy in Kenyatta National Hospital.
2. To evaluate the sociological challenges faced by caregivers with children undergoing chemotherapy in Kenyatta National Hospital.
3. To determine how the caregivers address/cope with the challenges.

4.1.1 Response rate

The study targeted 96 caregivers of children aged below 12 years 11 months undergoing chemotherapy at Kenyatta National Hospital as respondents. From the interviews conducted, the researcher was able to obtain adequate responses from 70 of the respondents translating into a response rate of 72.9%. The study was unable to obtain responses from all the respondents due to the prevailing Covid 19 pandemic. This response rate was, however, considered sufficient and representative and conforms to Mugenda and Mugenda (2003) stipulation that a response rate of 50% is adequate for analysis and reporting, a rate of 60% is good while a response rate of 70% and over is excellent.

4.2 Socio-Demographic Characteristics of the Caregivers

The study sought to establish the socio-demographic profile of the caregivers as the study participants. The socio-demographic attributes evaluated included: gender, age, education level, marital status, occupation, religion and how they related to the child. The findings were as depicted in Table 4.1 below.

Table 0.1 Respondents' demographic characteristics

		Frequency	**Percent**
Gender	Male	6	8.6
	Female	64	91.4
	Total	**70**	**100.0**
Age	18 - 29 years	13	18.6
	30 - 49 years	54	77.1
	50 years & above	3	4.3
	Total	**70**	**100.0**
Education level	No formal education	6	8.6
	Basic [Primary & Secondary]	47	67.1
	Tertiary	17	24.3
	Total	**70**	**100.0**
Marital status	Married	65	92.9
	Not married	5	7.1
	Total	**70**	**100.0**
Occupation	Unemployed	25	35.7
	In business	9	12.9
	Employed	36	51.4
	Total	**70**	**100.0**
Religion	Christian	70	100.0
	Other religions	0	0.0
	Total	**70**	**100.0**
How are you related to the child?	Parent	63	90.0
	Sibling	3	4.3
	Relative	4	5.7
	Total	**70**	**100.0**

The findings indicate that most (91.4%, n = 64) of the caregivers were female; most (77.1%, n = 54) were aged 30 - 49 years; most (67.1%, n = 47) had basic education level (that is, Primary and Secondary education); most (92.9%, n = 65) were married; about half (51.4%, n = 36) were employed while 35.7% (n = 25) were unemployed; all (100%, n = 70) were Christians and most (90%, n = 63) were parents of the child. This showed that most of the study participants were female parents of the children undergoing chemotherapy at KNH, who had basic education level, were married, professed the Christian faith and who were either employed or unemployed.

4.3 Socio-Demographic Characteristics of the Children

The study also sought to establish the socio-demographic profile of the children under study. The socio-demographic attributes evaluated included: the child’s gender, age, frequency of admission, whether the child had other pre-existing illness/illnesses apart from cancer and mode of admission. The findings were as shown in Table 4.2 below.

Table 0.2 Demographic characteristics of the children

		Frequency	**Percent**
Gender	Male	41	58.6
	Female	29	41.4
	Total	**70**	**100.0**
Age	Under 5 years	8	11.4
	5 - 12 years & 11 months	62	88.6
	Total	**70**	**100.0**
Is this the child’s first admission?	Yes	58	82.9
	No	12	17.1
	Total	**70**	**100.0**
Has the child been diagnosed with any other illness apart from cancer?	Yes	0	0.0
	No	70	100.0
	Total	**70**	**100.0**
Basis of admission	On referral basis	66	94.3
	Came here directly	4	5.7
	Total	**70**	**100.0**

The findings indicate that slightly over half (58.6%, n = 41) of the children were male while 41.4% (n = 29) were female; most (88.6%, n = 62) were aged 5 - 12 years & 11 months; most (82.9%, n = 58) were being admitted for the first time; all (100%, n = 70) had not been diagnosed with any other illnesses apart from cancer and most (94.3%, n = 66) had been admitted at KNH on referral basis.

This showed that the children diagnosed with cancer and who were under chemotherapy at KNH were largely of both genders, were largely aged between 5 and 12 years and 11 months, had no other illnesses apart from cancer and had been referred to KNH for further treatment, and were being admitted in the hospital for the first time.

4.4 Psychological Challenges Faced by Caregivers with Children Undergoing Chemotherapy in KNH

The first objective of the study sought to assess the psychological challenges faced by caregivers with children undergoing chemotherapy in Kenyatta National Hospital. The findings were as described in the subsequent subsections.

To assess the psychological challenges faced by caregivers with children undergoing chemotherapy in Kenyatta National Hospital, the caregivers of the said children were requested to indicate their level of agreement as to the extent to which they experienced a set of identified psychological difficulties in light of their children’s condition and treatment therapy the children were receiving.

The caregivers’ responses were rated on a scale of 1 - 5 where 1 - Strongly Disagree, 2 - Disagree, 3 - Neutral, 4 - Agree, 5 - Strongly Agree. The findings were however aggregated on the basis of agree or disagree, as illustrated in Table 4.3.

Table 0.3 Psychological challenges faced by caregivers of the pediatric cancer patients (N = 70)

	Disagree		**Agree**	
	F	**%**	**F**	**%**
I feel very anxious and depressed due to the fear of the unknown regarding the prognosis and treatment outcome of my child’s condition	0	0.0	70	100.0
I feel hopeless and helpless about my child’s health condition	8	11.4	62	88.6
I feel less optimistic about the treatment outcome of my child’s health condition	6	8.6	64	91.4
I feel great sorrow and sadness seeing my child in this condition	0	0.0	70	100.0
I no longer sleep and eat properly for fear that I am going to lose my child	3	4.3	67	95.7
I feel very anxious and concerned about whether the treatment on my child will be successful	0	0.0	70	100.0
I feel being under intense pressure owing to huge demands that comes with caring for a pediatric cancer patient	5	7.1	65	92.9
I feel extremely worn out, overwhelmed and in no mood for anything or anybody owing to being so preoccupied with my child’s condition and the treatment therapy	7	10.0	63	90.0
I feel very irritable and have been acting aggressively towards other people	11	15.7	59	84.3
I have had to totally re-adjust my routine responsibilities and the disruption to my normal life has been immense	0	0.0	70	100.0
I was filled with great disbelief, confusion and shock following my child’s diagnosis with cancer. I am yet to recover from these.	0	0.0	70	100.0

The caregivers unanimously agreed that they felt very anxious and depressed due to the fear of the unknown regarding the prognosis and treatment outcome of their child's condition (agree - 100%, n = 70).

Most of the caregivers agreed that they felt hopeless and helpless about their child's health condition (agree - 88.6%, n = 62).

Most of the caregivers did also agree that they felt less optimistic about the treatment outcome of their child's health condition (agree - 91.4%, n = 64).

The caregivers were also unanimous that they felt great sorrow and sadness seeing their child in that condition (agree - 100%, n = 70).

Most of the caregivers also agreed that they no longer slept and ate properly for fear that they were going to lose their child (agree - 95.7%, n = 67).

The caregivers were also unanimous that they felt very anxious and concerned about whether the treatment on their child would be successful (agree - 100%, n = 70).

Most of the caregivers did also agree that they felt being under intense pressure owing to huge demands that came with caring for a pediatric cancer patient (agree - 92.9%, n = 65).

Most of the caregivers also agreed that they felt extremely worn out, overwhelmed and in no mood for anything or anybody owing to being so preoccupied with their child's condition and the treatment therapy (agree - 90%, n = 63).

Most of the caregivers did also agree that they felt very irritable and had been acting aggressively towards other people (agree - 84.3%, n = 59).

All of the caregivers were also in agreement that they had had to totally re-adjust their routine responsibilities and the disruption to their normal life had been immense (agree - 100%, n = 70).

All of the caregivers also agreed that they were filled with great disbelief, confusion and shock following their child's diagnosis with cancer and that they were yet to recover from these (agree - 100%, n = 70).

The findings denoted that anxiety, sorrow/sadness, hopelessness, helplessness and mental distress were prevalent among the caregivers of children undergoing chemotherapy at KNH. This could be attributable largely to their appreciation of the terminal nature of the illness and its associated general poor prognosis. It could also be attributable to their love for the child and the pain of seeing the child suffering from the illness. Hence, this was evidence that most of the caregivers of the children diagnosed with cancer and undergoing chemotherapy at KNH experienced psychological challenges in light of their children's medical condition and treatment therapy that their children were receiving.

4.5 Sociological Challenges Faced by Caregivers with Children Undergoing Chemotherapy in KNH

The second objective of the study sought to evaluate the sociological challenges faced by caregivers with children undergoing chemotherapy in Kenyatta National Hospital. The findings were as described in the subsequent subsections.

4.5.1 Receipt of social support from family, friend(s) and/or relative(s)

The caregivers were asked whether they received any form of social support from family, friend(s) and/or relative(s) in view of their child's illness and treatment that the child was undergoing. The findings were as shown in Figure 4.6 below.

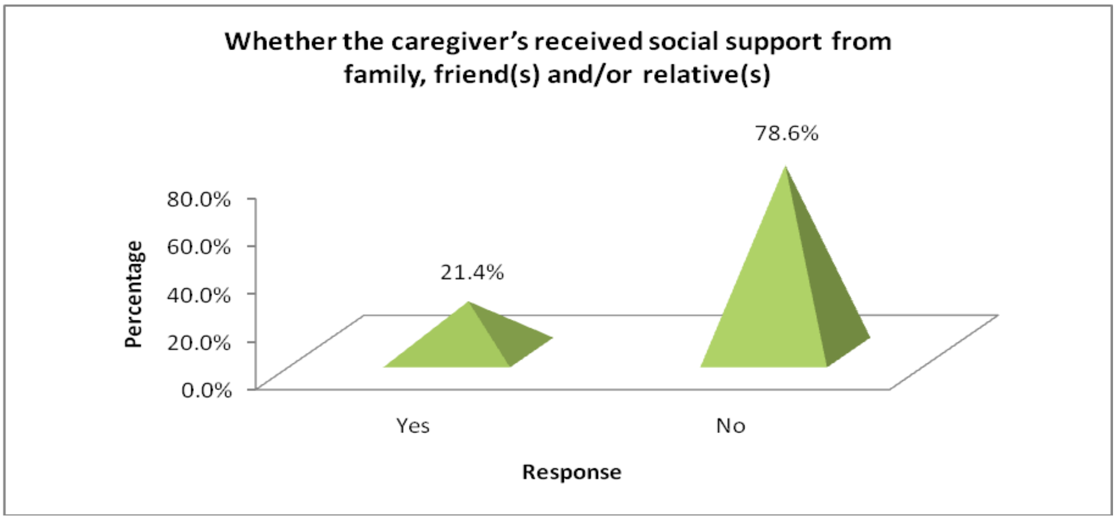

Figure 0.1 Whether the caregiver's received social support from family, friend(s) and/or relative(s)

Most (78.6%, n = 55) of the caregivers of children undergoing chemotherapy in KNH indicated that they did not receive any form of social support from family, friend(s) and/or relative(s) in view of their child's illness and treatment that the child was undergoing, as depicted in Figure 4.1 above.

For the 21.4% (n = 15) that indicated receiving social support from family, friend(s) and/or relative(s) in view of their child's illness and treatment that the child was undergoing, the study sought to know the kind of support that they received. Figure 4.2 shows the findings.

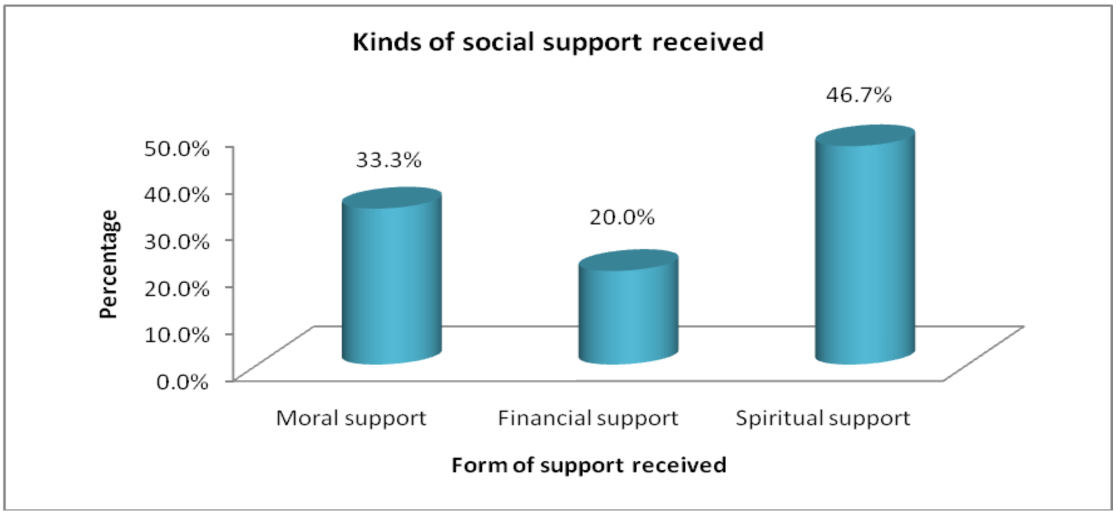

Figure 0.2 Kinds of social support received

The results indicated that close to half (46.7%, n = 7) of the caregivers received spiritual support; 33.3% (n = 5) received moral support while 20% (n = 3) indicated that they received financial support, as depicted in Figure 4.2 above.

The study also sought to find out possible reasons as to why the 78.6% (n = 55) of the caregivers of children undergoing chemotherapy in KNH did not receive any form of social support from family, friend(s) and/or relative(s) in view of their child's health condition. Table 4.4 below illustrates the findings.

Table 0.4 Possible reasons for the lack of support from family, friend(s) and/or relative(s) (N = 55)

	Frequency	**Percent**
Out of their own ignorance	9	16.4
They don’t love and care about me and my child	5	9.1
Don’t know why	41	74.5
Total	**55**	**100.0**

For the 78.6% (n = 55) of the caregivers who indicated that they did not receive any form of social support from family, friend(s) and/or relative(s) in view of their child’s medical condition, most (74.5%, n = 41) said they did not know why; 16.4% (n = 9) said it was out of ignorance on the part of the family, friend(s) and/or relative(s) while 9.1% (n = 5) said it was because the family, friend(s) and/or relative(s) did not love and care about them and their child.

This denotes that there was deficit/gap in relation to the level of social support that the caregivers of children undergoing chemotherapy at Kenyatta National Hospital received from their families, friend(s) and/or relative(s). Lack of adequate social support could imply that the caregivers of children diagnosed with cancer and undergoing chemotherapy at KNH bore the burden of the caregiving experience largely on their own which could be contributing to their being overwhelmed and distressed.

4.5.2 Disclosure of Information Regarding the Child’s Illness

The caregivers were asked whether they were comfortable sharing about the condition of the child with friends, relatives and/or community members. Figure 4.3 shows the findings.

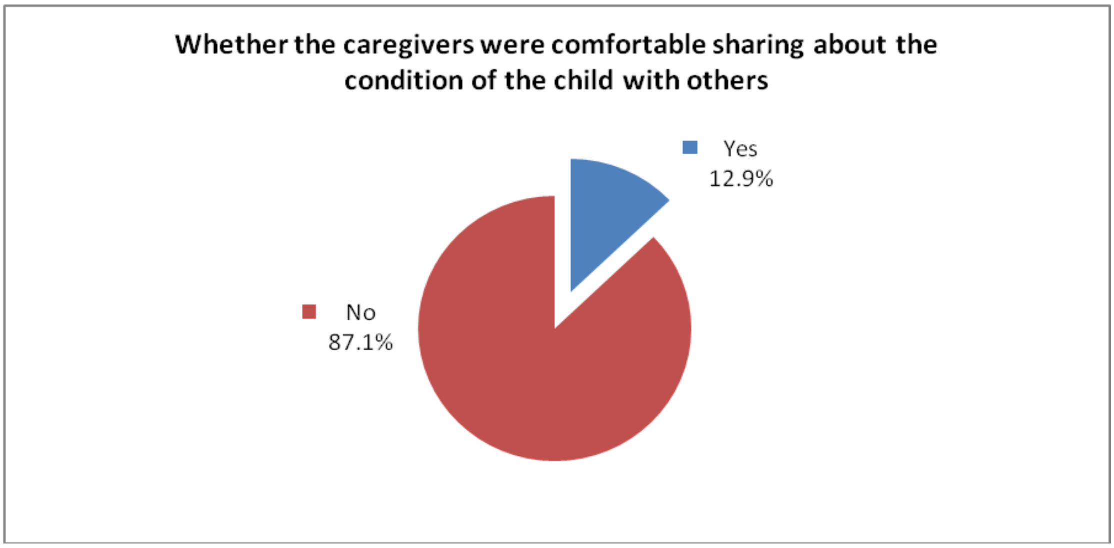

Figure 0.3 Whether the caregivers were comfortable sharing about the condition of the child with others

Most (87.1%, n = 61) of the caregivers of children undergoing chemotherapy in KNH indicated that they were not comfortable sharing about the condition of the child with friends, relatives and/or community members, as depicted in Figure 4.3 above.

For the 12.9% (n = 9) that indicated that they were comfortable sharing about the condition of the child with friends, relatives and/or community members, the reasons they cited for this included knowing that the friends, relatives and/or community members were empathetic, loving and supportive; to encourage others who may going through a similar experience and to create awareness about the disease.

The reasons cited by the 87.1% (n = 61) of the caregivers who were not comfortable sharing about the condition of the child with others were as summarized in Figure 4.4.

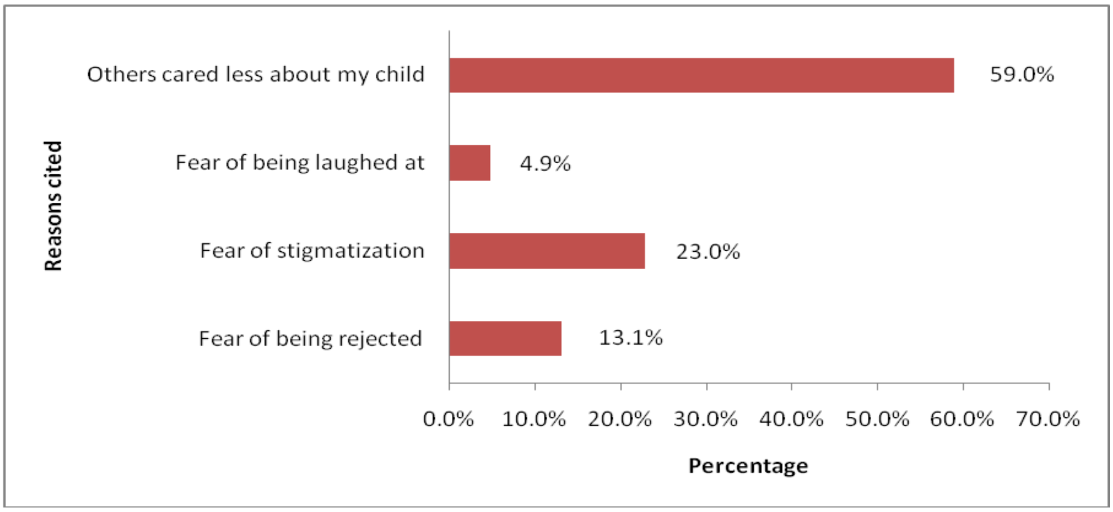

Figure 0.4 Reasons as to why the caregivers were uncomfortable sharing about their child's condition with others

It was established that perceiving friends, relatives and/or community members as being less caring about the sick child, fear of being stigmatized, fear of being rejected and fear of being laughed at, were the cited reasons that made the caregivers of the children undergoing chemotherapy in KNH not to be comfortable sharing about the condition of the child with others, as depicted in Figure 4.4 above.

This denoted that most of the caregivers of children diagnosed with cancer and undergoing chemotherapy at KNH would rather not disclose about their children's health condition to others, with perception of others not being adequately empathetic, fear of rejection and stigma being the main reasons behind their reluctance of sharing with others about their child's condition.

4.5.3 Whether the Caregivers Had Enough Emotional and Material Support

The caregivers were asked whether they felt they had enough emotional and material support from their significant others (family and/or close friends) to enable the child successfully complete the therapy schedule. The results were as shown in Figure 4.5.

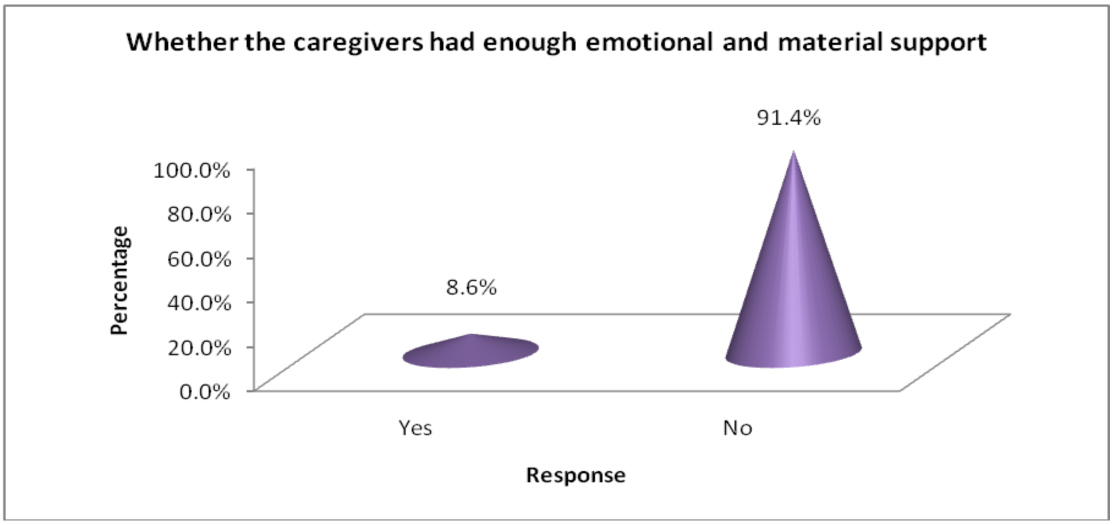

Figure 0.5 Whether the caregivers had enough emotional and material support to enable the child successfully complete the therapy schedule

Most (91.4%, n = 64), were unanimous that they did not have enough emotional and material support from their family/friends to enable their child successfully complete the therapy schedule, as depicted in Figure 4.5 above. This denotes that there were gaps in the level of social support being offered to the caregivers of children undergoing chemotherapy at KNH by their families and/or friends.

4.5.4 Social Related Challenges Faced by the Caregivers

The study sought to assess the social related difficulties that caregivers with children undergoing chemotherapy in KNH experienced owing to their children's health condition and the treatment therapy that the children were receiving.

To assess the social related difficulties/challenges faced by the caregivers, the caregivers of the said children were requested to indicate their level of agreement as to the extent to which they experienced a set of identified sociological difficulties in light of their children's condition and treatment therapy the children were receiving.

The caregivers' responses were rated on a scale of 1 - 5 where 1 - Strongly Disagree, 2 - Disagree, 3 - Neutral, 4 - Agree, 5 - Strongly Agree. The findings were however aggregated on the basis of agree or disagree, as shown in Table 4.5.

Table 0.5 Social related challenges faced by the caregivers of the pediatric cancer patients (N = 70)

	Disagree		**Agree**	
	F	**%**	**F**	**%**
I feel isolated and neglected by my extended family, friends and the community owing to my child's illness	8	11.4	62	88.6
I am experiencing difficulties in taking care of the other healthy sibling(s)	13	18.6	57	81.4
My social life is greatly restricted due to the increased burden in the caregiving process	0	0.0	70	100.0
As a family, we are experiencing lack of finances for treatment and other living expenses as my child's health condition has been economically expensive to manage	0	0.0	70	100.0
My daily routine has been completely disrupted due to intense caregiving needs arising from my child's condition	0	0.0	70	100.0
I am worried that I may lose my job/work due to not being able to report to work regularly as I care for my child	9	12.9	61	87.1
I feel that some of the family members and friends have not been very empathetic and supportive	17	24.3	53	75.7
I have experienced social stigmatization from some of the community members which arise from incorrect beliefs about my child's health condition	14	20.0	56	80.0
I feel ill prepared to deal with this crisis and no much social support is given at the hospital outside administration of treatment to the child	4	5.7	66	94.3
My spouse/partner and/or immediate family has not been very supportive	51	72.9	19	27.1
I am facing marital distress due to frequent hospitalizations as a result of my child's health condition	57	81.4	13	18.6

Most of the caregivers agreed that they felt isolated and neglected by their extended family, friends and the community owing to their child’s illness (agree - 88.6%, n = 62).

Most of the caregivers also agreed that they were experiencing difficulties in taking care of the other healthy sibling(s) (agree - 81.4%, n = 57).

All of the caregivers were also unanimous that their social life was greatly restricted due to the increased burden in the caregiving process (agree - 1000%, n = 70).

All of the caregivers also agreed that as a family, they were experiencing lack of finances for treatment and other living expenses as their child’s health condition had been economically expensive to manage (agree - 100%, n = 70).

There was also unanimity among all of the caregivers that their daily routine had been completely disrupted due to intense caregiving needs arising from their child’s condition (agree - 100%, n = 70).

Most of the caregivers also concurred that they were worried that they may lose their job/work due to not being able to report to work regularly as they cared for the child (agree - 87.1%, n = 61).

Most of the caregivers also concurred that they felt that some of the family members and friends had not been very empathetic and supportive (agree - 75.7%, n = 53).

Most of the caregivers also agreed that they had experienced social stigmatization from some of the community members which arose from incorrect beliefs about their child’s health condition (agree - 80%, n = 56).

Most of the caregivers also shared the view that they felt ill prepared to deal with the crisis and no much social support was given at the hospital outside administration of treatment to the child (agree - 94.3%, n = 66).

However, most of the caregivers disagreed with the view that their spouse/partner and/or immediate family had not been very supportive (disagree - 72.9%, n = 51).

Similarly, most of the caregivers did also disagree that they were facing marital distress due to frequent hospitalizations as a result of their child's health condition (disagree - 81.4%, n = 57).

The findings denoted that caregivers of children undergoing chemotherapy at KNH did experience isolation, neglect, stigma, financial difficulties, disruption of their normal life, worry over loss of work and lack of/inadequate emotional and material support - all of which point to gaps in the level of social support that they received. This could be attributable largely to the lack of awareness among the family, friends, relatives and community in general as to the significance of social support in aiding to ease the burden and difficult experiences of the caregivers of the pediatric cancer patients. Hence, this was evidence that most of the caregivers of the children diagnosed with cancer and undergoing chemotherapy at KNH experienced a wide range of sociological challenges in light of their children's medical condition and treatment therapy that their children were receiving.

4.6 Ways in Which the Caregivers Addressed/Coped with the Challenges

The last objective of the study sought to determine how the caregivers addressed/coped with these psychosocial challenges. The responses were qualitative in nature and were analyzed thematically as follows:

From the findings, four major themes were developed relating to mechanisms adopted by the caregivers of the children undergoing chemotherapy at KNH to cope with the psychosocial challenges that they experienced in light of their children's medical condition. The four themes were learning more about the disease and its treatment; seeking support from close family members and friends; joining forces with people with similar experiences and seeking divine intervention for their child's healing. These were as described herein;

Theme 1: Learning More about the Disease and its Treatment

One of the ways in which some of the caregivers of the children diagnosed with cancer and undergoing chemotherapy at KNH coped with the psychosocial challenges that they experienced was to learn more about the disease and its treatment. This was in a bid to gain a better understanding of their children’s medical condition and its prognosis. This was as enumerated in the following verbatim;

Participant 3 said that;

> “*Since my son was diagnosed with cancer, I have strived to learn as much as I can about the disease from the doctors, nurses and online sources. I knew so little about the disease before but now I know much more about it.*”

Participant 8 echoed the same words by indicating;

> “*Learning more about cancer, from the medical staff and literature materials online has been instrumental in my gaining better knowledge and understanding of my child’s health condition. It has also helped me cope with mental distress and anxiety that has plagued me since we were informed that our child had cancer. I hope more parents of cancer patients can do the same.*”

Participant 11 shared similar sentiments by stating that;

> “*To deal with my emotional pain attributable to my child’s medical condition, I started to learn as much as I could about cancer. I am eager to ask doctors any questions I have about my child’s condition. When possible, I also check via Google information relating to my child’s diagnosis. This has helped me gain a deeper insight of the disease my child is ailing and it has also helped reduce some of my worries regarding the therapy that she is being offered*”.

Participant 16 also added;

> “*This cancer thing has caused me and my family a lot of pain. Sometimes I am sad, other I am hopeful that all will end well. Through learning as much as I can about cancer in children, I am hopeful all is not lost and my daughter will recover*”.

Participant 5 also had this to say;

> "*I have many questions that run into my head. Why, why my child? While I may not get all the answers to all my questions regarding my child's diagnosis and treatment, I have endeavored to learn as much as I can about this condition and it has indeed been quite helpful*".

Theme 2: Seeking Support from Close Family Members and Friends

Another way in which some of the caregivers of the children diagnosed with cancer and undergoing chemotherapy at KNH coped with the psychosocial challenges that they experienced was to seek support from close family members and friends. Family support was a dominant theme in the caregivers' coping mechanisms. And close family and friends' support helped ease the caregiving burden while also providing reassurance and comforting words that all shall be well. This was as depicted in the following verbatim;

Participant 7 stated that;

> "*Were it not for my family and a few of my close friends, I do not know how I would have coped with this crisis. I am happy and thankful, they have stood with me and my child all through. Without their help, things would be so difficult*".

Participant 1 echoed these sentiments by noting;

> "*My family is my source of strength. Every time I feel like I cannot handle it any more, there are there to encourage and support me. I thank God for giving me a good family. They are the support that makes me see the positive amidst this very difficult experience*".

Participant 24 also underpinned the essence of the family in going through this experience noting;

> "*My close friends and family are the reason I am still here. Without their help, I don't know if we would come this far. They help ease my worries, anxieties and distress by their kind words and acts. I am so thankful to them*".

A sentiment also shared by Participant 15 who said;

> "*When I am worried and anxious about my child' health condition, I turn to my close friend and colleague. She gives me words of hope and reassures me that my child shall get well. Many a times, this is all I need to bounce back*".

Participant 33 added;

> "*For me, family is everything. My family has been very supportive. They go out of their way to offer me moral support and encourage me when I am down. Their support keeps me going and has been very instrumental during this experience*".

Theme 3: Joining Forces with People with Similar Experiences

Joining forces with people with similar experiences was also one of the ways in which some of the caregivers of the children diagnosed with cancer and undergoing chemotherapy at KNH coped with the psychosocial challenges that they experienced. This was largely for moral and emotional support in light of their shared experience, as depicted in these few excerpts;

Participant 4 pointed that;

> "*I have joined a group of other women with children diagnosed with cancer. We offer each other moral and emotional support and share our experiences relating to caring for a pediatric cancer patient*".

Similar sentiments were shared by participant 42;

> "*Were it not for the 'Lady Don't Give Up' - our group for women with pediatric cancer patients, I would long have drowned in sorrow and distress over my son's condition. I can not do without the emotional, moral and spiritual support that as a group we offer each other. It has been so helpful to me*".

Participant 2 added;

> "*Joining a group of fellow women with kids diagnosed with cancer was the best decision I made. We support each other in many ways - emotionally, socially and morally. The fellowship in this group renews my hope and keeps me going even when my child's health is not at its best*".

Participant 66 also added that;

> "*I am lucky I am part of a group of fellow mothers with a child currently diagnosed with cancer and those with a child previously diagnosed with cancer, alive or deceased. We share our experiences and stand with each other - supporting one another in every way possible*".

Participant 20 also saying;

> "*I turn to fellow women, here at the hospital, who are going through a similar situation and we encourage, support and pray for each other - it has been so good this far*".

Theme 4: Seeking Divine Intervention for their Child's Healing

Seeking divine intervention for the child's healing was also another of the main ways in which the caregivers of the children diagnosed with cancer and undergoing chemotherapy at KNH coped with the psychosocial challenges. This was largely in line with their religious belief that healing came from God and that nothing was beyond God’s ability to turn around situations, no matter how grim they seemed. This was as enumerated in the following verbatim;

Participant 51 noted that;

> “*I am a strong Christian believer and strongly believes that God will heal my child. Whenever, I feel overwhelmed, I go down on my knees to pray for strength. I pray a lot and hope God shall answer my prayer for my daughter’s full recovery*”.

Participant 9 shared similar sentiments noting;

> “*For me, God is everything. He who raised Lazarus shall cure my child. Whenever I am anxious and worried about my child’s condition, I turn to the scriptures and prayer. My belief is that doctors treat, God cures. I am always praying for my child’s healing*”.

Participant 3 remarked;

> “*Persistent prayer has been my secret for coping with this terrifying situation. I will keep on praying till my prayers are answered*”.

Participants 27 added;

> “*This experience has significantly led to grown in my faith. I am always seeking divine intervention for my baby’s case. Hope God answers me soon*”.

This denoted that the caregivers of children diagnosed with cancer and undergoing chemotherapy admitted at KNH largely relied on learning more about the disease and its treatment; seeking support from close family members and friends; joining forces with people with similar experiences and seeking divine intervention for their child’s healing to cope with the various psychosocial challenges that they faced.

CHAPTER FIVE: DISCUSSIONS, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

This chapter presents discussion of findings, conclusions and recommendations of the study in line with the study objectives. The study sought to determine the psychosocial challenges faced by caregivers of children diagnosed with cancer and undergoing chemotherapy at Kenyatta National Hospital's pediatric wards.

5.2 Discussion of Findings

5.2.1 Psychological Challenges Faced by Caregivers with Children Undergoing Chemotherapy in KNH

The study assessed the psychological challenges faced by caregivers with children undergoing chemotherapy in KNH. The key study finding was that the caregivers of children diagnosed with cancer and undergoing chemotherapy at KNH experienced psychological challenges, as evidenced by feelings of anxiety, mental distress, desperation and worry, in light of their children's medical condition and treatment therapy the children were receiving. It can thus be inferred that childhood cancer diagnosis was a traumatic event that occasioned huge psychological challenges among caregivers of the affected children.

Similar findings were reported by Kars et al. (2008), Silva-Rodrigues et al. (2016) and Walubita et al. (2018) who also established that caregivers of pediatric cancer patients experienced high levels of psychological challenges evidenced by extreme worry, anxiety and mental distress in light of their children's medical condition. As echoed by Chao et al. (2013), nothing pains and frightens a parent more than seeing their child in suffering as a result of ill health yet there is little they can do about it.

5.2.2 Sociological Challenges Faced by Caregivers with Children Undergoing Chemotherapy in KNH

The study evaluated the sociological challenges faced by caregivers with children undergoing chemotherapy in KNH. The key study finding was that the caregivers of children diagnosed with cancer and undergoing chemotherapy at KNH experienced a wide range of sociological (or social related) challenges, as evidenced by feelings of isolation, neglect, inadequate social, emotional and material support from family and friends and significant disruptions in their social life and normal daily routine, in light of their children's medical condition and treatment therapy the children were receiving. It can thus be inferred that childhood cancer diagnosis occasioned a wide range of sociological (or social-related) challenges among caregivers of the affected children.

These findings concurred with those of Chao et al. (2013) and Earle et al. (2016) who identified isolation and stigma, from family, friends and the community in general, as leading social challenges that parents of pediatric cancer patients endured. Similar sentiments were shared by Bayat et al. (2008) and James et al (2012) who identified lack of social support and disruption of one's normal life as key challenges experienced by caregivers of pediatric cancer patients. These observations were also affirmed by Holm et al (2013) and Walubita et al. (2018).

5.2.3 Ways in Which the Caregivers Addressed/Coped with the Challenges

This study also looked at how the caregivers addressed or coped with the identified psychosocial challenges attributable to the cancer diagnosis and treatment among their children. The key study finding was that, caregivers of children diagnosed with cancer and undergoing chemotherapy at KNH adopted four major ways of coping with the psychosocial challenges that they experienced. These were learning more about the disease and its treatment; seeking support from close family members and friends; joining forces with people with similar experiences and seeking divine intervention for their child's healing.

It can thus be inferred that seeking divine intervention for healing, associating with others facing a similar experience, seeking social, moral, physical and financial support from family and friends and learning more about childhood cancer and its treatment formed the core coping mechanisms adopted by caregivers of children diagnosed with cancer and undergoing chemotherapy at KNH.

This agreed with that of Van Schoors et al. (2017) and Gerhardt et al. (2017) who identified increased spiritual devotion and learning more about the disease as some of the major ways through which caregivers of cancer patients, in many settings, coped with the psychosocial challenges they faced. Engaging with social support groups, particularly among persons with similar experience, and relying on family support were also identified by Holm et al. (2003) and Earle et al. (2016) as common coping mechanisms among parents of children cancer patients, particularly among the children's mothers.

5.3 Conclusions

Based on the findings of the study, the researcher drew the following conclusions:

Anxiety, sorrow/sadness, hopelessness, helplessness and mental distress were prevalent among the caregivers of children undergoing chemotherapy at KNH, denoting that caregivers of children diagnosed with cancer and undergoing chemotherapy at KNH did experience psychological challenges in light of their children's medical condition and treatment therapy that their children were receiving.

Caregivers of children undergoing chemotherapy at KNH did experience isolation, neglect, stigma, financial difficulties, disruption of their normal life, worry over loss of work and inadequate emotional and material support - all of which point to gaps/ inadequacy in the level of social support that they received. This denoted that the caregivers did experience a wide range of sociological challenges in light of their children's medical condition and treatment therapy that their children were receiving.

Learning more about the disease and its treatment; seeking support from close family members and friends; joining forces with people with similar experiences and seeking divine intervention for their child's healing were the major ways for coping with the psychosocial challenges among the caregivers.

5.4 Recommendations

5.4.1 Action Recommendations

To address the psychological challenges that the caregivers of children diagnosed with cancer and undergoing chemotherapy at KNH faced, KNH's administration should institute regular counselling services for the caregivers of pediatric cancer patients.

To address the sociological challenges faced by caregivers of children undergoing chemotherapy at Kenyatta National Hospital, there is need for awareness creation among family members, relatives and the community in general on the harm of stigmatization, rejection and discrimination of pediatric cancer patients and their families and/or caregivers. To this end, KNH’s administration should develop social support systems for caregivers of pediatric cancer patients admitted in the hospital.

To enhance coping abilities of the caregivers of children undergoing chemotherapy at KNH, psychosocial therapy should be included as part of the management of the pediatric cancer patients. In addition, the caregivers of pediatric cancer patients at KNH need to be educated about the disease, its treatment therapy and prognosis.

5.4.2 Recommendations for Further Studies

Since the current study explored the psychosocial challenges experienced by caregivers with children undergoing chemotherapy at the Kenyatta National Hospital; a wider study involving other Level 5 and Level 4 hospitals that offer cancer treatment in the country is hereby recommended. This will facilitate a broader comparison and generalization of the study findings.

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APPENDICES

Appendix 1: Participants' Information Document

Title of Study: Psychosocial challenges experienced by parents with children undergoing cancer chemotherapy

Principal Investigator: Celine Sein Kilanya

Institutional Affiliation: University of Nairobi

Supervisors: Dr. Irene Mageto and Dr. Samuel Kimani

Introduction

My name is Celine Sein Kilanya, a student at the University of Nairobi pursuing a Master of Science Degree in Nursing (Oncology). I am undertaking a thesis study on 'Psychosocial challenges experienced by parents with children diagnosed with cancer undergoing chemotherapy the Pediatric Wards in Kenyatta National Hospital.

Purpose of the study

The aim of the study is to determine psychosocial challenges experienced by parents with children diagnosed with cancer undergoing chemotherapy at the oncology wards of Kenyatta National Hospital. I am requesting for your participation in this study by giving me your views and opinions regarding the study subject.

Study procedure

The study procedure will entail administration of the study tool to the caregivers of the children under study by the principal researcher. The questionnaire will be administered to the respondents by the principal researcher after providing an explanation to them on the purpose of the study and after obtaining their consent. If you choose to participate, the researcher will ask you a series of questions that seek to gather information relating to the psychosocial challenges you experience as a parent/caregiver of a child undergoing chemotherapy at KNH. The researcher will provide guidance to the respondents on answering the questions, without influencing their responses, to ensure that they answer the questions properly for efficient analysis. Once the questionnaires are responded to, the researcher will scrutinize the questionnaires for completeness before receiving them. The filled-in questionnaires will then be stored safely under lock and key in readiness for data entry and analysis.

Confidentiality

All the information provided will be treated in utmost confidentiality. In addition, all the information given herein will only be used for research purposes. Your name or anything else that may identify you will not appear anywhere in the study as the study will use statistics.

Voluntary participation

Your participation in this study is voluntary. There will be no penalties for any decline and you can withdraw at any stage of data collection with no penalties. However, I will greatly appreciate your participation because your views are very important for the success of this study.

Benefit

This research work is for academic purposes only and if you agree to participate, the information that you will provide will be of great importance to various stakeholders in improving the quality of care for pediatric oncology patients admitted with their parents and particularly with respect to addressing the psychosocial challenges that may be experienced by these patients’ caregivers in the course of their care giving.

In addition, if you are found to be experiencing (or to be suffering from) emotional distress or any other psychological condition, you will be referred to a counselor / psychology specialist, within the facility, for help/support.

However, there will be no monetary gains or any other form of payment for participating.

Risks

There will be no any harm to you or your family as a result of your participation in this study. However, in view of the existing Covid 19 pandemic, the researcher will strictly adhere to the issued Covid 19 prevention guidelines during the data collection exercise including ensuring that the researcher and participants wear face masks during the interviews, no hand shaking, adhering to recommended social distancing rule during the interviews and ensuring that the researcher and participants sanitize adequately prior to and after participation. These measures will help limit risk of Covid 19 transmission.

Contacts

For any queries regarding this study, kindly contact;

Principal researcher: Celine Sein Kilanya   mobile phone number - 0714863897

OR

Secretary, Ethics and Research Committee of KNH/UON, Telephone: 020-2726300
Ext 44355

[*Please ensure that you have read the following, or that the following has been read to you, and that you fully understand what is involved in participating in this study and that your role as respondent has been fully explained to you*.]

Appendix 2: Consent Form

Respondent’s Declaration

I have been fully informed about the nature of the study, I know the benefits, and understand that there are no risks involved. I hereby give my consent to participate in this study.

Signature of participant …………………. Date ………………………….

Researcher’s Declaration

I have fully disclosed all the relevant information concerning this study to the study respondent.

Signature of researcher …………………. Date …………………………

Appendix 3: Questionnaire

Introduction

My name is Celine Sein Kilanya, a student at the University of Nairobi pursuing a Master of Science Degree in Nursing (Oncology). I am undertaking a research study on ‘psychosocial challenges experienced by parents with children diagnosed with cancer undergoing chemotherapy in Kenyatta National Hospital’s Pediatric Wards. The aim of this questionnaire is to help me gather information relating to the psychosocial challenges you experience as a parent/caregiver of a child undergoing chemotherapy at KNH.

Instructions

i. Kindly do not write your name or any other personal data on the questionnaire.
ii. Kindly answer the questions honestly and comprehensively.
iii. The information given herein will remain confidential.

Section A: Caregivers’ socio-demographic information

1. What is your gender? Male ( ) Female ( )

2. What is your age in years (in complete years)? …………………………

3. What is your education level?

No formal education ( ) Primary ( )

Secondary ( ) Tertiary (college/university) ( )

4. What is your marital status?

Single ( ) Married ( ) Separated ( ) Divorced ( )

5. What is your occupation?

Unemployed ( ) In business ( ) Employed ( )

6. What is your religion?

Christian ( ) Muslim ( ) Traditionalist ( ) No religion ( )

7. How are you related to the child?

Mother ( ) Father ( ) Sibling ( ) Relative ( )

Other(s) specify ……………………..

Section B: Demographic Characteristics of the Child

1. What is the child's gender: Male ( ) Female ( )

2. What is the child's age? ....

3. a) Is this the child's first admission? Yes ( ) No ( )

b) If not how many times has the child been admitted? …………………

4. Has the child been diagnosed with any other illness apart from cancer?

Yes ( ) No ( )

If Yes, which other illness(es), (specify) …………………………………..

5. Are you here on referral basis or you came here directly?

Here after being referred ( ) Came here directly ( )

Section C: Psychological challenges faced by caregivers of pediatric cancer patients

1. To what extent do you experience the following psychological difficulties owing to your child's health condition and treatment therapy the child is receiving. Use a scale of 1 – 5 where 1 - Strongly Disagree, 2 - Disagree, 3 - Neutral, 4 - Agree, 5 - Strongly Agree.

	Statements on psychological related challenges	**1**	**2**	**3**	**4**	**5**
A	I feel very anxious and depressed due to the fear of the unknown regarding the prognosis and treatment outcome of my child’s condition					
B	I feel hopeless and helpless about the treatment outcome of my child’s health condition					
C	I feel less optimistic about the treatment outcome of my child’s health condition					
D	I feel great sorrow and sadness seeing my child in this condition					
E	I no longer sleep and eat properly for fear that I am going to lose my child					
F	I feel very anxious and concerned about whether the treatment on my child will be successful					
G	I am under intense pressure owing to huge demands that comes with caring for a pediatric cancer patient					
H	I feel extremely worn out, overwhelmed and in no mood for anything or anybody owing to being so preoccupied with my child’s condition and the treatment therapy					
I	I feel very irritable and have been acting aggressively towards other people					
J	I have had to totally re-adjust my routine responsibilities and the disruption to my normal life has been immense					
K	I was filled with great disbelief, confusion and shock following my child’s diagnosis with cancer. I am yet to recover from these.					

Section D: Social challenges faced by caregivers of pediatric cancer patients

1. Do you get any form of social support from family, friend(s) and/or relative(s) in view of the child’s illness and treatment that he/she is undergoing?

Yes ( ) No ( )

If Yes, what kind of social support do they give you?

…………………………………………………………………………………
…………………………………………………………………………………
……………….

If No, what could be the possible reasons?

…………………………………………………………………………………
…………………………………………………………………………………
……………….

2. Are you comfortable sharing about the condition of the child with friends, relatives and/or community members?

Yes ( ) No ( )

If Yes, explain why?

…………………………………………………………………………………
…………………………………………………………………………………
……………….

If No, what could be the possible reasons?

a) Fear of being rejected

b) Fear of stigmatization

c) Fear of being turned a laughing stock

d) Others, specify..

3. According to you, do you feel you have enough emotional and material support from your family/friends to enable the child successfully complete the therapy schedule?

Yes ( ) No ( )

If Yes, explain why?

…………………………………………………………………………………
…………………………………………………………………………………
……………….

If No, why do you feel so?

……………………………………………………………………………………………

…………………………………………………………………………………….

4. To what extent do you experience the following social related difficulties owing to your child's health condition and treatment therapy the child is receiving. Use a scale of 1 – 5 where 1 – Strongly Disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly Agree.

	Statements on social aspects chemotherapy	**1**	**2**	**3**	**4**	**5**
A	I feel isolated and neglected by my extended family, friends and the community owing to my child's illness					
B	I am experiencing difficulties in taking care of the other healthy sibling(s)					
C	My social life is greatly restricted due to the increased burden in the caregiving process					
D	As a family, we are experiencing lack of finances for treatment and other living expenses as my child's health condition has been economically expensive to manage					
E	My daily routine has been completely disrupted due to intense caregiving needs arising from my child's condition					
F	I am worried that I may lose my job/work due to not being able to report to work regularly as I care for my child					
G	I feel that some of the family members and friends have not been very empathetic and supportive					
H	I have experienced social stigmatization from some of the community members which arise from incorrect beliefs about my child's health condition					
I	I feel ill prepared to deal with this crisis and no much social support is given at the hospital outside administration of treatment to the child					
J	My spouse/partner and/or immediate family has not been very supportive					
K	I am facing marital distress due to frequent hospitalizations as a result of my child's health condition					

Section E: Ways in which the caregivers addressed/coped with the challenges

In your own words, how do you cope with these challenges?

…………………………………………………………………………………………
…………………………………………………………………………………………
…………………………………………………………………………………………
……………………….

Thank you for your participation

Appendix 4: Letter to KNH-UoN Ethical and Research Committee

Celine Sein Kilanya,

Reg. No. H56/12467/2018,

School of Nursing Sciences,

College of Health Sciences,

University of Nairobi.

The Secretary,

KNH/UoN - Ethics and Research Committee,

P.O. Box 20723-00202,

Nairobi.

Dear Sir/Madam,

RE: <u>Approval To Conduct A Research Study</u>

My name is Celine Sein Kilanya a student at the University of Nairobi, School of Nursing Sciences undertaking a Masters of Science in Oncology Nursing Degree. I am hereby requesting for your approval to carry out a research study on "psychosocial challenges experienced by caregivers with children undergoing chemotherapy at the oncology wards in Kenyatta National Hospital", as a requirement in partial fulfillment for the award of the said degree.

Thank you in advance.

Yours faithfully,

Celine Sein Kilanya.

Appendix 5: Letter to the Departmental Head – Paediatric Unit of KNH

Celine Sein Kilanya,
Reg. No. H56/12467/2018,
School of Nursing Sciences,
College of Health Sciences,
University of Nairobi.

The Head of Department,
Paediatric Unit – KNH,
Nairobi.

Dear Sir/Madam,

RE: Authority To Carry Out A Research Study at KNH

My name is Celine Sein Kilanya a student at the University of Nairobi, School of Nursing Sciences undertaking a Masters of Science in Oncology Nursing Degree. I am undertaking a research study on "psychosocial challenges experienced by caregivers with children undergoing chemotherapy at the oncology wards in Kenyatta National Hospital", as a requirement in partial fulfillment for the award of the said degree.

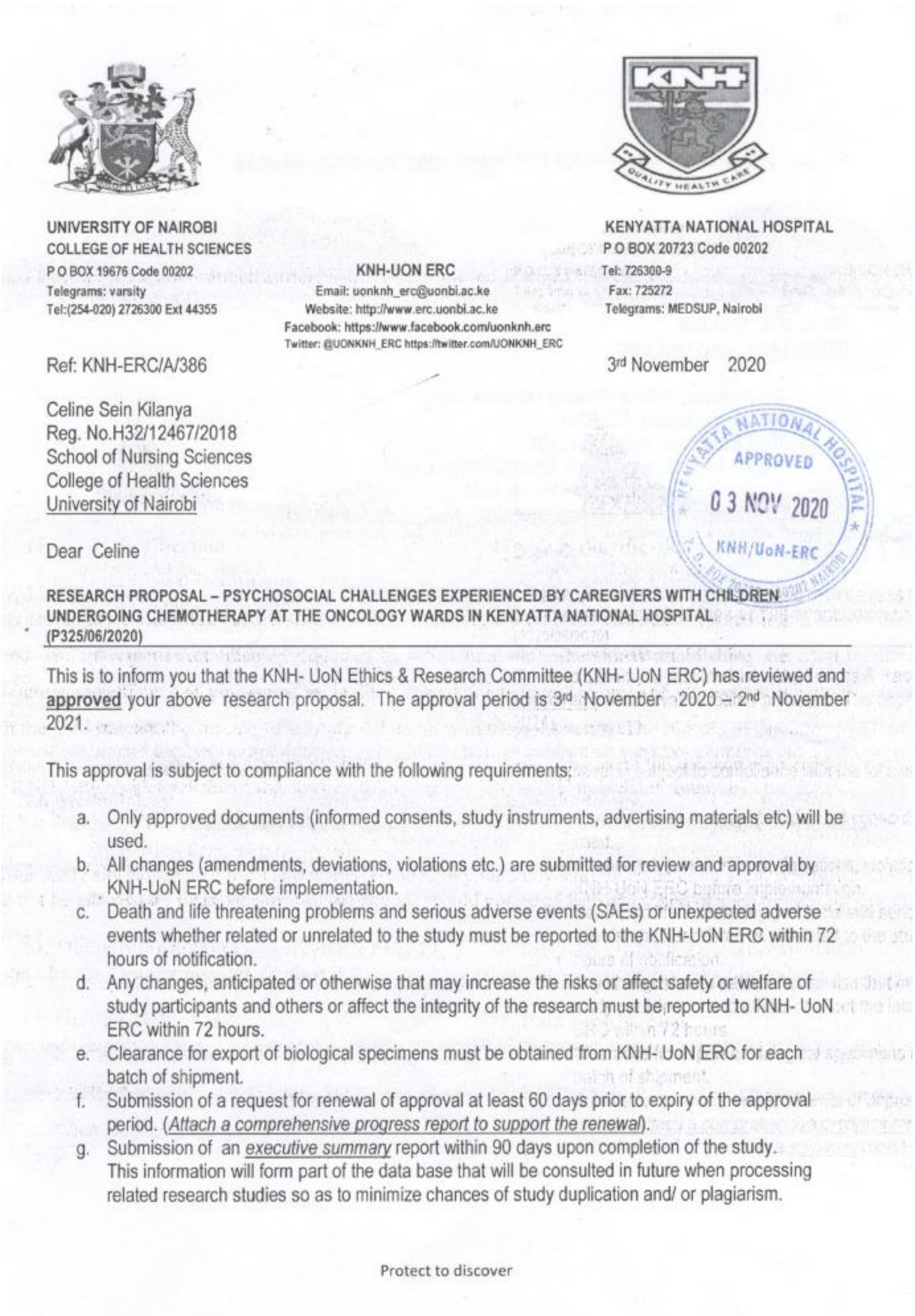
I am therefore hereby requesting for your authorization to conduct data collection within the Peadiatric Unit of KNH among caregivers of children aged below 12 years 11 months admitted with cancer and undergoing chemotherapy in the hospital.

Thank you in advance.

Yours faithfully,

Celine Sein Kilanya.

Appendix 6: Approval Letter from KNH-UoN ERC



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

KNH-UON ERC
Email: uonknh_erc@uonbi.ac.ke
Website: http://www.erc.uonbi.ac.ke
Facebook: https://www.facebook.com/uonknh.erc
Twitter: @UONKNH_ERC https://twitter.com/UONKNH_ERC

KENYATTA NATIONAL HOSPITAL
P O BOX 20723 Code 00202
Tel: 726300-9
Fax: 725272
Telegrams: MEDSUP, Nairobi

Ref: KNH-ERC/A/386

3rd November 2020

Celine Sein Kilanya
Reg. No.H32/12467/2018
School of Nursing Sciences
College of Health Sciences
University of Nairobi

APPROVED
03 NOV 2020
KNH/UoN-ERC

Dear Celine

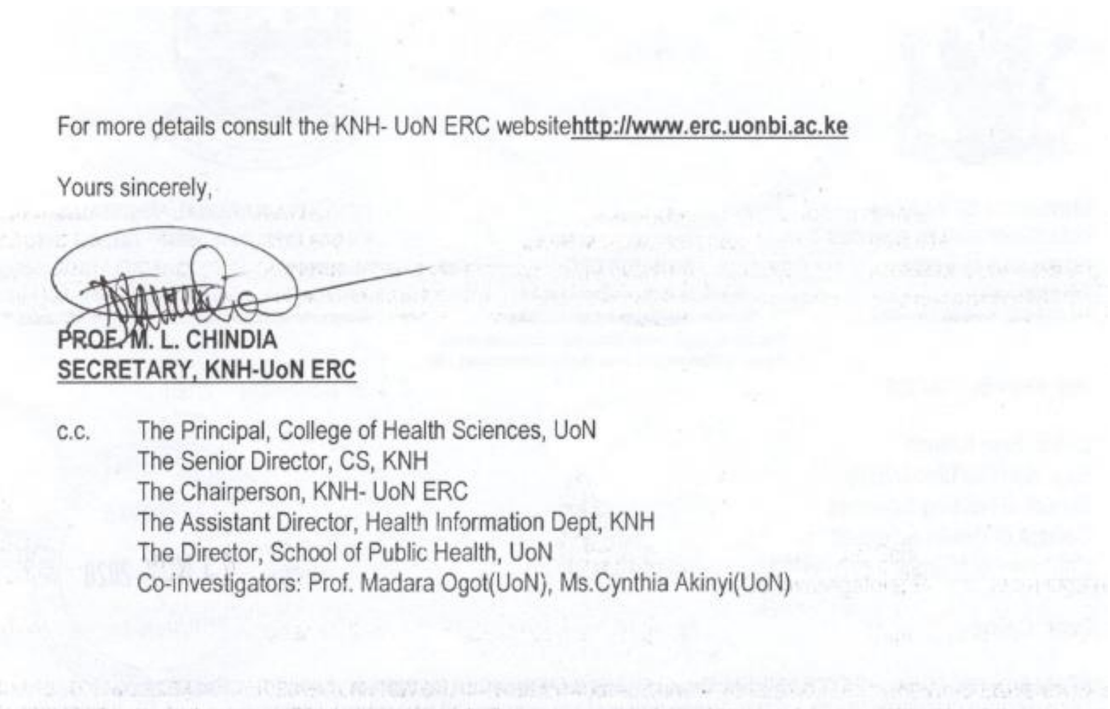
RESEARCH PROPOSAL – PSYCHOSOCIAL CHALLENGES EXPERIENCED BY CAREGIVERS WITH CHILDREN UNDERGOING CHEMOTHERAPY AT THE ONCOLOGY WARDS IN KENYATTA NATIONAL HOSPITAL (P325/06/2020)

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 3rd November 2020 – 2nd November 2021.

This approval is subject to compliance with the following requirements;

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

Protect to discover



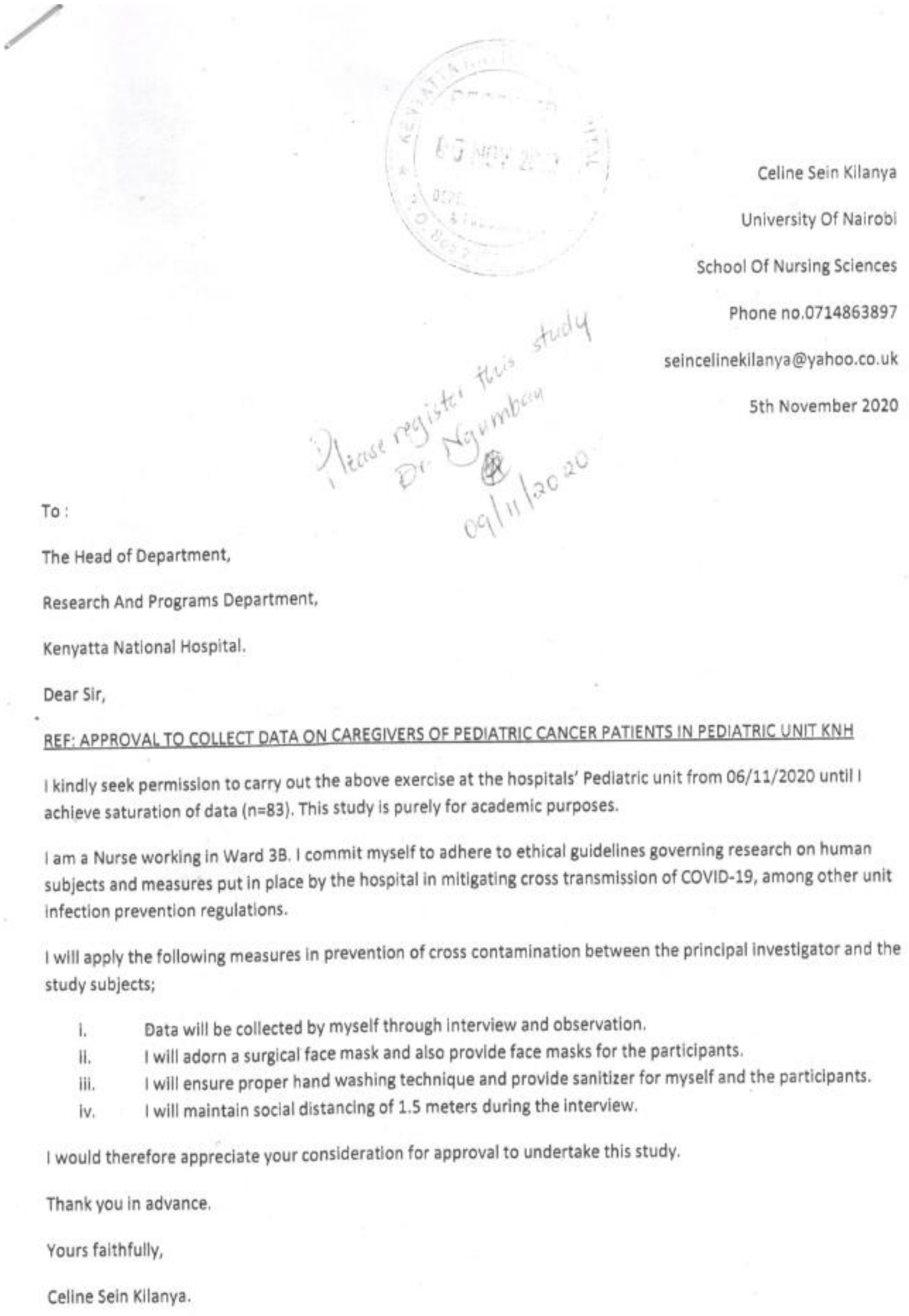
For more details consult the KNH- UoN ERC website**http://www.erc.uonbi.ac.ke**

Yours sincerely,

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

c.c. The Principal, College of Health Sciences, UoN
The Senior Director, CS, KNH
The Chairperson, KNH- UoN ERC
The Assistant Director, Health Information Dept, KNH
The Director, School of Public Health, UoN
Co-investigators: Prof. Madara Ogot(UoN), Ms.Cynthia Akinyi(UoN)

Appendix 7: Approval Letter from Kenyatta National Hospital



Celine Sein Kilanya
University Of Nairobi
School Of Nursing Sciences
Phone no.0714863897
seincelinekilanya@yahoo.co.uk

5th November 2020

Please register this study
Dr. Ngumbau
09/11/2020

To :

The Head of Department,
Research And Programs Department,
Kenyatta National Hospital.

Dear Sir,

REF: APPROVAL TO COLLECT DATA ON CAREGIVERS OF PEDIATRIC CANCER PATIENTS IN PEDIATRIC UNIT KNH

I kindly seek permission to carry out the above exercise at the hospitals' Pediatric unit from 06/11/2020 until I achieve saturation of data (n=83). This study is purely for academic purposes.

I am a Nurse working in Ward 3B. I commit myself to adhere to ethical guidelines governing research on human subjects and measures put in place by the hospital in mitigating cross transmission of COVID-19, among other unit infection prevention regulations.

I will apply the following measures in prevention of cross contamination between the principal investigator and the study subjects;

i. Data will be collected by myself through interview and observation.
ii. I will adorn a surgical face mask and also provide face masks for the participants.
iii. I will ensure proper hand washing technique and provide sanitizer for myself and the participants.
iv. I will maintain social distancing of 1.5 meters during the interview.

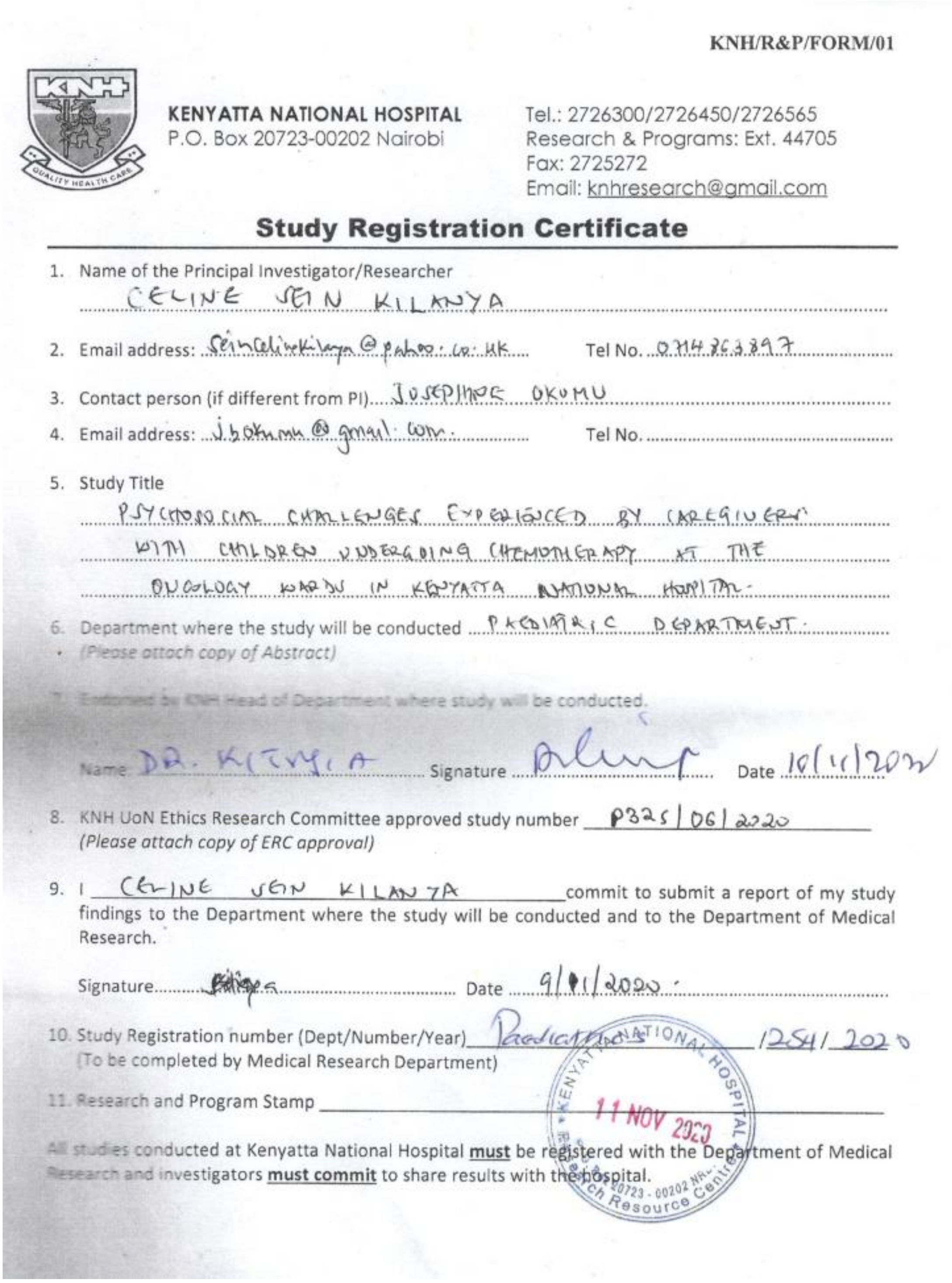
I would therefore appreciate your consideration for approval to undertake this study.

Thank you in advance.

Yours faithfully,

Celine Sein Kilanya.

Appendix 8: Study Registration Certificate



KNH/R&P/FORM/01

KENYATTA NATIONAL HOSPITAL
P.O. Box 20723-00202 Nairobi

Tel.: 2726300/2726450/2726565
Research & Programs: Ext. 44705
Fax: 2725272
Email: knhresearch@gmail.com

Study Registration Certificate

1. Name of the Principal Investigator/Researcher
CELINE SEIN KILANYA

2. Email address: seincelinekilanya@yahoo.co.uk Tel No. 0714863897

3. Contact person (if different from PI) JOSEPHINE OKUMU

4. Email address: j.bokumu@gmail.com. Tel No.

5. Study Title
PSYCHOSOCIAL CHALLENGES EXPERIENCED BY CAREGIVERS WITH CHILDREN UNDERGOING CHEMOTHERAPY AT THE ONCOLOGY WARDS IN KENYATTA NATIONAL HOSPITAL.

6. Department where the study will be conducted PAEDIATRIC DEPARTMENT.
- *(Please attach copy of Abstract)*

7. Endorsed by KNH Head of Department where study will be conducted.

Name DR. KITONYI A Signature Date 10/11/2020

8. KNH UoN Ethics Research Committee approved study number P325/06/2020
(Please attach copy of ERC approval)

9. I CELINE SEIN KILANYA commit to submit a report of my study findings to the Department where the study will be conducted and to the Department of Medical Research.

Signature Date 9/11/2020.

10. Study Registration number (Dept/Number/Year) Paediatrics/1254/2020
(To be completed by Medical Research Department)

11. Research and Program Stamp 11 NOV 2020

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

Appendix 9: Work Plan

	2020						
Activity	**Apr**	**May - Jul**	**Aug**	**Sep**	**Oct**	**Nov**	**Dec**
Development of the concept	🟩						
Proposal writing and presentation		🟩					
Submission of proposal to Ethics Board			🟩				
Pretesting the instrument				🟩			
Data collection and analysis				🟩	🟩		
Report writing and corrections						🟩	
Presentation of the project							🟩
Project results dissemination							🟩

Appendix 10: Budget

Item	Quantity	Unit Cost	Total Cost
HB pencils	20	@ Ksh.35.00x20	Ksh. 700
Pens	10	@ Ksh.20.00x10	Ksh.200
Foolscaps	1 ream	@ Ksh.500.00	Ksh. 500
Printing papers	2 reams	@ Ksh.1,000.00x2	Ksh. 2,000
Note books	10	@ Ksh.500.00x4	Ksh. 2,000
Proposal writing			
Fair copies printing	3 copies, 100 pgs	@Ksh.(5per page x 100)3	Ksh. 1500
Final copy printing	2 copies, 100 pgs	@ Ksh.(5 per page x100)2	Ksh. 1,000
Final copies photocopy	4 copies, 100 pgs	@Ksh.(5 per page x100)4	Ksh.2000
Binding	6 copies	@ ksh. (1,000 per copy)6	Ksh. 6000
Project Writing			
Data analysis statistician	1	@Ksh 100,000	Ksh.100,000
Fair copies printing	2 copies, 100 pgs	@ Ksh.(5 per page x100)2	Ksh. 1,000
Final copy printing	4 copies, 100 pgs	@Ksh.(5 per page x100)4	Ksh.2000
Binding	3 copies	@ ksh. (1000 per copy)3	Ksh. 3,000
Transport cost	1 person for 21 days	@ Ksh 500 x 21 days	Ksh. 10,500
Meals	@1000 per day	@1000 x 21 days	Ksh. 21,000
Tape Recorder		@Ksh. 10,000	Ksh. 10,000

KNH-UoN processing fee			Ksh. 500
Project results dissemination			
Publication in a peer reviewed journal		@Ksh. 40,000	Ksh. 40,000
		Sub-total	**Ksh. 203,900**
Contingencies	10%		20,390
		Grand Total	**Ksh. 224,290**

Psychosocial Challenges Experienced By Caregivers With Children Undergoing Chemotherapy At The Pediatric Unit Of Kenyatta National Hospital

ORIGINALITY REPORT

6%	6%	1%	4%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

PRIMARY SOURCES

1	journals.lww.com Internet Source	3%
2	Submitted to University of Nairobi Student Paper	1%
3	Submitted to Mohave Community College Student Paper	1%
4	ecommons.aku.edu Internet Source	1%
5	Submitted to Kenyatta University Student Paper	1%
6	Lucy W. Meng'anyi, Lilian A. Omondi, Margaret N. Muiva. "Assessment of nurses interventions in the Management of Clinical Alarms in the critical care unit, Kenyatta National Hospital, a cross sectional study", BMC Nursing, 2017 Publication	<1%