DETERMINANTS OF PARENTS' PERCEPTION OF QUALITY OF PAEDIATRIC ONCOLOGY CARE AT KENYATTA NATIONAL HOSPITAL

EUNICE MMBONE KEIZA

H56/69833/2013

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE AWARD OF THE DEGREE OF MASTER OF NURSING SCIENCES (PAEDIATRIC) OF THE UNIVERSITY OF NAIROBI.

NOVEMBER, 2015

DECLARATION

I, Eunice M. Keiza, declare that this research project is my original work and that it has not been presented in any institution for an academic award.

Signature é é é é é é é é é é .. Date é é é é é é é é é é .

CERTIFICATE OF APPROVAL

This research project has been supervised and approved by:

Dr. Margaret N. Chege PhD, MSC, BSC, DAN, RN, RM, RPHN.

Senior Lecturer, School of Nursing Sciences

University of Nairobi

Signature é é é é é é é é é é é é é é é Date é é é é é é é é é ..

Dr. Blasio O. Omuga M. B., ch B., M. Med (Obs/Gynae).

Senior Lecturer, School of Nursing Sciences

University of Nairobi

Signature é é é é é é é é é é é é é é é Date é é é é é é é é é ..

DEDICATION

I dedicate this work to my husband Nathan Keiza and our children Jane, Ian, Judy and Noelle for their constant support, love and patience.

ACKNOWLEDGEMENT

I thank the Almighty God for his grace and favour throughout my study period. I am grateful to my supervisors, Dr. Margaret N. Chege and Dr. Blasio O. Omuga for their commitment and tireless guidance as well as support that has facilitated the completion of this work. I thank the management of Kenyatta National Hospital for giving me an opportunity to further my studies. I also thank my lecturers from the University of Nairobi, School of Nursing Sciences and the entire staff for their support. I thank my colleagues and friends for their support and encouragement during the entire study period. I appreciate my family for their support throughout the entire period of my study. May God bless all those who contributed towards completion of this study.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST ABBREVIATIONS

FGD: Focused Group Discussion

IOM: Institute of Medicine

KEMRI: Kenya Medical Research Institute

KNH: Kenyatta National Hospital

KSHS: Kenya shillings

KMTC: Kenya Medical Training College

MDG: Millennium Development Goal

MOH: Ministry of Health

PEU: Paediatric Emergency Unit

POPC: Paediatric Outpatient Clinic

SPSS: Statistical Package for Social Sciences

UON: University of Nairobi

WHO: World Health Organization

OPERATIONAL DEFINITIONS

Parents: Refers to care givers who are the biological, adoptive or foster, or legal guardians of paediatric oncology patients admitted at Kenyatta National Hospital.

Parents' perception: Refers to the process of regarding, understanding and interpreting issues by parents.

Positive perception: Feeling satisfied with care and having benefited from the care provided.

Negative perception: Feeling dissatisfied with care and having not benefited from the care given

Quality care: The degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with professional knowledge. In this study, the investigator looks at the health care outcome which is parentsô satisfaction with the care provided.

Structures: These are the physical and organizational aspects of care settings such as facilities, equipment, personnel, operational and financial processes supporting provision of care. In this study, the investigator looks at the physical ward environment, equipment and supplies.

Processes: This refers to what is actually done in giving and receiving care. It is the interaction between health care givers and patients during which structural inputs from the health care system are transformed into health outcomes. In this study, the investigator looks at care delivery practices.

Outcome: This is the effect of care on the health status of patients and populations. This is measured in terms of health status, death, promotion of recovery, functional restoration, survival and patient satisfaction. In this study, the investigator looks at the parentsô perception.

Paediatric oncology care: This is the health care service provided by the physicians, nurses, paramedical staff and the health institution as a whole to childhood cancer patients.

Quality paediatric oncology care: This is the care that meets the expectations and needs of childhood cancer patients and their parents.

Patients' satisfaction: This is the patientôs feeling of contentment after their expectations and needs have been met.

ABSTRACT

Background: Global childhood cancer morbidity and mortality is on the increase. Quality care for childhood cancer patients is an important determinant of disease outcome in regard to mortality, quality of life and satisfaction with the care. Patientsô assessment of care provided is an important dimension of quality care provision. Existing literature indicate there is an increasing demand for high quality cancer care. However little is known of what constitutes quality care for cancer patients. Hence there is inadequate knowledge in regard to current perceptions of what quality cancer care is. Determining parentsô perception of quality of paediatric oncology care at Kenyatta National Hospital is necessary to establish baseline information on the current quality of care being provided to childhood cancer patients admitted at the hospital.

Objective: To determine factors contributing to parentsô perception of quality of paediatric oncology care at Kenyatta National Hospital.

Study methodology: This was a cross sectional descriptive quantitative and qualitative study at the paediatric oncology wards of Kenyatta National Hospital. The wards were purposively selected and systematic sampling was used to select study participants in each ward, who were the parents of childhood cancer patients admitted at the hospital. Data collection was done by use of a semi structured questionnaire which was administered to the parents. Focused group discussions with parents who had not been subjected to the questionnaire were conducted with the aim of obtaining in-depth qualitative information on their experiences regarding paediatric cancer care delivery processes at Kenyatta National Hospital. The sample size consisted of 107 parents. Data was analyzed using the statistical program for social sciences (SPSS) version 20 by

use of descriptive and inferential statistics. Chi square test was used to establish significance between variables and the data was presented in tables as well as bar and pie charts.

Results: Out of 107 parents of childhood cancer patients, 57.9% were satisfied with the care services they received whereas 42.1% were dissatisfied. This satisfaction was determined by adequate availability of resources for pediatric cancer treatment [OR=3.10; 95%CI=1.39-6.90; P=0.005], sufficient care delivery processes [OR=2.87; 95%CI=1.28-6.43; P=0.009] and adequate infrastructure/environment [OR=2.59; 95%CI=1.17-5.74; P=0.018]. The main reasons attributed to dissatisfaction as mentioned by FGD participants include; delay in commencement of treatment, unavailability of chemotherapy drugs and blood, delay in carrying out tests and availing of results, lack of information about their childrenôs illness and treatment and congestion.

Conclusion: Even though 57.9% of the respondents were satisfied with the care services, a considerable number (42.1%) were dissatisfied. There is need for the hospital management to enhance effective communication between parents and service providers and to address the issue of congestion as well as unavailability of required resources and amenities for the care of childhood cancer patients. There is also need for the hospital to involve parents in support groups.

CHAPTER ONE: INTRODUCTION

1.1 Background information

Childhood cancer morbidity and mortality is on the increase globally with about 200, 000 children being diagnosed every year (Kellie and Howard, 2008). Developing countries account for 80% of childhood cancers and 90% deaths. (Rodriguez- Galindo et al., 2013). In Africa, it is estimated that 40, 000 ï 50, 000 new cases of cancer will occur yearly (Stefan, 2014). According to the Ministry of Health (2013), Kenyaôs local incidence of new cases of childhood cancers is estimated to be 3000 annually. At Kenyatta National Hospital, childhood cancer burden is on the increase. Statistics obtained indicate that morbidity increased from 389 to 881 while mortality increased from 92 to 153 between 2009 and 2014 respectively among children aged 1 - 12 years (Kenyatta National Hospital medical records, 2015).

Recent research has established that provision of good quality health care can greatly reduce childhood deaths in low income countries where mortality is high (Ntoburi et al., 2010). Existing literature indicate there is an increasing demand for high quality cancer care. However what constitutes quality care for cancer patients is not well defined. Hence there is inadequate knowledge in regard to current perceptions of what quality cancer care is (Hess and Gerhardt, 2013). Without assessing parentsôperception of what constitutes quality care in childhood cancer patients, standards of care that meet parentsô and paediatric cancer patientsô needs and expectations may not be achieved. This is because health care service providers may set their own standards which may not favour the patients. Given the magnitude of paediatric cancer burden, it is important to review the quality of care provided to these group of patients by determining the parentsô perception of the care given. Studies have shown that provision of

quality care to childhood cancer patients can reduce the treatment related complications and improve their survival and quality of life as well as their parents (Knops, 2011).

Since the outcome of childhood cancer patients greatly depends on the quality of care they receive, there is need to evaluate the care provided to this group of patients and their parents by establishing their perception regarding the quality of care provided. This is in order to be able to provide care aimed at meeting their needs and expectations in accordance to the requirements of World Health Organization (WHO) as pertains to quality care (WHO, 2006). Evaluating patientsô experiences provides vital information on their perception of the quality of care and treatment provided by the health care providers and the hospital as a whole. Factors affecting provision of paediatric oncology quality care cannot be adequately addressed without establishing the parentsô perspectives on the quality of care that they and their children receive. Hence the need for this study to establish from the viewpoint of parents, factors that contribute to their perception in regard to the quality of paediatric oncology care at Kenyatta National Hospital.

The history of health care quality begun with Florence Nightingale in the mid 19th century. From her quality improvement documentation, it is noted that improvement of the hospital environment greatly reduced the mortality rate of British troops in the year 1855. This indicates the key role nursing has in improving quality of care (Mitchell, cited in Hughes, 2008). In this 21st century, health care systems worldwide are focusing on efforts to improve quality of health care delivered to their population (Sheingold and Hahn, 2014). The primary goal of health care provision is to improve the patientsô health care outcomes. These health care outcomes are determined by the structures and processes involved in the delivery of health care services. This shows the linkages among the structural attributes of the settings in which care occurs, the

processes of care and the outcomes of care. Information about the structures and processes and how they influence care outcome can be obtained from interviewing the patients and healthcare providers (Muntlin et al., 2006).

1.2 Problem statement

About 200, 000 children globally are being diagnosed with cancer every year (Kellie and Howard, 2008). It is estimated that 40, 000 - 50, 000 new cases of cancer will occur yearly in Africa (Stefan, 2014). In Kenya, the local incidence is estimated to be 3000 new cases of childhood cancer that will occur yearly (Ministry of Health, 2013). At Kenyatta National Hospital, childhood cancer burden is on the increase. Statistics obtained indicate that morbidity increased from 389 to 881 while mortality increased from 92 to 153 between 2009 and 2014 respectively among children aged 1 - 12 years (Kenyatta National Hospital medical records, 2015).

The quality of care provided in many primary and referral health facilities in low income countries is considered to be generally poor. High mortality rate is also reported in these countries (Ntoburi et al., 2010). This is supported by Rodriguez- Galindo et al. (2013) who say developing countries account for 80% of childhood cancers and 90% deaths. This outcome is attributed to factors such as high prevalence of malnutrition and other co-morbidities as well as suboptimal supportive and palliative care (Rodriguez- Galindo et al., 2013). This could lead to negative perception and dissatisfaction among parents of children with cancer. There is an increasing demand for high quality cancer care, however little is known of what constitutes quality cancer care. Therefore there is a gap in knowledge in regard to current perceptions of what quality cancer care is (Hess and Gerhardt, 2013). The parentsô perception of quality of paediatric oncology care at Kenyatta National Hospital is still largely unknown. From the

literature review, there is no published information on parentsô perspectives on quality of paediatric oncology care at Kenyatta National Hospital.

According to Kam et al. (2008), parents of children with chronic illnesses perceive the quality of hospital care they receive to be low. This makes childhood cancer patients among those whose parents perceive they receive low quality of hospital care (Kam et. al, 2008). Negative perception can lead to patients avoiding the health care system which they regard to have poor quality or using it as a last resort measure and this can affect preventive care and early detection of the disease (Andaleeb, 2001). Parentsô perception will determine their continued use of the care provided and also their recommendation of the care to others. In order to ensure parents are satisfied with the care given, health care providers have to provide care that meets their needs. Understanding parentsôperception is important in regard to tailoring the care to meet their needs. The provision of quality care could help in reducing mortality and hence contribute towards achieving the fourth millennium development goal (MDG), which is aimed at reducing child mortality. Parentsôperceptions should therefore be central in planning of health care services.

1.3 Justification

The primary goal of health care provision is to improve the patientsô health care outcomes. Quality care for childhood cancer patients is an important determinant of disease outcome in regard to mortality, quality of life and satisfaction with the care. These health care outcomes are determined by the structures and processes involved in the delivery of health care services. This shows the linkages among the structural attributes of the settings in which care occurs, the processes of care and the outcomes of care. Information about the structures and processes and how they influence care outcome can be obtained from interviewing the patients (Muntlin et al.,

2006). The proposed study intends to establish the viewpoints of parents of paediatric oncology inpatients in regard to the hospitalôs structures and processes involved in the delivery of health care. This is in order to establish how they affect the care received by these patients while in hospital which eventually contributes to their disease outcome in regard to mortality, quality of life and satisfaction with the care provided. Previous studies have shown that it is important to determine the parentsô requirements in terms of information and emotional support in order to improve the services provided to the families. Physical, psychological and educational needs of the parents of children with cancer require to be addressed by health care providers and these can be established from their perspectives of the care provided (Lock et al., 2012).

At Kenyatta National Hospital, there are no published studies on parentsôperception of quality of childhood cancer care, hence there is need to establish the current state in regard to the quality of paediatric cancer care at the hospital. Without assessing parentsô perception of what constitutes quality care in childhood cancer patients, standards of care that meet parents and paediatric cancer patientsô needs and expectations may not be achieved. The study will help to inform policies and guidelines on paediatric oncology care that will be geared towards high quality care provision and hence reduce treatment related complications and improve survival and quality of life of paediatric oncology patients and their parents. Assessing parentsôperception of paediatric oncology care will provide baseline information on the current quality of care and treatment provided by the health care team and the hospital as a whole. This information can be used by the hospital management in decision making in regard to setting of standards for paediatric oncology care as well as making policies that are aimed at improving the care of childhood cancer patients. This will enhance quality of life and satisfaction of childhood cancer patients

and their parents and also help in contributing towards achieving the fourth millennium development goal (MDG), which is aimed at reduction of child mortality.

1.4 Research question

What are the factors that determine the perception of parents on quality of paediatric oncology care at Kenyatta National Hospital?

1.5 Hypothesis

There is no relationship between the institutionôs structures and care delivery processes and parentsôperception of quality of paediatric oncology care at Kenyatta National Hospital.

1.6 Purpose of study

To ascertain parentsô assessment of quality of paediatric oncology care at Kenyatta National Hospital and determine factors that contribute to their perception of the care provided.

1.7 Broad objective

To determine the factors contributing to parentsô perception of quality of paediatric oncology care at Kenyatta National Hospital.

1.8 Specific objectives

1. To assess the parentsôperspectives on the structures and care delivery processes in regard to the quality of paediatric oncology care at Kenyatta National Hospital.
2. To establish parentsôviews towards health care service providers in regard to the quality of paediatric oncology care at Kenyatta National Hospital.

3. To determine the parentsô level of overall satisfaction with paediatric oncology care services at Kenyatta National Hospital.

1.9 Study benefits

The study will contribute knowledge regarding factors that determine parentsô perception of quality of paediatric oncology care at Kenyatta National Hospital. This information can be used by the hospital management in setting standards for paediatric oncology care as well as making policies that are aimed at improving the care of childhood cancer patients. The use of study findings to improve care will in turn improve the patientsô quality of life and enhance their satisfaction with the care given.

CHAPTER TWO: LITERATURE REVIEW

2.1: Introduction

Literature review was done based on previous studies that have been carried out on parentsô perception of quality care of paediatric oncology patients. Literature on adult patientsôperception of quality of oncology care was also reviewed. Parentsôperception of the factors contributing to quality paediatric oncology care has also been discussed. These factors are related to the structures and processes within the health care institution and have an impact on the outcome of care of children with cancer.

According to the Institute of Medicine (IOM), quality care is defined as ótthe degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with the current professional knowledge. The outcomes are required to meet the expectations of health care users (Mainz, 2003). In order for care to be considered high quality, it should be patient centered, timely, efficient and effective, accessible, equitable and safe (WHO, 2006).

Peoplesô perceptions are influenced by desires, needs and the personality of the person (Chodzaza and Bultemeier, 2010). What people perceive as good or bad influences their behaviour in a particular situation. Negative perceptions of patient- doctor relationship can have an effect either positively or negatively on the care of the patient, such as patientôs following of medical advice or delaying needed care. Negative perception among patients lead to feelings of being treated with disrespect or looked down upon (Blanchard and Luvie, 2004). Positive perception influences patientsô satisfaction positively. This could serve as a motivation to do better to recover. Negative perception can lead to patients avoiding the health care system or

using it as a last resort measure and this can affect preventive care and early detection of the disease (Andaleeb, 2001).

2.2 Nursing theories in paediatric oncology

The humanistic theory by Paterson and Zderad according to Pearson et. al. (2005) views nursing as an interhuman event where the dignity, interests and values of the nurse and the person being nursed are of great importance. The theory further views nursing as a ólived dialogueô whereby the nurse experiences a call for help and responds to the client in a human and deliberate way, through purposeful two way communication leading to the needs of the patient being identified and addressed (Pearson et al., 2005). From literature, it is noted that provision of palliative care to children with cancer enhances quality of life and minimizes suffering. This requires effective communication among the child, family and health care providers. Research has shown ineffective communication to be a barrier which prevents the delivery of consistent and appropriate care. Effective communication allows the medical, psychological, spiritual and social needs of the child to be known and included in the plan of care. Communication among health care professionals with the child and the family members is of great importance and needs to be clear and consistent (Hubble et al. 2008).

According to the human becoming theory by Parse (Pearson et. al. 2005), the goal of nursing is for clients to achieve more or improve the quality of their lives according to the individualôs and familyôs perspective of what constitutes quality of life (Pearson et al., 2005). The theory further says that being with a person implies a physical presence as well as an ability to accept his/her perceptions, values and beliefs (Pearson et al., 2005). The principles of paediatric nursing include encouraging the child and the family to participate in goal setting and the provision of

holistic and proactive care through communication (Kolcaba and Marguerite, 2005). Comfort theory by Kolcaba and Marguerite defines comfort as the immediate state of being strengthened through having the human needs for relief, ease and transcendence addressed in four contexts of experience which include the physical, psycho spiritual, sociocultural and environmental aspects. When discomfort such as pain cannot be prevented, children and families can be assisted to experience partial or incomplete transcendence through comfort (Kolcaba and Marguerite, 2005).

2.3: Determinants of parents' perception of quality of paediatric oncology care

Literature identifies determinants of perceptions of cancer care to be associated to structures and processes of care within a health care institution. According to a study by Lock et al. (2012), clinical service delivery, physician patient interaction and patient information contributes greatly to parentsô perception of care. Findings from this study indicate that parents were satisfied with availability of drugs, degree of performance by oncology nurses as well as amenities provided for parents and children. It is further noted from the study that parents were dissatisfied with lack of clear instructions on who was in charge and who to consult when they needed to request for assistance (Lock et al., 2012). A study by Boutopoulou et al. (2010) on parentôs satisfaction concerning their childôs care identified adequate pain management, involvement of parents in care, trusting relationship and staff attitudes to be the most important determinants of parental satisfaction. Parents reported dissatisfaction from lack of information concerning routines and staff work environment (Boutopoulou et al. (2010). A study by Lis et al. (2009), found out that patient- provider relationship, facility setting and information on diagnosis and treatment were major determinants of patientsô willingness to recommend a facility to a friend. According to findings from a study by Mack et al. (2005), parents of children who die of cancer regarded doctor - patient communication as the main determinant of high quality physician care.

2.3.1 Socio-demographic factors determining parents' perception of quality of care

Sociodemographic factors play a role in influencing parentsô perception of the quality of childhood cancer care given. According to a study done by McKenna et al. (2010), it was noted that age played a great role in regard to decision making regarding the childôs treatment. Younger parents expressed need for family involvement in treatment decisions while older parents received and desired to have more input from medical staff members before making the decision. It is also noted from this study that parents who had attained a higher level of education are reported to have a short time frame for decision making (McKenna et al., 2010).

Literature documents the effects of childhood cancer on the emotional and physical functioning of the parents. A study done among parents of children receiving cancer treatment in a hospital in Malaysia found out that parents with higher income and education reported higher cancer knowledge and reduced stress and anxiety (Azizah et al., 2011). Parental stress can interfere with the care giving role hence affecting quality of care of the child. Therefore psychological assessment and intervention can reduce parental stress by increasing coping hence reducing childrenôs psychological problems since distress in parents is correlated to distress in children (Azizah et al., 2011).

2.3.2 Institutional factors determining parents' perception of quality of care

Patients perceive institutional factors as having a major role to play in quality of care. According to a study done at a Swedish university hospital, organizational structures and processes play a great role in patientôs perception of level of quality (Muntlin et al., 2006). The nursing work environment influences patientsô experiences of quality care. Hospitals that have poor nurse practice environment are likely to experience a high number of mortality rates (Shang et al.

2012). Patients and nurses have higher positive experiences in hospitals where work environment is better (Kieft et al., 2014). The staffsô work environment impacts on their health care performance hence affecting how patients view the quality of care provided (Ygge, 2004). In low and middle income countries, the absence of specialized oncology nurse training programs contributes to sub optimal outcomes and low nurse staffing contributes to increased mortality and adverse effect on patient outcomes (Stefan and Rodriguez- Galindo, 2013). Lack of drugs for patients in government hospitals contribute to clientsô perception of low quality of service (Nyongesa et al., 2013).

2.3.3 Care delivery process factors determining parents' perception of quality of care

Literature identifies quality cancer care from the patientôs perspective to include information, communication and coordination of care, timeliness of care, personalized care, psychosocial support and attention from health care providers. It further says that patient barriers to quality care include lack of information and communication as well as lack of attention to care and coordination by the health care workers (Hess and Gerhardt, 2013). Health care providers need to ensure good communication between them and the patientsô parents. Improved quality of communication with a parent of a hospitalized child can have the most positive impact on a hospitalôs overall quality of care rating (Patrick et al. (2003). From literature, it is noted that parents perceive being given clear information on what to expect for example in the end of life period and doctor patient communication to be quality care (Mack et al. 2005). A study done in Italy on health care quality in two peadiatric oncology centers for treating children with cancer highlights the importance of high psychological and sociological support as well as communication between the health care team and parents of children with cancer as determinants of perceived quality among the parents (Chiaradia et al. 2008). According to Arora et al. (2010),

inadequate communication provided to parents by health care providers is related to abandonment of treatment. Nurses and doctors can contribute towards the provision of quality care to paediatric oncology patients by actively communicating to the parents and involving them in the childôs care (Arora et al. (2010).

Provision of palliative care to children with cancer enhances quality of care and minimizes suffering. This requires effective communication among the child, family and health care providers. Research has shown ineffective communication to be a barrier which prevents the provision of consistent appropriate care (Hubble et al. 2008). Effective communication allows the medical, psychological, spiritual and social needs of the child to be known and hence be included in the plan of care. Communication among health care professionals with the child and the family members is therefore of great importance and needs to be clear and consistent (Hubble et al. 2008). According to a study done by Hess and Gerhardt (2013) it was found out that perception of quality care by parents, care givers and health care providers include, better patient information, improvement in care coordination, psychosocial support, timeliness of care, personalized care and improved communication with care providers.

A study done by Sandoval et al. (2006), on factors that influence cancer patientsô overall perception of the quality of care, it is noted that patients identified the following areas as priority to improve cancer care services. These include; information, technical competence, interpersonal and communication skills, time spent talking with the doctors and accessibility of the nurses. Literature suggests that many patient complaints and dissatisfaction are due to doctor patient relationship (Ha and Longnecker, 2010). Good communication can lead to patient satisfaction with care and this can help in identifying the patientôs problems or needs, their perception and expectations as well as the adherence to medical advice and the required treatment regime (Ha

and Longnecker, 2010). A study done in Europe and the United States on patient safety, satisfaction and quality of hospital care, found out that nursesô involvement in decision making and positive nurse doctor relationship are associated with improved patient outcomes (Aiken et al., 2012).

A study by Izumi et al., (2010) shows that patients regarded quality nursing care to include competency of the nurse and professionalism which includes responsibility and commitment which are required to be provided in a caring as well as a friendly and respectful manner. According to Copp et al., (2006) elderly patients with advanced cancer receiving palliative care valued the provision of medical information that was given in an honest manner. Cancer patientôs satisfaction with the care provided can be enhanced by health care professionals through appropriate caring behaviours (Zamanzadeh et al., 2010). When discomfort such as pain cannot be prevented, children and families can be assisted to experience partial or incomplete transcendence through comfort interactions that convey hope, success, caring and support for their fear (Kolcaba and Marguerite, 2005).

2.3.4 Service provider factors determining parents' perception of quality of care

A nurse is the primary care provider and spends more time with the patients as compared to other care providers. The major service delivered in a hospital being nursing is a main factor that influence patientsô perception of overall care quality delivered in the hospital. A study by Izumi et al., (2010) shows that patients regarded quality nursing care to include competency of the nurse and professionalism which includes responsibility and commitment which are required to be provided in a caring as well as a friendly and respectful manner.

2.3.5 Care giver empowerment factors determining parents' perception of quality of care

Findings from literature indicate that although family care givers are involved in the care of patients with chronic illnesses, many report they do not have the required skills and knowledge to provide the necessary care yet these are important to enable them to be able to make decisions and solve problems (Given et al., 2008). Since their care giving role requires them to be involved in the patientôs plan of care, the knowledge is important for them to be able to perform tasks such as administering medications to the child and monitoring any new signs and symptoms as well as any adverse events that could arise (Given et al., 2008). According to Gunawan et al. (2014), parents require to be given better explanations about the side effects of chemotherapy in their children. Inaccurate and inconsistent information can contribute to high abandonment rate especially during induction. Therefore an experienced health care provider needs to provide the information about the side effects of treatment (Gunawan et al. 2014).

2.4 Gaps in literature review

It has been noted from the literature that provision of information to the parents of children with cancer regarding the illness and the treatment by the clinician is still a challenge that needs to be addressed due to its importance. Even though, there are still gaps in literature that need to be addressed such as when parents want to be provided with information and to what level of detail the information needs to be provided. There is also need to determine whether parents require information or emotional support so as to improve the services provided to the families. It is noted that there is need to identify approaches which are efficient for strengthening parentsô perceived support. From literature, it is also noted that there are gaps pertaining to the physical, psychological and educational needs of the parents of children with cancer that require to be addressed by the health care providers (Lock et al., 2012).

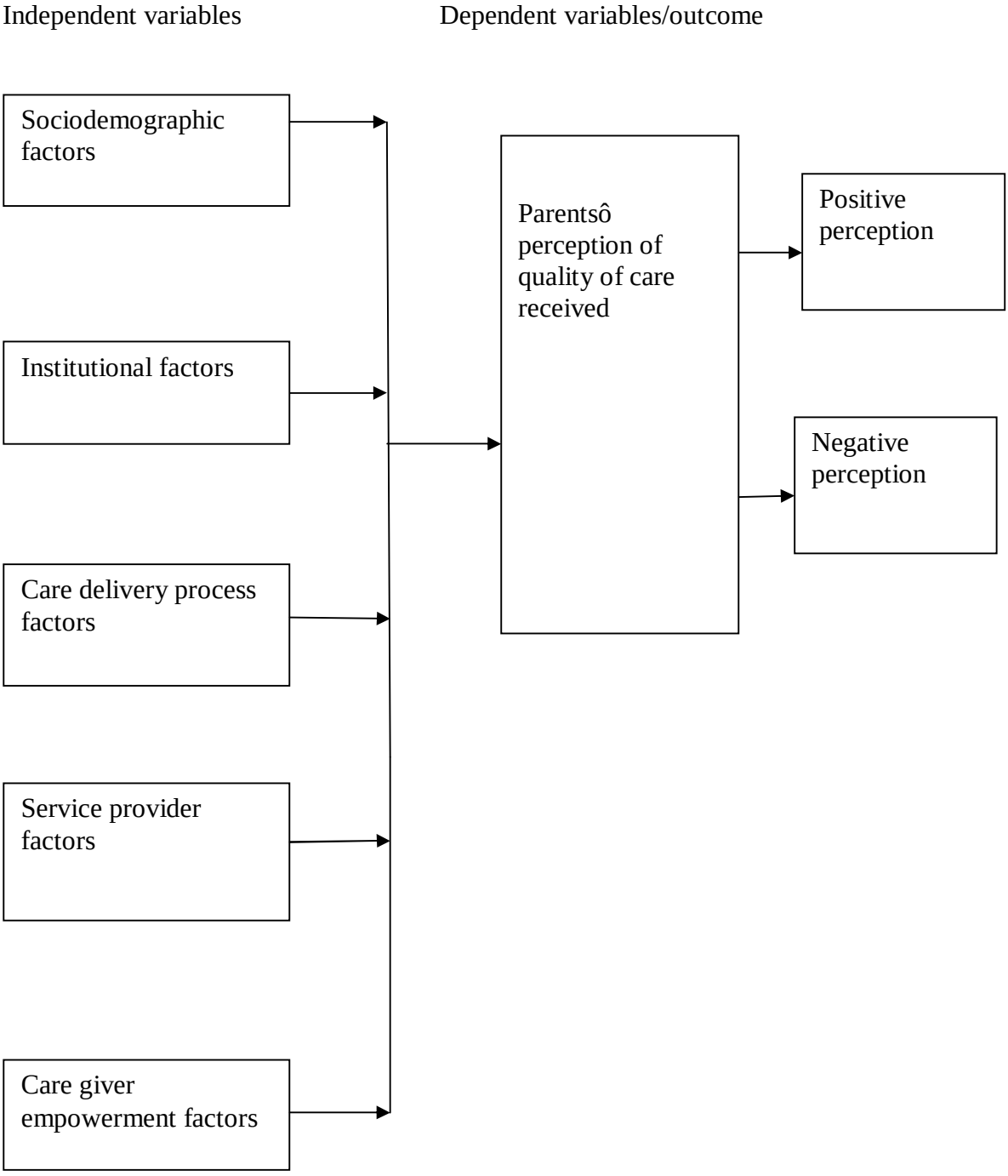
2.5 Theoretical framework

This study was guided by Avedis Donabedianôs framework model (1966) for assessing quality care. Donabedian is considered as the pioneer in the field of health care quality. He developed a framework that is used in health care institutions to help in quality improvement efforts. He defined the health care triad of structures, processes and outcome and sees structures as a driving force for care processes and health outcomes (Glickman et al., 2007). According to Donabedian, measurement of health care quality needs to be based on these three components as each component has a direct influence on the other (El Haj et al., 2013). The framework illustrates the relationship between the structures, processes and outcomes. The structures and processes are essential for provision of high quality care and they contribute to quality outcomes. This framework model was used for assessing the structures and processes within Kenyatta National Hospital and their combined influence on determining parentsô perception of the quality of care of childhood cancer patients admitted at the health care facility. According to this model, the structures of health care are defined as the physical and organizational aspects of care settings such as facilities, equipment, personnel, operational and financial processes supporting provision of care. In this study the structures include the physical environment which comprises the ward and work environment and availability of staff as well as the resources required. The processes of patient care include interactions between care givers and patients and these rely on the structures to provide resources and mechanism for those participating to be able to carry out patient care activities which are aimed at outcomes such as promotion of recovery, functional restoration, survival and patient satisfaction (McDonald et al., 2007). The processes of care which involve the way care is delivered includes the technical and interpersonal aspects. Technical aspects involve timeliness and accuracy of diagnosis, coordination of care and

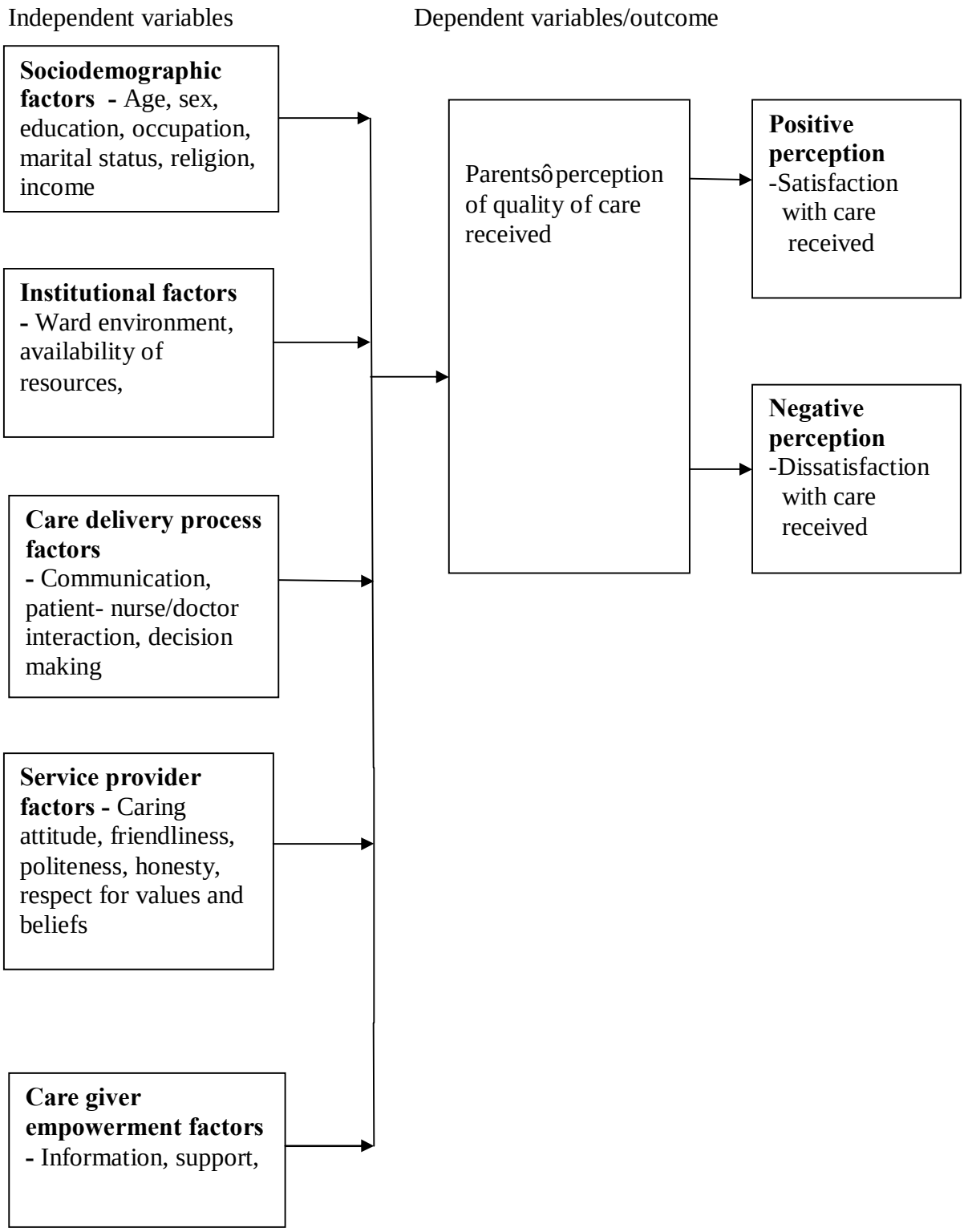
appropriateness of therapy whereas interpersonal aspects involve clinician- patient relationship, information and involvement in decision making (El Haj et al., 2013). In this study care processes include patient- nurse/physician relationship and communication, as well as service provider factors such as attitude, competence, responsiveness, knowledge and caring behaviour.

According to Donabedian, one of the outcomes of care includes client satisfaction. It is considered to be of great importance when measuring quality of care. This is because it gives information about the success of the health care provided in regard to meeting the clientôs needs and expectations. If patients are not satisfied, then health care has not achieved its goal (Ygge, 2004). In this study patient outcomes include parentsô satisfaction with the care provided to children with cancer. Based on this theory, this study examined factors which determined the parentsô perception of quality of paediatric oncology care in regard to their satisfaction with the care provided. These factors include the ward/working environment, availability of resources, care delivery processes and service provider factors such as attitude and caring behaviours. Family care giver empowerment factors such as information, involvement in care and decision making as well as support were also assessed.

2.6 Conceptual Framework



2.7 Operational Framework



2.8 Key variables

2.8.1 Independent variables

Sociodemographic factors: age, sex, occupation, marital status, education, religion, income.

Institutional factors: ward environment, availability of resources.

Care delivery process factors: communication, patient- nurse/doctor interaction, decision making.

Service provider factors: caring attitude, friendliness, politeness, honesty, respect for values and beliefs.

Care giver empowerment factors: information, support.

2.8.2 Dependent variables/outcome

Parentsô perception of quality of paediatric oncology care received

- Positive perception: satisfaction with care received.
- Negative perception: dissatisfaction with care received.

CHAPTER THREE: STUDY METHODOLOGY

3.1 Study Design

This was a descriptive cross- sectional study where both qualitative and quantitative data was collected to determine factors contributing to parentsô perception of quality of paediatric oncology care at Kenyatta National Hospital.

3.2 Study area

The study was carried out at Kenyatta National Hospitalôs paediatric oncology wards 1E, 3A, 3B, 3C and 3D. Kenyatta National Hospital is in Nairobi County and is located off Ngong Road along Hospital Road. It covers an area of 45.7 hectares and within its complex is the college of Health Sciences of the University of Nairobi (UON), the Kenya Medical Training College (KMTC), Kenya Medical Research Institute (KEMRI) and the National Laboratory Service (Ministry of Health). Kenyatta National Hospital is the largest National referral, teaching and research hospital in Kenya with a bed capacity of about 1800. Out of the total bed capacity, 209 beds cater for prime care centre (private wing) which is located on the ninth and tenth floors as well as first floor (ward 1C). Founded in 1901, Kenyatta National Hospital is the largest in Eastern and Southern Sahara. The hospitalôs mandate is to provide specialized quality health care, facilitate medical training and research and participate in National health policy. It is the primary teaching hospital of the University of Nairobi and Kenya Medical Training College - Nairobi. It receives patients from various parts of the country as well as from East and Central Africa. It has 50 wards, 22 outpatient clinics, 24 theatres (16 specialized) and an Accident and Emergency department. Administratively, the hospital is divided into various departments according to the different specialities. Paediatric oncology care is one of the specialized health

care provided by Kenyatta National Hospital. The hospitalôs tower block has ten floors with four wards on each floor namely A, B, C, and D. Paediatric oncology is under the department of paediatrics. Oncology ward 1E is located on the first floor of the old hospital building while wards 3A, 3B, 3C and 3D are located on the third floor of the hospitalôs tower block. The paediatric oncology wards admit patients aged 0 - 12 years. The patients are admitted through the paediatric outpatient clinic (POPC) and the pediatric emergency unit (PEU).

3.3 Study population

The study population consisted of parents of paediatric oncology inpatients.

3.4 Inclusion criteria

1. Parents of children with cancer aged 0-12 years admitted at Kenyatta National Hospitalôs paediatric wards.

2. Parents of children with cancer who consented to participate in the study.

3.5 Exclusion criteria

Parents of children with cancer who did not consent to participate in the study.

3.6 Study sample size determination

Statistical records obtained from the health information department indicated that 881 children with cancer aged 0-12 years were admitted at Kenyatta National Hospital between January 2014 and December 2014 which is an average of about 73 children being admitted every month. The study was conducted within a period of two months, therefore the total population available was

considered to be 146 (73 admissions monthly for two months). The desired sample size was determined by the following formula by Fisher as cited by Mugenda and Mugenda (2003).

$$n = \frac{Z^2 pq}{d^2}$$

Where:

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

Z = the standard normal deviate at 95% confidence interval = (1.96)

p = the proportion in the target population estimated at 0.5

Since the parentsô perception on paediatric oncology care is not known, p is taken as 50%

q = 1-p

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

Substituting these figures in the above formula:

$n = (1.96)^2 x\ (0.5) x\ (0.5)/(0.05^2)$

n= 384

Since the target population is less that 10 000, the sample size calculation was adjusted for finite population using Fisherôs formula as follows;

nf = n/1+(n/N)

Where:

nf = desired sample size for population less than 10 000

n = desired sample size for population greater than 10 000

N = estimate of the population size (146)

nf = 384/1+(384/146)

nf = 106.6 which is approximately 107

The required sample size is 107 parents.

3.7 Sampling method

Purposive selection of paediatric oncology wards was done and systematic sampling was used to select study participants. A list of patients in each ward was obtained as follows;

3A - 9

3B -12

3C -11

3D - 9

1E -24

From the sample size obtained above, proportionate allocation of study participants based on the number of patients in each ward was calculated using the following formula; n_1/n_2 x nf

whereby;

n1 = number of patients in the ward

n2 = total number of patients in paediatric oncology wards

nf = calculated sample size of the study participants

The number of study participants per ward is illustrated in Table 3.1 below.

Table 3.1: Selection of study participants from paediatric oncology wards

Ward	Number of patients in the ward	Total number of patients in paediatric oncology wards	Calculated sample size	Total number of parent participants	Percentage
3A	9	65	107	9/65 x 107 = 15	14.01%
3B	12	65	107	12/65 x 107 = 20	18.69%
3C	11	65	107	11/65 x 107 = 18	16.82%
3D	9	65	107	9/65 x 62 = 15	14.01%
1E	24	65	107	24/65 x 62 = 39	36.44%

3.8 Sampling interval

$$\text{Sampling interval} = \frac{\text{Sample size}}{\text{Total population}} = 107/65 = 1.6 = \text{approximately } 2$$

Every second parent according to the patientsô (childrenôs) list in each ward was systematically sampled until the required number of participants in each ward was reached.

3.9 Recruitment and enrollment of study participants

Parents of children with cancer admitted at Kenyatta National Hospital were identified and sampled from the various paediatric department oncology wards. The researcher approached each identified parents, introduced herself to them and informed them of the intended study to be carried out. Consent was obtained from the parents who agreed to participate in the study either by being subjected to a semi structured interview or by participating in a focused group discussion. Those who consented to participate were recruited and enrolled for the study. The parents who were not subjected to a semi structured interview participated in the focused group discussion.

3.10 Recruitment and Training of Research Assistant

The researcher identified one research assistant among registered BScN nurses who underwent a one day training session. The training involved identification of study participants, sampling methodology, administration of the questionnaire and verification of the completeness of the questionnaire after it had been filled.

3.11 Study Instruments

Data was collected using a semi structured questionnaire (Appendix IV) and a focused group discussion guide (Appendix VI) by the principle investigator together with the research assistant.

The parentsô questionnaire was in English and Swahili versions and the interview was conducted in English or Swahili where appropriate**.**

3.12 Pre- testing of study instruments

Following the training of the research assistant, pre testing of the questionnaire was done by the researcher in ward 1F (9D) which is one of the wards where paediatric oncology patients are cared for. However this ward was not part of the study area since it falls under a different department (ophthalmology) and is therefore not under paediatric department. Pre- testing of the study instrument was done to verify the data collection tool before data was collected and also to help estimate the time that would be taken in administering the questionnaire to each respondent. The pre- test results were used to improve the study tool for validity and reliability.

3.13 Data collection

Data for this study were collected in two phases over a period of two months. The first phase consisted of administering a pre- tested semi structured questionnaire, which was in English and Swahili languages. The second phase consisted of focus group discussions. Two sessions of FGDs were held with the participants. All the FGDs were audio taped. Each FGD took an average of fifty minutes. The researcher approached the study participants and introduced herself and thereafter informed them about the intended study. The parents were presented with a consent form (Appendix III) and the study purpose, procedure, risks, confidentiality, benefits of the study as well as their right to refuse or withdraw from the study was explained in the language they understood i.e. in English or Swahili. The parents who agreed to participate in the study were requested to sign the consent form, (Appendix III). The parents were interviewed either in English or Swahili according to the language they understood through a semi structured

questionnaire (Appendix IV). Information was elicited concerning the parentsô assessment of the hospital environment, their experiences with availability of resources, care delivery processes, service providers, their (parentsô) empowerment and overall satisfaction with the care given. Two focused group discussions were held with the parents who had not been subjected to semi structured questionnaire. The parents were presented with a consent form (Appendix V) and the study purpose, procedure, confidentiality, benefits of the study as well as their voluntary participation in the study was explained in the language they understood i.e. in English or Swahili. The parents who agreed to participate in the study were requested to sign the consent form, (Appendix V). The focused group discussions were conducted in English or Swahili according to the language the parents understood using a focused group discussion guide (Appendix VI). Field notes were taken and also an audio recording was done during the focused group discussion. In depth information from the parentsô experiences of the care given was elicited and their perception of the quality of paediatric oncology care in relation to the environment, the care delivery processes as well as the service providers was established. Their overall satisfaction with the care given was also established. The information gathered was grouped into key themes. The filled questionnaires were checked for completeness and the information was cleaned before data entry. Data was entered into the SPSS computer system version 20 for analysis at the end of the study. This is because it has extensive data handling capabilities and many statistical analysis features that can analyze small to very large data.

3.14 Data analysis and Presentation

3.14.1 Quantitative data

The data collected were coded and entered into a computer using the statistical program for social sciences (SPSS). Data analysis was done using SPSS version 20. Inferential and

descriptive statistics were used to analyze data. Descriptive analysis of data was done using the mean, frequencies and proportions. Inferential data analysis was done using Pearsonôs chi square which was used to study the associations between variables. The chi square test was used to establish the association of parentsô perception of quality of paediatric oncology care (satisfaction) as a dependent variable and the hospitalôs structures and care delivery processes as well as health care service provider factors as independent variables. The level of significance was set at p value less than 0.05. The results were presented in descriptive form using frequency tables, pie charts, bar charts, figures and percentages. Statistical test of association and significance were given where applicable.

3.14.2 Qualitative data

Qualitative data from FGDs and field notes were transcribed and translated. Analysis was done manually by reviewing the field notes/listening to the audio tape from the focused group discussion and grouping the research findings according to key themes. Different positions emerging under each key theme were identified according to the study objectives and a summary written.

3.15 Study limitations

1. The study was limited to parents of paediatric oncology patients admitted at Kenyatta National Hospital, therefore the low patient turnover and the short study period limited coverage of a bigger sample size.

2. Parents fear to give their views regarding the care provided, however they were constantly reminded of confidentiality.

3.16 Ethical considerations

Before the study was conducted, the research proposal was submitted to Kenyatta National Hospital ï University of Nairobi (UON) Ethics and Research Committee for clearance and approval. Full information on the purpose and benefits of the study was given to the subjects to ensure voluntary and informed consent for participation. The participants were assured that the findings of the study would be kept confidential and that no names would be entered on the questionnaire. Written informed consent to participate in the study was obtained from all the participants using appendices III and V forms. Dignity and privacy of the participants were also assured.

3.17 Dissemination plan

The study results will be disseminated to the University of Nairobi and Kenyatta National Hospital. Further dissemination will be through workshops, report prints, seminar presentations and publications in Nursing/Medical journals.

CHAPTER FOUR: RESULTS

4.1: Introduction

This chapter presents the findings of the study. The findings are presented and interpreted based on the quantitative and qualitative data collected from 107 respondents (parents) and two focus group discussions (FGDs). The results are presented in tables and graphs form in descriptive and inferential analysis.

4.2 Parent's/child's socio-demographic characteristics

4.2.1 Parent's socio-demographic characteristics

The distribution of socio-demographic characteristics among the parents/care takers who participated in this study is shown in Table 4.1. The mean age of the respondents was 33 years. The findings show that almost about half 53(49.5%) of respondents were aged between 30-39 years followed by 36(33.6%) aged 20-29 years. The age group of 40 years and above was 18(16.8%). Majority 88(82.2%) of the respondents were females. More than half 59(55.1%) were rural inhabitants while 45(42.1%) were urban residents. Majority of the respondents 78 (72.9%) were married and 68(63.8%) were Protestant followers.

Out of the 107 respondents, 8(7.5%) had never attended school whereas those who had attained primary, secondary and college/university level of education were 40(37.4%), 28(26.2%) and 31(29.0%) respectively. Table 4.1 further shows that the highest percentage of the respondents 42(39.3%) were casual workers.

Table 4. 1: Parent's socio-demographic characteristics

Socio-demographic characteristics	Frequency (n=107)	Percentage (%)
Mean age (+SD) 33.0(±6.8)		
Age in years		
20-29	36	33.6
30-39	53	49.5
40 and above	18	16.8
Gender		
Male	19	17.8
Female	88	82.2
Residence		
Urban	45	42.1
Semi ï Urban	3	2.8
Rural	59	55.1
Level of education attained		
Never attended	8	7.5
Primary	40	37.4
Secondary	28	26.2
College/University	31	29.0
Marital status		
Never married	25	23.4
Married	78	72.9
Divorced	2	1.9
Widowed	2	1.9
Religious Affiliation		
Protestant	68	63.6
Catholic	31	29.0
Muslim	5	4.7
Others	3	2.8
Occupation		
Professional	21	19.6
Businessperson	30	28.0
Casual worker	42	39.3
Farmer	14	13.1

4.2.1.1 Income level

Figure 4.1 shows the income status of the respondents. The highest percentage 44(41.1%) were earning between Kshs. 5, 000 - 9,000 per month followed by 25(23.4%) who had a monthly income of less than 5, 000. Those who were earning between Kshs. 10, 000 - 15, 000 were 20(18.7%) while those who were earning a monthly income exceeding Kshs. 15, 000 were 18(16.8%).

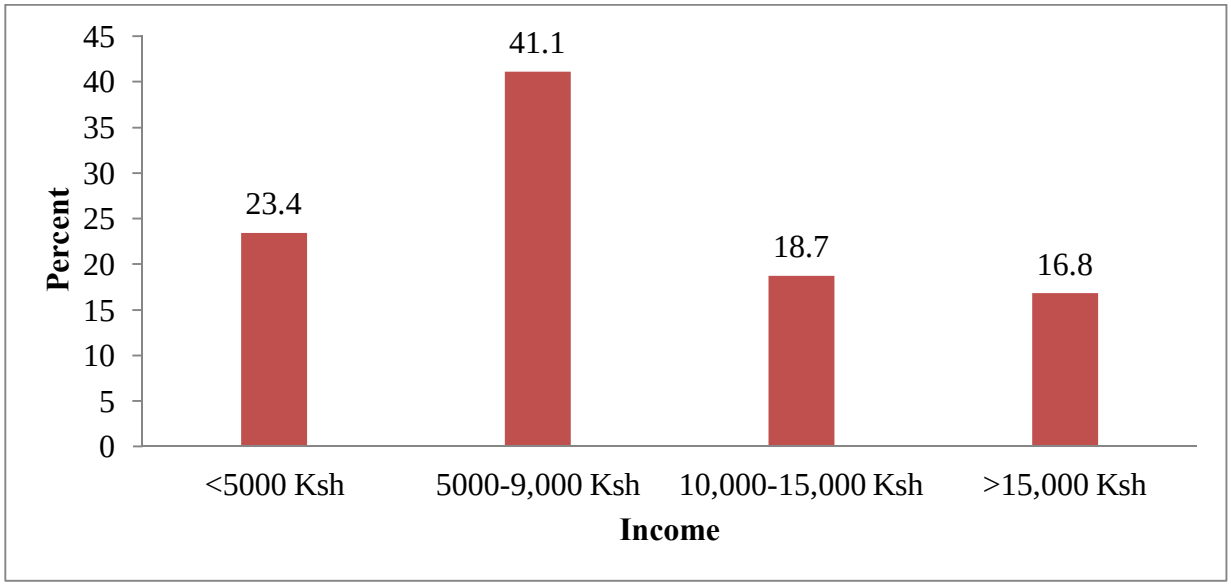


Figure 4. 1: Income level

4.2.2 Selected demographic characteristics of the child

The mean (±SD) age of the children was 6.9(±3.2) years. The age group 0 - 3 years were 19 (17.8%). The children aged 4 - 6 years were 34(31.8%) and those aged 7 - 9 years and 10 -12 years were 27(25.2%) each. The highest percentage of the children 44(41.1%) had been hospitalized for a period of 1 - 2 weeks. Majority of the children 64(59.8%) had a history of hospitalization in the past while 43(40.2%) of the children had not been hospitalized in the past (Table 4.2).

Table 4. 2: Selected demographic characteristics of the child

Variables	Frequency (n=107)	Percentage (%)
Mean of age in years (±SD) = 6.9(±3.2)		
Age in years		
0 to 3	19	17.8
4 to 6	34	31.8
7 to 9	27	25.2
10 to 12	27	25.2
Period of child's hospitalization		
1 - 2 weeks	44	41.1
3 - 4 weeks	22	20.6
5 - 6 weeks	29	27.1
7 - 8 weeks	10	9.3
Above 8 weeks	2	1.9
Child's past hospitalization history		
Yes	64	59.8
No	43	40.2

4.2.3 Number of the child's siblings

About one third 36(33.6%) of the parents interviewed indicated that they had one more other child and about a quarter 28(26.2%) had two other children. Parents who had three and four or more children were 10(9.3%) and 14(13.1%) respectively as depicted in Figure 4.2.

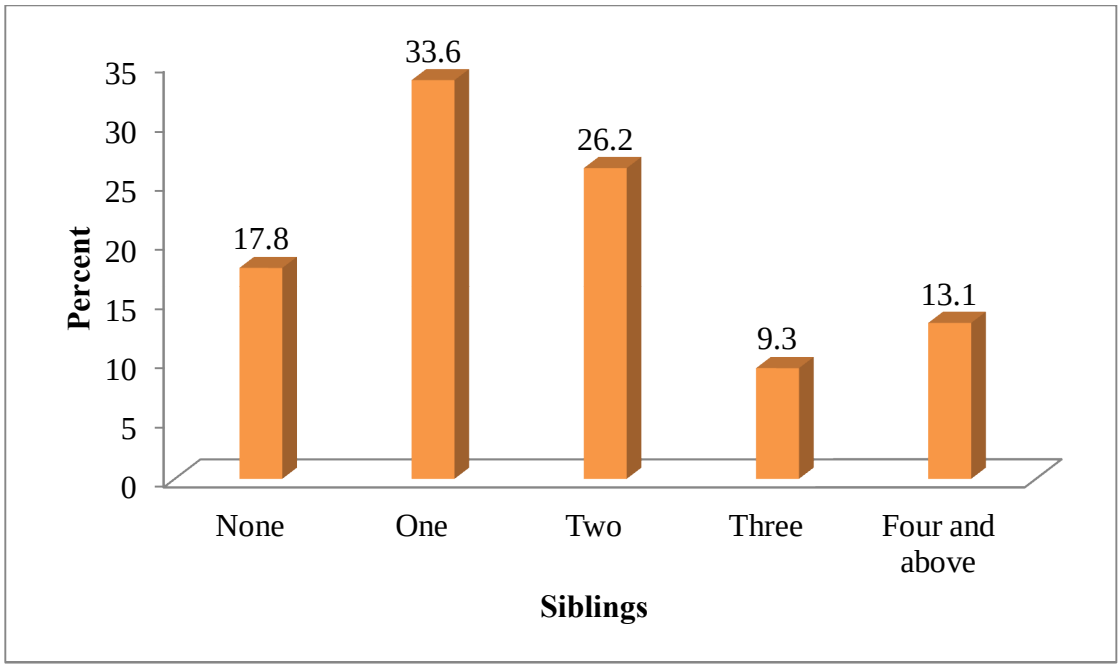


Figure 4. 2: Number of the child's siblings

4.2.4 Age of first child on line

Figure 4.3 shows that 37(34.6%) of the parents had their first born child aged between 6 and 10 years. These were followed by 31(29.0%) and 22(20.6%) whose first born child was aged 11-15 years and 0-5 years respectively.

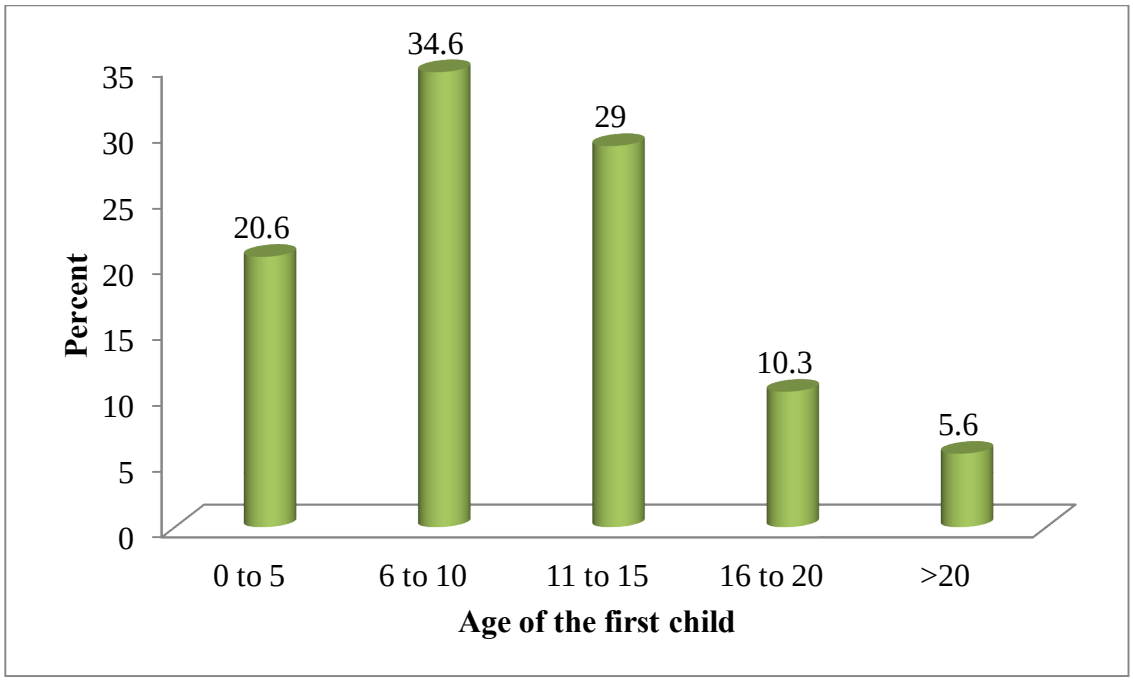


Figure 4. 3: Age of the first child

4.3 Parents' perception on the infrastructure/environment

Descriptive analysis of parentsô perception towards the infrastructure/environment on six (6) statements is presented in Table 4.3. The table shows that majority of the participants were satisfied with all of the statements. Most of the respondents 92(86%), 89(83.2%), 88(82.2%) and 83(77.6%) were satisfied with cleanliness of the wards, size of the bed, ventilation and wash room facilities respectively. Even though 69(64.5%) were satisfied with the space in the ward and 64(59.8%) were satisfied with availability of play facilities, a considerable number of respondents 38(35.5%) and 43(40.2%) were not satisfied with the above respectively.

Table 4. 3: Parents' perception on the infrastructure/environment

Statement	Yes, n(%)	No, n(%)
Satisfied with the space in the ward	69(64.5%)	38(35.5%)
Satisfied with the cleanliness of the ward	92(86%)	15(14%)
Satisfied with the size of the bed/cot for the child	89(83.2%)	18(16.8%)
Satisfied with the ventilation of the ward	88(82.2%)	19(17.8%)
Satisfied with the wash room facilities for the child	83(77.6%)	24(22.4%)
Availability of play facilities for the child	64(59.8%)	43(40.2%)

4.3.1 Level of parents' perception on infrastructure/environment

The overall score of parentsô perception on infrastructure/environment was assessed using the six (6) statements presented in Table 4.3. Responses that indicate in-adequate infrastructure/ environment was recorded as value '0' and adequate infrastructure/environment was given a value of '1'. This means that the score 1 represented the option ñyesò while score 0 on the scale represented the category ñnoò.

The overall score was generated by aggregating the scores. The maximum attainable total score was 6. The mean score was 4.5 and scores above 4.5 were considered as adequate infrastructure /environment and below 4.5 were considered as in-adequate infrastructure/environment. Sixty four (59.8%) respondents indicated that the infrastructure/environment was adequate while the remaining 43(40.2%) reported it was in-adequate (Figure 4.4).

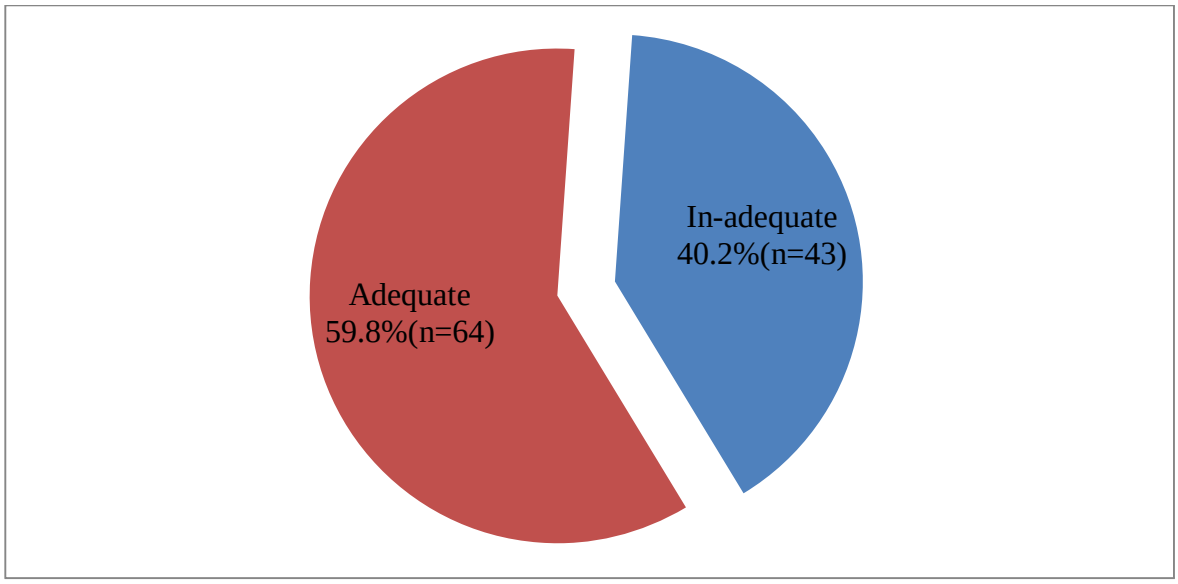


Figure 4. 4: Level of parents' perception on infrastructure/environment

4.3.3 Reasons for dissatisfaction with infrastructure/environment

Congestion was the main reason mentioned by 27(83.2%) of the parents who were not satisfied with the space in the wards. In addition, sharing bed 14(77.8%), closing the windows most of the time 19(100%) and untidy toilets 15(62.5%) were the main concerns stated among those who were dissatisfied with size of the bed, ventilation and wash room facilities respectively (Table 4.4). It was also pointed out from the FGDs in the following quotes;

> ñ*A patient has rights while in the ward such as being treated well and sleeping in a comfortable place,* s*leeping is a problem because children are sharing beds"*(FGD 1, Participant 1)

> ñ*Services such as availing of hot water for the children need to be provided"* (FGD 1, Participant 3).

Table 4. 4: Reasons for dissatisfaction with infrastructure/environment

Reasons	n	(%)
Reasons for not satisfied with the space in the ward		
Space is congested	27	83.2
Parent has no bed to sleep	11	16.8
Dissatisfaction with the size of the bed/cot for the child		
Sharing of the bed among children	14	77.8
The size of the bed is small	4	22.2
Reasons for not satisfied with the ventilation of the ward		
Windows remain closed most of the time	19	100.0
Dissatisfaction with the wash room facilities for the child		
Bathrooms and toilets are not clean	15	62.5
Hot water is not available	9	37.5

4.4 Parents' perception on availability of resources

The respondents were asked about their perception in regard to availability of resources related to their childrenôs treatment (Table 4.5). Among the respondents, 65(60.7%) reported to be satisfied with the quality of meals provided in the hospital. Those who were found to be dissatisfied with the statement were 42(39.3%). Sixty eight (63.6%) respondents were satisfied with the availability of linen in the hospital, whereas 37(36.4%) were not satisfied. Majority of the children 74(69.2%) had ever received chemotherapy treatment and 63(85.1%) reported that the chemotherapy drugs were available in the hospital. However, 11(14.9%) reported that they lacked the drugs in the hospital. Furthermore, the FGD participants stated as follows;

> *"Since I came on admission, I have been told the chemotherapy drug is not available. That is what is delaying me"* (FGD 2, Participant 6).

ñ*Sometimes we miss drugs and are told to buy and the drugs are very expensive, for example one of the parents was told to buy the drug and its cost was fifteen thousand shillings. The issue of availability of chemotherapy drugs needs to be looked at. For example if my child is supposed to get chemotherapy today and you tell me to buy the drugs and I don't have money , time elapses and the child delays to get the treatment"*(FGD 2, Participant 3).

Among those who received radiotherapy 59(55.1%), 33(55.9%) indicated that they were satisfied with radiotherapy treatment. Similarly for children who ever received blood/blood products transfusion 63(58.9%), most of the parents 47(74.6%) were satisfied with the availability of blood. However**,** 26(44.1%) and 17(25.4%) were not satisfied with radiotherapy treatment and blood transfusion respectively. These findings were supported by the FGDs in the following statements;

"We appeal to the government to consider children with cancer because they have great challenges. For example like now the radiotherapy machine has broken down and if one is told to go home and arrange for radiotherapy treatment in a private hospital, it is just like the child is being condemned to die"(FGD 2, Participant 4).

"Sometimes chemotherapy treatment is delayed due to unavailability of blood. My child has twice not received treatment on time due to delay as a result of unavailability of blood" (FGD 2, Participant 6).

"A child can stay for about a month before being given chemotherapy due to unavailability of blood. This prevents children from getting good care" (FGD 2, Participant 1). About two thirds of the respondents 66(61.7%) reported that the investigations required for the children were done on time after they were requested for. However, 41 (38.3%) of the

respondents reported that the investigations were not done on time after they were requested for. Sixty three respondents comprising 58.9% reported that the investigation results were availed on time whereas 44 (41.1%) of the respondents reported delays in results delivery. One of the FGD respondentsô also stated that:-

"Investigation results for CT scan take a very long time to be availed" (FGD 1, Participant 2).

In regard to availability of doctors, 69(64.5%) of the respondents reported that the doctors were available whenever needed by the patients. However, 38 (35.5%) of the respondents reported that the doctors were not available whenever they sought to reach them. Eighty one (75.7%) of the respondents reported that the nurses were available whenever needed. However, 26 (24.3%) of the respondents reported that the nurses were unavailable to them whenever required.

Table 4. 5: Parents' perception of availability of resources

Statement	Yes, n(%)	No, n(%)
Satisfied with the hospital meals provided	65(60.7%)	42(39.3%)
Satisfied with availability of linen	68(63.7%)	39(36.4%)
Child ever received chemotherapy treatment	74(69.2%)	33(30.8%)
Availability of chemotherapy drugs	63(85.1%)	11(14.9%)
Child ever received radiotherapy treatment	59(55.1%)	48(44.9%)
Satisfied with radiotherapy treatment	33(55.9%)	26(44.1%)
Child ever experienced pain related to the illness at any given time while in the ward	60(56.1%)	47(43.9%)
Availability of pain relieving drug	59(98.3%)	1(1.7%)
Satisfied with the child's pain relieve	60(100.0%)	0(0.0%)
Child ever received blood/blood products transfusion	63(58.9%)	44(41.1%)
Availability of blood/blood products on time	47(74.6%)	17(25.4%)
Investigations required for the child done on time after they are requested for	66(61.7%)	41(38.3%)
Investigation results for the child availed on time	63(58.9%)	44(41.1%)
Availability of doctors when needed	69(64.5%)	38(35.5%)
Availability of nurses when needed	81(75.7%)	26(24.3%)

Bolded statements were used for the overall score on resource availability

4.4.1 Overall score of parents' perception on availability of resources

The overall score of parentsô perception on availability of resources was assessed using the six (6) bolded statements presented in Table 4.5. Responses that indicate in-adequate resources were recorded as value '0' and adequate resources were given a value of '1'. This means that the score 1 represented the option ñyesò while score 0 represented the option ñnoò.

The overall score was generated by aggregating the scores. The maximum attainable total score was 6. The mean score was 3.8 and scores above 3.8 were considered as adequate resources and below 3.8 were considered as in-adequate resources. Sixty two (57.9%) of the respondents indicated that the resources were adequate whereas 45(42.1%) indicated the resources were inadequate (Figure 4.5).

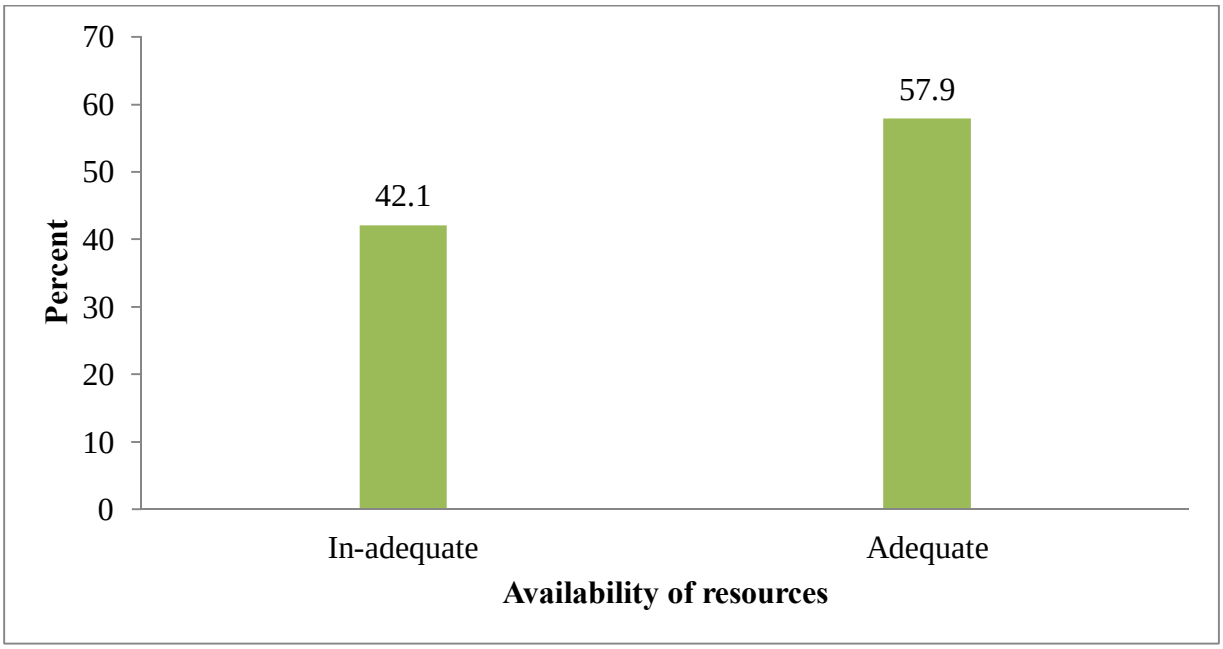


Figure 4. 5: Overall score of parents' perception on availability of resources

4.4.2 Reasons for dissatisfaction with availability of resources

Table 4.6 summarizes the main reasons for dissatisfaction regarding availability of resources. The main dissatisfaction mentioned were, not well cooked food (92.9%), inadequate linen (84.6%), delay in waiting for radiotherapy treatment (65.4%) and inconsistent radiotherapy treatment (42.3%)

Table 4. 6: Reasons for dissatisfaction with availability of resources

Reasons	n	(%)
*** Dissatisfaction with the hospital meals provided**		
Food is sometimes not well cooked	39	92.9
Parent is not given food	13	31.0
Dissatisfaction with availability of linen		
Linen is inadequate	33	84.6
Blankets are light	1	2.6
Blankets are short	1	2.6
Linen is not clean	4	10.3
*** Dissatisfaction with radiotherapy treatment**		
There is delay in waiting for radiotherapy treatment	17	65.4
Radiotherapy treatment is not consistent	11	42.3

*Multiple response

4.5 Parents' perspectives on care delivery processes

Table 4.7 presents the parentsô perspectives on care delivery processes. Majority 64(59.8%) of the parents indicated that they did not have any information about their child's illness and treatment. Among those who were provided with information about their child's illness and treatment, only 17(39.5%) were satisfied while 26(60.5%) were dissatisfied. Among the respondents, 76(71%) reported that they were satisfied with the response given by the doctors in regard to their questions and concerns. Thirty one (29%) respondents on the other hand reported

dissatisfaction with the responses obtained on their inquiry about the childôs illness. Likewise, 72(67.3%) of the respondents reported to be satisfied with the responses given to their questions and concerns from the nurses whereas 35(32.7%) of the respondents on the other hand were dissatisfied.

Majority 69(64.5%) of the respondents were found to have been satisfied with their involvement in the decision making regarding the childôs treatment. Seventy nine (73.8%) of the respondents reported that they were satisfied with the explanation from the nurses and doctors about any procedure and tests done to the children. However, 28 (26.2%) of the respondents reported that they were not satisfied with the explanation received. Sixty nine (64.5%) of the respondents reported that they were satisfied with their communication with the doctors whereas 38(35.5%) were not satisfied. Majority of the respondents 76(71%) were found to be satisfied with their communication with the nurses, whereas the rest who were 31(29%) reported that they were not satisfied with the communication.

Table 4. 7: Parents' perspectives on care delivery processes

Statement	Yes, n(%)	No, n(%)
Information about the child's illness and treatment	43(40.2%)	64(59.8%)
Satisfied with the information provided about the child's illness and treatment	17(39.5%)	26(60.5%)
Satisfied with the response of the doctors to the parentsô questions and concerns	76(71%)	31(29%)
Satisfied with the response of the nurses to the parentsô questions and concerns	72(67.3%)	35(32.7%)
Satisfied with the involvement in decision making and care of the child	69(64.5%)	38(35.5%)
Satisfied with the explanation from the nurses/doctors about any procedure and test done to the child	79(73.8%)	28(26.2%)
Satisfied with the doctor-parent/child communication	69(64.5%)	38(35.5%)
Satisfied with the nurse-parent/child communication	76(71%)	31(29%)

4.5.1 Level of parents' perspective on care delivery processes

The overall score of parentsô perception on care delivery processes was assessed using the eight (8) statements presented in Table 4.7. Responses that indicate in-sufficient care delivery processes were recorded as value '0' and sufficient care delivery processes were given a value of '1'. This means that the score 1 represented the option ñyesò while score 0 represented the option ñnoò.

The overall score was generated by aggregating the scores. The maximum attainable total score was 8. The mean score was 5.1 and scores above 5.1were considered as sufficient care delivery processes and below 5.1 were considered as in-sufficient care delivery processes. More than half 58(54.2%) of the respondents scored in-sufficient care delivery processes (Figure 4.6).

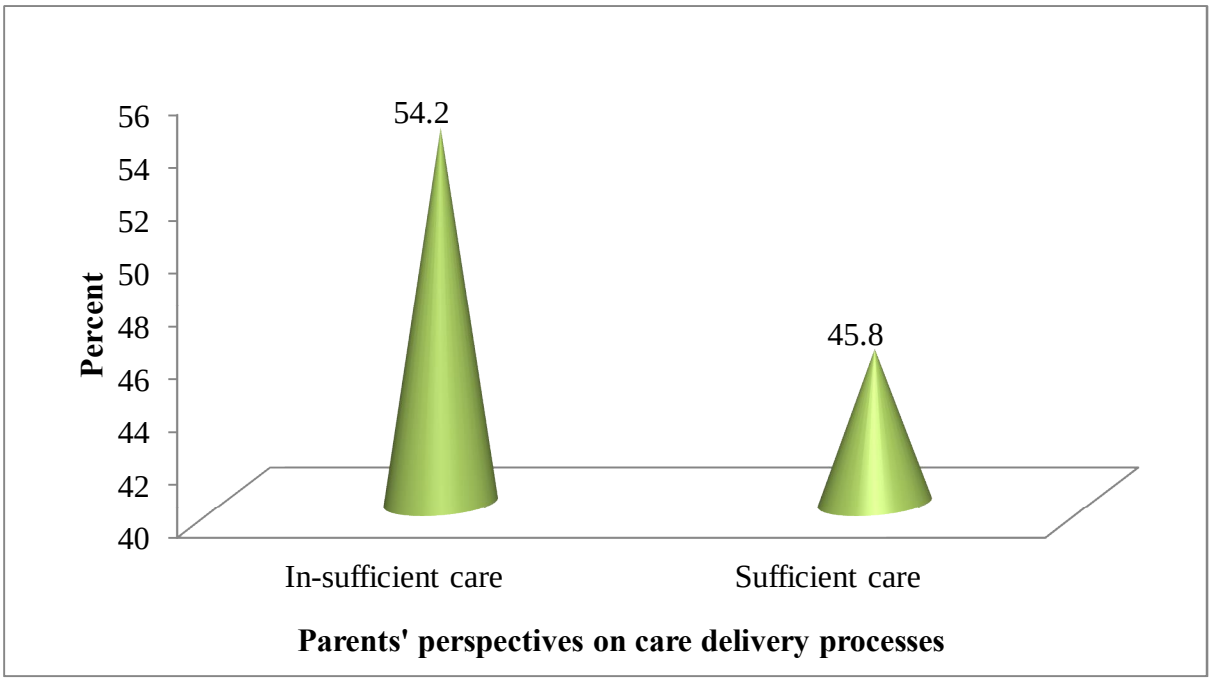


Figure 4. 6: Level of parents' perspective on care delivery processes

4.5.2 Reasons for dissatisfaction with care delivery processes

Among the parents who were dissatisfied with the information provided about the child's illness and treatment, this was attributed to lack of information about the treatment and duration 55(85.9%) and not being informed about the illness and its stage 49(76.6%). Majority 20(64.5%) of the parents indicated that questions and concerns were not responded to satisfactorily from the doctors and 23(65.7%) reported that questions raised to the nurses were referred to the doctors.

Not communicating in an understanding way even after consultation with the doctors 27(71.1%) was the main reason among those who were not satisfied with the involvement in decision making and care of the child. Table 4.8 shows that the main dissatisfaction in regard to communication between the doctor/nurse and parent/child in regard to the child's care and treatment were that questions and concerns raised were not addressed satisfactorily, communication was not done in a polite way and no information was given in regard to what is expected of the parents.

Table 4. 8: Reasons for dissatisfaction with care delivery processes

Reasons	n	(%)
*** Dissatisfaction with the information provided about the child's illness and treatment**		
Not informed about the treatment and duration	55	85.9
Not informed about the illness and its stage	49	76.6
*** Dissatisfaction with the response of the doctors to the parents' question and concerns**		
Questions and concerns were not answered on time	9	29.0
No response given to the questions and concern raised	5	16.1
Questions and concerns not responded to satisfactorily	20	64.5
***Dissatisfaction with the response of the nurse to the parents' questions and concerns**		
No response to the questions and concerns raised	12	34.3
Questions raised referred to the doctor for response	23	65.7
*** Dissatisfaction with the involvement in decision making and care of the child**		
Require more involvement in decision making	16	42.1
Decision made is not communicated in an understanding way	27	71.1

***Dissatisfaction with the explanation from the nurses/doctors about any procedure and test done to the child**		
Parent is not informed about procedures and tests done	21	75.0
Reasons for test done is not explained to parent	12	42.9
*** Dissatisfaction with the doctor-parent/child communication**		
Questions and concerns are not addressed satisfactorily	32	84.2
Child's care and treatment is not communicated to parents	19	50.0
Communication is not done in a polite way	25	65.8
Parent's concerns raised are not listened to	10	26.3
*** Dissatisfaction with the nurse-parent/child communication**		
Questions and concerns raised are not addressed satisfactorily	18	58.1
Communication is not done in a polite way	27	87.1
No information of what is expected of the parent is given	22	71.0

*Multiple response

4.6 Parents' satisfaction with the service providers

The parents were asked about their perception in regard to the health care providers (Table 4.9). Seventy one (66.4%) of the respondents reported to be satisfied with the caring attitude of the doctors whereas 36(32.7%) were not satisfied. Seventy (65.4%) of the respondents reported that they were satisfied with the friendliness of the doctors while 37(34.6%) were not. Sixty five (60.7%) of the respondents reported that the doctors were polite however, 42(39.3%) of the respondents were not satisfied with the politeness of the doctors. Seventy eight (72.9%) of the respondents felt that the doctors were honest. However, 29(27.1%) of the parents felt that the doctorsô honesty was not satisfactory to their expectations.

From the findings presented, 80(74.8%) of the parents were satisfied with the respect for their values and beliefs by the doctors. However 27(25.2%) of the respondents on the other hand were not satisfied. In regard to the parentsô perception of the nurses, 76(71%) of the respondents reported that they were satisfied with the caring attitude of the nurses whereas 31(29%) were not.

Seventy (65.4%) of the respondents were satisfied with the friendliness of the nurses whereas 37(34.6%) respondents said some of the nurses were not friendly. Sixty six (61.7%) of the respondents were satisfied with the nursesô politeness whereas 41(38.3%) of the respondents were not satisfied with the nursesôpoliteness.

Majority of the respondents, 73(68.2%) were satisfied with the honesty of the nurses. On the other hand, 34 (31.8%) of the respondents were not satisfied. Eighty two (76.6%) of the respondents were satisfied with the respect for their values and beliefs shown by the nurses while 25(23.4%) of the respondents were not satisfied with this aspect.

Table 4. 9: Parents' satisfaction with the service providers

Statement	Yes, n(%)	No, n(%)
Satisfied with the caring attitude of the doctors	71(66.4%)	36(33.6%)
Satisfied with the friendliness of the doctors	70(65.4%)	37(34.6%)
Satisfied with the politeness of the doctors	65(60.7%)	42(39.3%)
Satisfied with the honesty of the doctors	78(72.9%)	29(27.1%)
Satisfied with the respect for parentôs values and beliefs by the doctors	80(74.8%)	27(25.2%)
Satisfied with the caring attitude of the nurses	76(71%)	31(29%)
Satisfied with the friendliness of the nurses	70(65.4%)	37(34.6%)
Satisfied with the politeness of the nurses	66(61.7%)	41(38.3%)
Satisfied with the honesty of the nurses	73(68.2%)	34(31.8%)
Satisfied with the respect for parentôs values and beliefs by the nurses	82(76.6%)	25(23.4%)

4.6.1 Overall score of parents' satisfaction towards health providers

The overall score of parentsô views towards health care providers was assessed using the ten (10) statements presented in Table 4.9. Responses that indicate dissatisfaction with health care providers were recorded as value '0' and satisfaction with health care providers were given a value of '1'. This means that the score 1 represented the option ñyesò while score 0 on the scale represented the category ñnoò.

The overall score was generated by aggregating the scores. The maximum attainable total score was 10. The mean score was 6.8 and scores above 6.8 were considered as satisfied with health care providers and below 6.8 were considered as dissatisfied with health care providers. Sixty one (57.0%) of the respondents reported that they were satisfied with health care providers while 46(43.0%) were not satisfied with the health care providers (Figure 4.7).

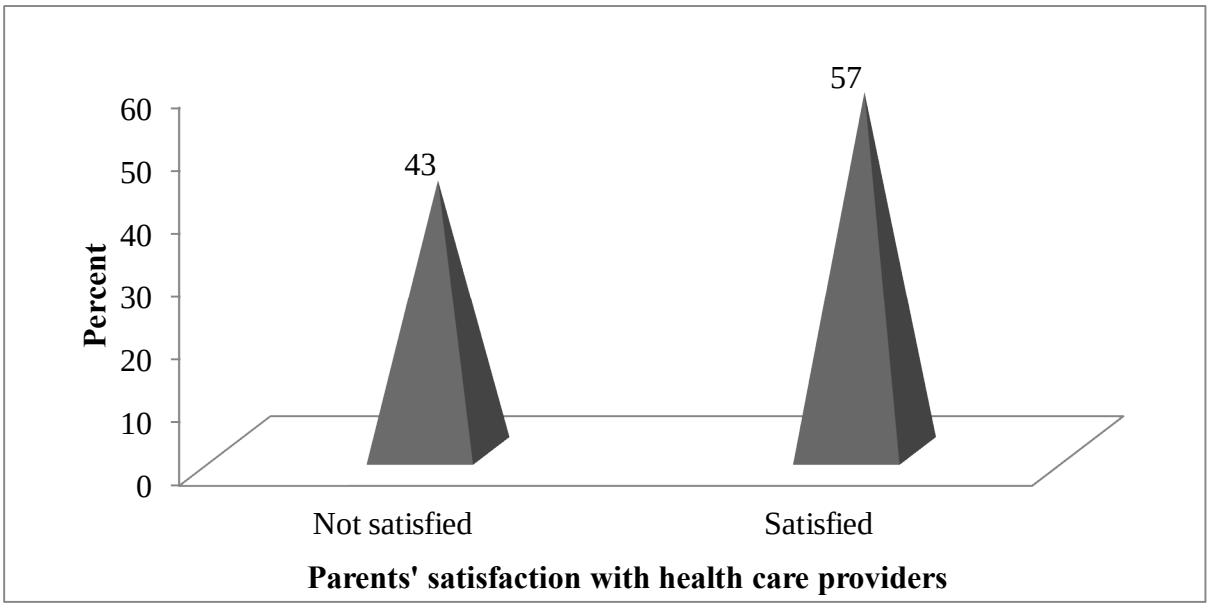


Figure 4. 7: Overall score of parents' satisfaction with health care providers

4.6.2 Reasons for dissatisfaction with health care providers

Table 4.10 presents the main concerns of parents who were not satisfied with health care providers. Delays in carrying out investigations on the child 22(61.1%) and not reviewing the patients on a daily basis 12(33.3%) were mentioned as main dissatisfaction with the caring attitude of the doctors. Likewise, not responding to concerns/needs related to the child's care was the main reason of dissatisfaction 27(87.1%) with the caring attitude of the nurses. The reason for dissatisfaction with the politeness of the doctors was that some of the doctors and nurses did not communicate politely in that they were harsh when communicating to them. Table 4.10 further shows the main reason for dissatisfaction with the respect for parentôs values and beliefs by the doctors was that the doctors did not listen to parents views 24(88.9%). Dissatisfaction with the honesty of the doctors was attributed to the fact that they did not give honest information about the child's illness 20(69.0%) and they did not provide full information to patients 9(31.0%). The parents expressed that the information given about the child's progress and care by nurses was not honest 25(73.5%). These findings are also supported by the FGDs as stated in the following quotes:-

> *"If we are honestly informed about the child's condition, we become satisfied"* (FGD 2, Participant 2).

> ñ*Let the doctors be open, the parents would like to know the results of the child, for example the blood levels. In every step of treatment, let the doctors be open to the parents. When I ask for information about the child, I am not given full information, so let them be open to us so that we can know what is going on"*(FGD 2, Participant 5).

Table 4. 10: Reasons for dissatisfaction with health care providers

Reasons	N	(%)
Dissatisfaction with the caring attitude of the doctors		
Delays in carrying out investigations on the child	22	61.1
Do not review patients everyday	12	33.3
Dissatisfaction with the politeness of the doctors		
Majority do not communicate politely/Harsh when Communicating	42	100.0
Dissatisfaction with the honesty of the doctors		
Not giving honest information about child's illness	20	69.0
Not providing full information to parents	9	31.0
Dissatisfaction with the respect for parent's values and beliefs by the doctors		
Do not respect spiritual beliefs	3	11.1
Do not listen to parentôs views	24	88.9
Dissatisfaction with the caring attitude of the nurses		
Majority do not respond to concerns/needs related to the child's care	27	87.1
Do not follow up drugs ordered on time	4	12.9
Dissatisfaction with the politeness of the nurses		
Do not communicate politely/harsh when communicating	41	100.0
Dissatisfaction with the honesty of the nurses		
Majority give contradicting information	9	26.5
Information given about child's progress and care is not honest	25	73.5

4.7 Parent's awareness about child's care

The respondents were asked about their perception in regard to their awareness of the childôs care (Table 4.11). Seventy five (70.1%) of the respondents were aware of the side effects of their childrenôs treatment whereas 32(29.9%) were not aware. Moreover, the respondents from the FGDs indicated that they would like to know the treatment and side effects which they stated as follows;

> *"My child is getting treatment for cancer though I do not know which kind of cancer it is and I would like to know''*(FGD 2, Participant 2).
>
> ñ*When a child has been found to have cancer and is required to be given chemotherapy or radiotherapy, it would be good for the health care providers to counsel the parent about the side effects of treatment. There are side effects that children get and this makes one (parent) to think that the end has come. Parents need to be counseled on what to expect so that they don't panic much"* (FGD 1, Participant 5).
>
> ñ*After the doctor knows it is cancer, it is important for the parent to be told the treatment, whether the child will begin with chemotherapy or radiotherapy and what is expected after radiotherapy. I feel they need to counsel the parent''* (FGD 1, Participant 4).

Out of 107 parents interviewed, 83 (77.6%) had been advised on the types of food that their children needed to take. Seventy (65.4%) of the respondents reported that they had inadequate information about their childrenôs illness and treatment therefore they would like to know more. Fifty eight (54.2%) of the parents said that they were counseled in relation to their childrenôs illness and treatment. However, 43.9% of the respondents reported that they had never received

any counseling support in relation to their childrenôs illness and treatment. Some of the FGD participants stated that;

> ñ*We have inadequate information about our children's illness and treatment so we need to be informed more concerning our children's illness and treatment"* (FGD 1, Participant 6).

> ñ*We need to know the stage of the disease, the duration of the treatment and the effects of the treatment"* (FGD 2, Participant 4).

Majority of the parents 95(88.3%) were not aware of the existence of any support group related to the child's illness while only 12(11.7%) had information about the support groups. Many parents 72 (67.3%) reported that they would like to be involved in the activities of support groups. Some participants from the FGD stated that:-

> *"Involving us in the groups would provide us and our children encouragement and psychological support, we would be educated about cancer and our children's nutritional care needs"*(FGD 1, Participant 1).

> *"If parents of children with cancer can have a support group, it can be of help"*(FGD 2, Participant 3)

Table 4. 11: Parent's awareness about child's care

Statement	Yes, n(%)	No, n(%)
Aware of the side effects of the child's treatment	75(70.1%)	32(29.9%)
Advised on the type of food the child needs to take	83(77.6%)	24(22.4%)
Information parent would like to know about the child's illness and treatment	70(65.4%)	37(34.6%)
Do you receive counseling support in relation to childôs illness and treatment	58(54.2%)	49(45.8%)
Parentôs awareness of any support group related to the child's illness	12(11.7%)	95(88.3%)
Do you think you require to be involved in a support group	72(75.8%)	23(24.2%)

4.7.1 Level of awareness about child's care

The overall score of parentsô level of awareness about childôs care was assessed using the six (6) statements presented in Table 4.11. Responses that indicate in-adequate awareness were recorded as value '0' and adequate awareness were given a value of '1'. This means that the score 1 represented the option ñyesò while score 0 on the scale represented the category ñnoò.

The overall score was generated by aggregating the scores. The maximum attainable total score was 6. The mean score was 3.9 and scores above 3.9 were considered as adequate awareness about childôs care and below 3.9 were considered as in-adequate awareness about childôs care. Sixty nine (64.5%) of the respondents scored adequate awareness about childôs care whereas 38(35.5%) scored in-adequate awareness about childôs care (Figure 4.8).

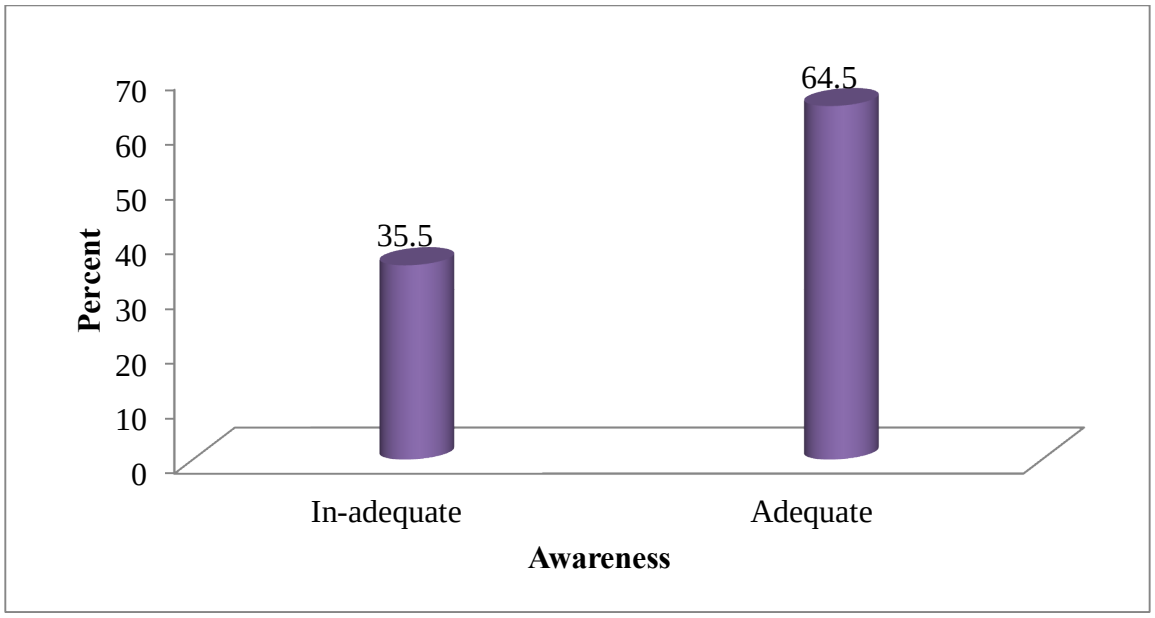


Figure 4. 8: Level of awareness about child's care

4.8 Satisfaction with the overall care received

Respondents were asked whether they were satisfied with the overall care services received and 62(59.7%) were satisfied. However, 45(42.1%) were not satisfied with the overall care services they received (Figure 4.9). Some of the statements given by the participants of the FGDs are;

> *"We are satisfied because the children have improved compared to when they came, however the services are very slow''* (FGD 1, Participants 2and 4).

> *"Services will not be satisfactory when drugs are not available"* (FGD 2, Participant 6).

Other participants in the FGD expressed their concerns in regard to the cost related to their childrenôs treatment by stating the following:-

> *"Cancer treatment is expensive. For example after you are discharged and you don't have money to pay for the drug charges, you end up staying in the ward for a longer time,*

even until the readmission date reaches. Our view is that NHIF needs to cover all the treatment costs" (FGD 2, Participant 5).

"Services such as CT scan investigation is expensive and sometimes the parent is not able to pay for it" (FGD1, Participant 3).

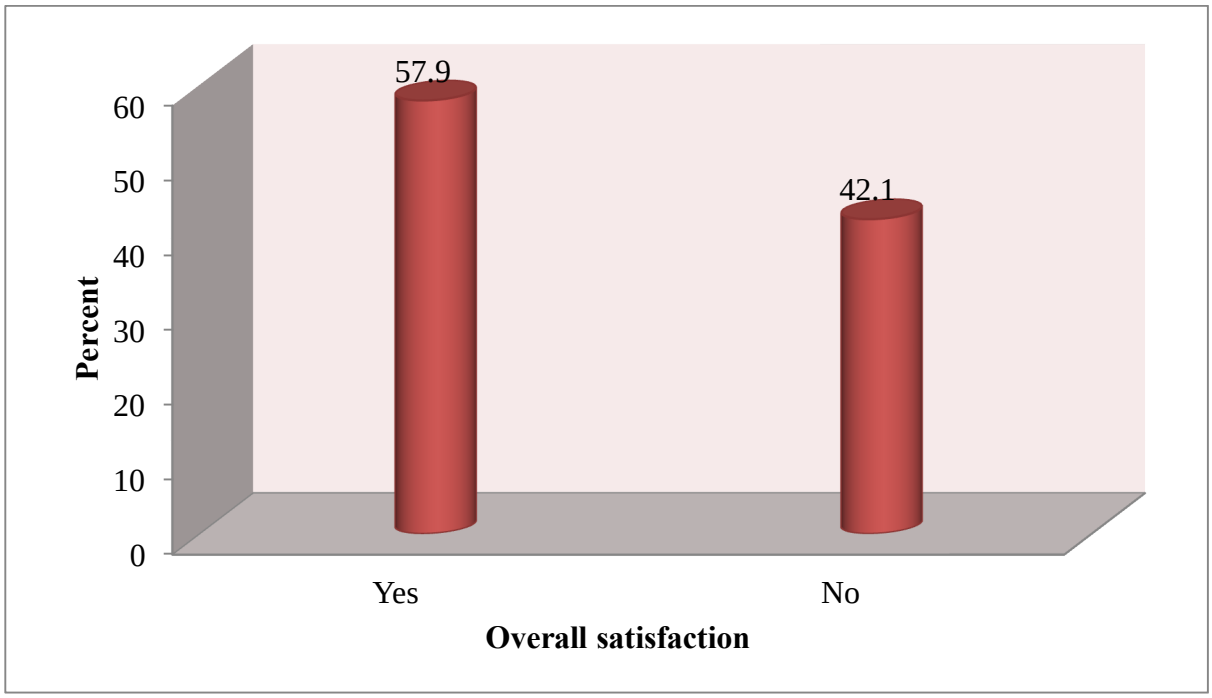


Figure 4. 9: Satisfaction with the overall care received

4.8.1 Suggestions on how to improve the care

The parents outlined provision of comfortable space, availing chemotherapy drugs, availing blood, carrying out investigations and availing results on time as well as provision of timely chemotherapy and radiotherapy treatment as the main areas that they felt needed to be improved on for provision of quality care as indicated in Figure 4.10. The following suggestions were also pointed out from the FGDs participants;

- Provision of comfortable space in the ward
- Provision of necessary amenities such as hot water in the washrooms
- Availability of adequate resources such as chemotherapy drugs, blood, radiotherapy treatment machines, health care providers (doctors and nurses).
- Carrying out investigations and availing of results on time.
- Commencement of treatment (chemotherapy, surgery and radiotherapy) on time without delays.
- Providing information about the childôs illness and treatment to the parent in an honest and understanding way.
- Counseling and psychological support to the parents.
- Support to the parents in terms of payment of the hospital bills through National Hospital Insurance Fund (NHIF).
- Enhancement of communication between the parents and the care providers (doctors and nurses).
- Caring attitude from the health care providers (doctors and nurses).

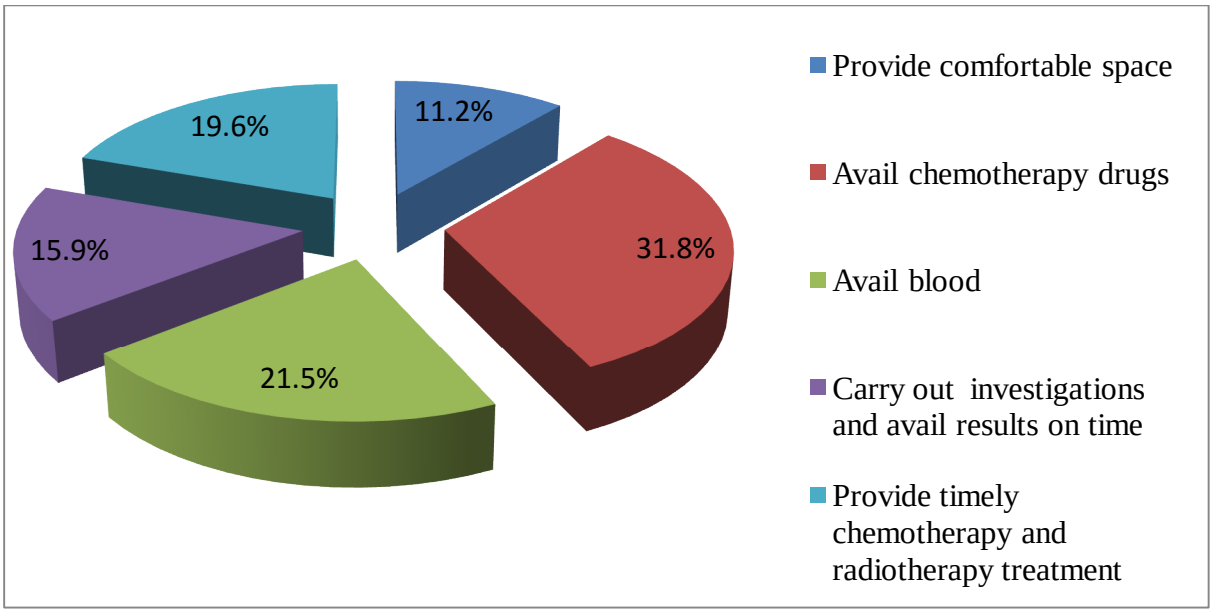


Figure 4. 10: Suggestions on how to improve the care

4.9. Factors determining parent's satisfaction with quality of care services

Table 4.12 shows the factors associated with overall satisfaction with care services among parents in regard to childhood cancer management. Parents who indicated adequate availability of resources for cancer treatment were significantly more satisfied 43(69.4%)[OR=3.10; 95%CI=1.39-6.90; P=0.005] than those who reported in-adequate availability of resources 19(42.2%). Respondents who said the care delivery processes were sufficient were significantly more satisfied 35(71.4%)[OR=2.87; 95%CI=1.28-6.43; P=0.009] than those who said care delivery processes were insufficient 27(46.6%). Similarly, respondents who indicated adequate infrastructure/environment were significantly more satisfied 43(67.2%)[OR=2.59; 95%CI=1.17-5.74; P=0.018] compared to those who indicated in-adequate infrastructure/environment 19(44.2%).

Table 4. 12: Determinants of overall satisfaction of care services among parents

Variables	Overall satisfaction		OR	95%CI		Test
	Satisfied, n(%)	Not satisfied, n(%)		Lower	Upper	P value
Level of awareness about child's care						
In-adequate awareness	24(63.2%)	14(36.8%)	0.72	0.32	1.61	0.417
Adequate awareness	38(55.1%)	31(44.9%)	Ref			
Overall score on availability of resources						
Adequate	43(69.4%)	19(30.6%)	**3.10**	**1.39**	**6.90**	**0.005**
In-adequate	19(42.2%)	26(57.8%)	Ref			
Level of parents' perspective on care delivery processes						
Sufficient	35(71.4%)	14(28.6%)	**2.87**	**1.28**	**6.43**	**0.009**
In-sufficient	27(46.6%)	31(53.4%)	Ref			
Overall score of parents' satisfaction with health provider						
Adequate satisfaction	39(63.9%)	22(36.1%)	1.77	0.81	3.86	0.148
In-adequate satisfaction	23(50.0%)	23(50.0%)	Ref			
Level of perception on infrastructure/environment						
Adequate	43(67.2%)	21(32.8%)	**2.59**	**1.17**	**5.74**	**0.018**
In-adequate	19(44.2%)	24(55.8%)	Ref			

OR= Odds Ratio, CI= Confidence Interval, Ref= Reference

4.10 Association between socio-demographic characteristics and overall satisfaction with care services

Table 4.13 shows the relationship of socio-demographic characteristics among the parents and overall satisfaction with care services in regard to childhood cancer management. Male respondents were significantly more satisfied with the overall care services 15(78.9%) [OR=3.27; 95%CI=1.01-10.64; P=0.041] compared to female respondents 47(53.4%).

There was a significant relationship between overall satisfaction with care services and residence of the respondents. Rural residents were significantly more satisfied with the overall childhood cancer care services 41(69.5%) [OR=2.85; 95%CI=1.27-6.39; P=0.011] than urban residents 20(44.4%).

There was also statistically increased proportion of satisfaction among parents who did not have past hospitalization history for their children 31(72.1%) [OR=2.75; 95%CI=1.20-6.29; P=0.017] compared to those who had past hospitalization history 31(48.4%).

Table 4. 13: Association between socio-demographic characteristics and overall satisfaction with care service

Socio-demographic characteristics	Overall satisfaction		OR	95%CI		χ^2 test
	Satisfied, n(%)	Not satisfied, n(%)		Lower	Upper	P value
Age in years						
20-29	21(58.3%)	15(41.7%)	1.12	0.36	3.51	0.846
30-39	31(58.5%)	22(41.5%)	1.13	0.38	3.31	0.828
40 and above	10(55.6%)	8(44.4%)	Ref			
Gender						
Male	15(78.9%)	4(21.1%)	**3.27**	**1.01**	**10.64**	**0.041**
Female	47(53.4%)	41(46.6%)	Ref			
Residence						
Urban	20(44.4%)	25(55.6%)	Ref			
Rural	41(69.5%)	18(30.5%)	2.85	**1.27**	**6.39**	**0.011**
Level of education attained						
Never attended	5(62.5%)	3()37.5%	1.56	0.32	7.70	0.583
Primary	21(52.5%)	19(47.5%)	1.04	0.41	2.65	0.941
Secondary	20(71.4%)	8(28.6%)	2.34	0.80	6.91	0.122
College/University	16(51.6%)	15(48.4%)	Ref			
Marital status						
Never married	12(48.0%)	13(52.0%)	0.61	0.25	1.51	0.281
Married	47(60.3%)	31(39.7%)	Ref			
Religious Affiliation						
Protestant	39(57.4%)	29(42.6%)	0.34	0.04	3.17	0.341
Catholic	18(58.1%)	13(41.9%)	0.35	0.04	3.47	0.367
Muslim	4(80.0%)	1(20.0%)	Ref			
Occupation						
Formally employed	11(52.4%)	10(47.6%)	0.44	0.10	1.86	0.264
Businessperson	13(43.3%)	17(56.7%)	0.31	0.08	1.20	0.089
Casual worker	28(66.7%)	14(33.3%)	0.80	0.21	3.01	0.741
Others (Farmer)	10(71.4%)	4(28.6%)	Ref			
Income						
<5000 Ksh	17(68.0%)	8(32.0%)	2.66	0.76	9.30	0.127
5000-9,000 Ksh	25(56.8%)	19(43.2%)	1.65	0.55	4.96	0.377
10,000-15,000 Ksh	12(60.0%)	8(40.0%)	1.88	0.52	6.81	0.340
>15,000 Ksh	8(44.4%)	10(55.6%)	Ref			
Period of child's hospitalization						
1 - 2 weeks	20(45.5%)	24(54.5%)	0.48	0.20	1.15	0.099
3 - 4 weeks	16(72.7%)	6(27.3%)	1.54	0.50	4.78	0.456
5 weeks and above	26(63.4%)	15(36.6%)				
Child's past hospitalization history						
Yes	31(48.4%)	33(51.6%)	Ref			
No	31(72.1%)	12(27.9%)	**2.75**	**1.20**	**6.29**	**0.017**

OR= Odds Ratio, CI= Confidence Interval, Ref= Reference

4.11 Relationship between socio-demographic characteristics and level of perception on infrastructure

Bivariate analysis of association between socio-demographic characteristics and level of perception on infrastructure is summarized in Table 4.14. However, there was no significant association (P<0.05) observed between socio-demographic characteristics and level of perception on infrastructure.

Table 4. 14: Relationship between socio-demographic characteristics and perception on infrastructure

Socio-demographic characteristics	Perception on infrastructure		OR	95%CI		χ2 test
	In-adequate, n(%)	Adequate, n(%)		Lower	Upper	P value
Age in years						
20-29	15(41.7%)	21(58.3%)	2.50	0.69	9.12	0.165
30-39	24(45.3%)	29(54.7%)	2.90	0.84	9.97	0.092
40 and above	4(22.2%)	14(77.8%)	Ref			
Gender						
Male	5(25.0%)	15(75.0%)	0.43	0.14	1.29	0.124
Female	38(43.7%)	49(56.3%)	Ref			
Residence						
Urban	19(42.2%)	26(57.8%)	1.14	0.52	2.52	0.739
Rural	23(39.0%)	36(61.0%)	Ref			
Level of education attained						
Never attended	3(37.5%)	5(62.5%)	0.64	0.13	3.16	0.583
Primary	18(45.0%)	22(55.0%)	0.87	0.34	2.24	0.777
Secondary	7(25.0%)	21(75.0%)	0.36	0.12	1.08	0.067
College/University	15(48.4%)	16(51.6%)	Ref			
Marital status						
Never married	11(44.0%)	14(56.0%)	1.19	0.48	2.96	0.706
Married	31(39.7%)	47(60.3%)	Ref			
Religious Affiliation						
Protestant	26(38.2%)	42(61.8%)	0.93	0.15	5.93	0.938
Catholic	14(45.2%)	17(54.8%)	1.24	0.18	8.46	0.830
Muslim	2(40.0%)	3(60.0%)	Ref			
Occupation						
Formally employed	11(52.4%)	10(47.6%)	2.75	0.65	11.62	0.169
Businessperson	7(23.3%)	23(76.7%)	0.76	0.18	3.20	0.709
Casual worker	21(50.0%)	21(50.0%)	2.50	0.68	9.25	0.170
Others (Farmer)	4(28.6%)	10(71.4%)	Ref			

Continuation from Table 4.14

Income						
<5000 Ksh	10(40.0%)	15(60.0%)	0.83	0.24	2.84	0.771
5000-9,000 Ksh	16(36.4%)	28(63.6%)	0.71	0.23	2.18	0.554
10,000-15,000 Ksh	9(45.0%)	11(55.0%)	1.02	0.28	3.68	0.973
>15,000 Ksh	8(44.4%)	10(55.6%)	Ref			
Period of child's hospitalization						
1 - 2 weeks	18(40.9%)	26(59.1%)	1.34	0.55	3.23	0.521
3 - 4 weeks	11(50.0%)	11(50.0%)	1.93	0.67	5.54	0.223
5 weeks and above	14(34.1%)	27(65.9%)	Ref			
Child's past hospitalization history						
Yes	26(40.6%)	38(59.4%)	1.05	0.48	2.30	0.910
No	17(39.5%)	26(60.5%)	Ref			

OR= Odds Ratio, CI= Confidence Interval, Ref= Reference

4.12 Association between socio-demographic characteristics and perception on availability of resources

An analysis of the relationship between socio-demographic characteristics and perception on availability of resources is shown in Table 4.15.

However, there was no significant association ($P<0.05$) observed between socio-demographic characteristics and availability of resources.

Table 4. 15: Association between socio-demographic characteristics and perception on availability of resources

Socio-demographic characteristics	Availability of resources		OR	95%CI		χ2 test
	In-adequate, n(%)	Adequate, n(%)		Lower	Upper	P value
Age in years						
20-29	17(47.2%)	19(52.8%)	3.13	0.86	11.37	0.083
30-39	24(45.3%)	29(54.7%)	2.90	0.84	9.97	0.092
40 and above	4(22.2%)	14(77.8%)	Ref			
Gender						
Male	8(42.1%)	11(57.9%)	1.00	0.37	2.74	0.996
Female	37(42.0%)	51(58.0%)	Ref			
Residence						
Urban	16(35.6%)	29(64.4%)	0.57	0.26	1.27	0.166
Rural	29(49.2%)	30(50.8%)	Ref			
Level of education attained						
Never attended	2(25.0%)	6(75.0%)	0.53	0.09	3.06	0.476
Primary	16(40.0%)	24(60.0%)	1.06	0.40	2.76	0.912
Secondary	15(53.6%)	13(46.4%)	1.83	0.65	5.15	0.254
College/University	12(38.7%)	19(61.3%)	Ref			
Marital status						
Never married	10(40.0%)	15(60.0%)	0.82	0.33	2.05	0.669
Married	35(44.9%)	43(55.1%)	Ref			
Religious Affiliation						
Protestant	27(39.7%)	41(60.3%)	0.44	0.07	2.80	0.384
Catholic	15(48.4%)	16(51.6%)	0.63	0.09	4.28	0.632
Muslim	3(60.0%)	2(40.0%)	Ref			
Occupation						
Formally employed	8(38.1%)	13(61.9%)	1.11	0.27	4.51	0.886
Businessperson	11(36.7%)	19(63.3%)	1.20	0.32	4.47	0.786
Casual worker	21(50.0%)	21(50.0%)	1.98	0.57	6.91	0.284
Others (Farmer)	5(35.7%)	9(64.3%)	Ref			
Income						
<5000 Ksh	9(36.0%)	16(64.0%)	1.63	0.47	6.39	0.409
5000-9,000 Ksh	23(54.5%)	21(45.5%)	3.12	0.95	10.26	0.061
10,000-15,000 Ksh	8(40.0%)	12(60.0%)	1.73	0.44	6.79	0.430
>15,000 Ksh	5(27.8%)	13(72.2%)	Ref			
Period of child's hospitalization						
1 - 2 weeks	17(38.6%)	27(61.4%)	0.87	0.41	2.29	0.947
3 - 4 weeks	10(45.5%)	12(54.5%)	1.07	0.38	3.02	0.906
5 weeks and above	18(43.9%)	23(56.1%)	Ref			
Child's past hospitalization history						
Yes	28(43.8%)	36(56.2%)	0.89	0.45	2.14	0.964
No	17(39.5%)	26(60.5%)	Ref			

OR= Odds Ratio, CI= Confidence Interval, Ref= Reference

4.13 Relationship between socio-demographic characteristics and perception of care delivery processes

Table 4.16 shows the relationship between socio-demographic characteristics of the parents and their perception of care delivery processes. Respondents with negative a perspective on care delivery processes were significantly more among the age group of 20-29 years 23(63.9%) [OR=6.19; 95%CI=1.68-22.79; P=0.006] and 30-39 years 31(58.5%) [OR=4.93; 95%CI=1.43-17.01; P=0.012] compared to those aged 40 years and above 4(22.2%).

There was no significant association (P<0.05) observed between the other socio-demographic characteristics and parentsô perception of care delivery processes.

Table 4. 16: Relationship between socio-demographic characteristics and perception on care delivery process

Socio-demographic characteristics	Care delivery process		OR	95%CI		χ2 test
	Negative perspective, n(%)	Positive perspective, n(%)		Lower	Upper	P value
Age in years						
20-29	23(63.9%)	13(36.1%)	**6.19**	**1.68**	**22.79**	**0.006**
30-39	31(58.5%)	22(41.5%)	**4.93**	**1.43**	**17.01**	**0.012**
40 and above	4(22.2%)	14(77.8%)	Ref			
Gender						
Male	11(55.0%)	9(45.0%)	1.04	0.39	2.76	0.937
Female	47(54.0%)	40(46.0%)	Ref			
Residence						
Urban	23(51.1%)	22(48.9%)	0.82	0.38	1.79	0.625
Rural	33(55.9%)	26(44.1%)				
Level of education attained						
Never attended	2(25.0%)	6(75.0%)	0.31	0.05	1.80	0.192
Primary	25(62.5%)	15(37.5%)	1.56	0.60	4.05	0.358
Secondary	15(53.6%)	13(46.4%)	1.08	0.39	3.01	0.880
College/University	16(51.6%)	15(48.4%)	Ref			
Marital status						
Never married	14(56.0%)	11(44.0%)	1.04	0.42	2.57	0.939
Married	43(55.1%)	35(44.9%)	Ref			

Continuation from Table 4.16

Religious Affiliation						
Protestant	42(61.8%)	26(38.2%)	2.42	0.38	15.49	0.350
Catholic	12(38.7%)	19(61.3%)	0.95	0.14	6.53	0.956
Muslim	2(40.0%)	3(60.0%)	Ref			
Occupation						
Formally employed	12(57.1%)	9(42.9%)	1.33	0.34	5.19	0.678
Businessperson	13(43.3%)	17(56.7%)	0.77	0.21	2.73	0.679
Casual worker	26(61.9%)	16(38.1%)	1.63	0.48	5.50	0.435
Others (Farmer)	7(50%)	7(50%)	Ref			
Income						
<5000 Ksh	15(60.0%)	10(40.0%)	1.20	0.35	4.09	0.771
5000-9,000 Ksh	22(50%)	22(50%)	0.80	0.27	2.41	0.691
10,000-15,000 Ksh	11(55.0%)	9(45.0%)	0.98	0.27	3.52	0.973
>15,000 Ksh	10(55.6%)	8(44.4%)	Ref			
Period of child's hospitalization						
1 - 2 weeks	23(52.3%)	21(47.7%)	1.15	0.49	2.69	0.748
3 - 4 weeks	15(68.2%)	7(31.8%)	2.25	0.76	6.67	0.143
5 weeks and above	20(48.8%)	21(51.2%)	Ref			
Child's past hospitalization history						
Yes	33(51.6%)	31(48.4%)	0.77	0.35	1.67	0.503
No	25(58.1%)	18(41.9%)	Ref			

OR= Odds Ratio, CI= Confidence Interval, Ref= Reference

4.14 Association between socio-demographic characteristics and satisfaction with the service providers

Bivariate analysis of association between socio-demographic characteristics and level of satisfaction with the service providers is summarized in Table 4.17.

There was significantly high proportion of low satisfaction with service providers among parents who had stayed in the hospital for 3 - 4 weeks 13(59.1%)[OR=3.85; 95%CI=1.31-11.32; P=0.014] and 5 weeks and above 21(51.2%)[OR=2.80; 95%CI=1.14-6.91; P=0.025] compared to those who had stayed in the hospital for 1 - 2 weeks 12(27.5%).

Table 4. 17: Association between socio-demographic characteristics and satisfaction with the service providers

Socio-demographic characteristics	Satisfaction with the service providers		OR	95%CI		χ2 test
	Low, n(%)	High, n(%)		Lower	Upper	P value
Age in years						
20-29	12(33.3%)	24(66.7%)	0.50	0.16	1.59	0.239
30-39	25(47.2%)	28(52.%)	0.89	0.31	2.60	0.836
40 and above	9(50%)	9(50%)	Ref			
Gender						
Male	11(55.0%)	9(45.0%)	2.04	0.73	4.39	0.270
Female	33(37.9%)	54(62.1%)	Ref			
Residence						
Urban	24(53.3%)	21(46.7%)	1.03	0.45	3.20	0.789
Rural	31(52.5%)	28(47.5%)	Ref			
Level of education attained						
Never attended	3(37.5%)	5(62.5%)	1.09	0.22	5.45	0.916
Primary	21(52.5%)	19(47.5%)	2.01	0.77	5.26	0.155
Secondary	11(39.3%)	17(60.7%)	1.18	0.41	3.38	0.763
College/University	11(35.5%)	20(64.5%)	Ref			
Marital status						
Never married	9(36.0%)	16(64.0%)	0.66	0.26	1.66	0.373
Married	36(46.2%)	42(53.8%)	Ref			
Religious Affiliation						
Protestant	26(38.2%)	42(61.8%)	0.41	0.07	2.64	0.350
Catholic	16(51.6%)	15(48.4%)	0.71	0.10	4.86	0.728
Muslim	3(60.0%)	2(40.0%)	Ref			
Occupation						
Formally employed	10(47.6%)	11(52.4%)	1.21	0.31	4.73	0.782
Businessperson	11(36.7%)	19(63.3%)	0.77	0.21	2.81	0.695
Casual worker	19(45.2%)	23(54.8%)	1.10	0.33	3.73	0.877
Others (Farmer)	6(42.9%)	8(57.1%)	Ref			
Income						
<5000 Ksh	11(44.0$)	14(56.0%)	2.04	0.56	7.49	0.281
5000-9,000 Ksh	22(50%)	22(50%)	2.60	0.79	8.54	0.115
10,000-15,000 Ksh	8(40.0%)	12(60.0%)	1.73	0.44	6.79	0.430
>15,000 Ksh	5(27.8%)	13(72.2%)	Ref			
Period of child's hospitalization						
1 - 2 weeks	12(27.5%)	32(72.7%)	Ref			
3 - 4 weeks	13(59.1%)	9(40.9%)	**3.85**	**1.31**	**11.32**	**0.014**
5 weeks and above	21(51.2%)	20(48.8%)	**2.80**	**1.14**	**6.91**	**0.025**
Child's past hospitalization history						
Yes	25(39.1%)	39(60.9%)	0.67	0.31	1.47	0.317
No	21(48.8%)	22(51.2%)	Ref			

OR= Odds Ratio, CI= Confidence Interval, Ref= Reference

4.15 Association between socio-demographic characteristics and awareness about child's care

Bivariate analysis of the association between socio-demographic characteristics and awareness about the childôs care is presented in Table 4.18. However, there was no significant association (P<0.05) observed between socio-demographic characteristics and level of awareness about the childôs care.

Table 4. 18: Association between socio-demographic characteristics and awareness about child's care

Socio-demographic characteristics	Awareness		OR	95%CI		χ2 test
	In-adequate, n(%)	Adequate, n(%)		Lower	Upper	P value
Age in years						
20-29	10(27.8%)	26(72.2%)	1.00	0.28	3.54	1.000
30-39	23(43.4%)	30(56.6%)	1.99	0.62	6.40	0.246
40 and above	5(27.8%)	13(72.2%)	Ref			
Gender						
Male	10(50.0%)	10(50.0%)	2.11	0.79	5.64	0.133
Female	28(32.2%)	59(67.8%)	Ref			
Residence						
Urban	18(40.0%)	27(60.0%)	1.30	0.58	2.91	0.522
Rural	20(33.9%)	39(66.1%)	Ref			
Level of education attained						
Never attended	4(50.0%)	4(50.0%)	1.21	0.26	5.76	0.807
Primary	10(25.0%)	30(75.0%)	0.41	0.15	1.11	0.078
Secondary	10(35.7%)	18(64.3%)	0.68	0.24	1.92	0.462
College/University	14(45.2%)	17(54.8%)	Ref			
Marital status						
Never married	5(20.0%)	20(80.0%)	0.40	0.14	1.18	0.090
Married	30(38.5%)	48(61.5%)	Ref			
Religious Affiliation						
Protestant	24(35.3%)	44(64.7%)	0.14	0.01	1.29	0.082
Catholic	10(32.3%)	21(67.7%)	0.12	0.01	1.21	0.072
Muslim	4(80.0%)	1(20.0%)	Ref			
Occupation						
Formally employed	9(42.9%)	12(57.1%)	1.88	0.44	7.96	0.394
Businessperson	13(43.3%)	17(56.7%)	1.91	0.49	7.49	0.352
Casual worker	12(28.6%)	30(71.4%)	1.00	0.26	3.82	1.000
Others (Farmer)	4(28.6%)	10(71.4%)	Ref			

Continuation from Table 4.18

Income						
<5000 Ksh	10(40.0%)	15(60.0%)	0.67	0.20	2.26	0.516
5000-9,000 Ksh	14(31.8%)	30(68.2%)	0.47	0.15	1.43	0.183
10,000-15,000 Ksh	5(25.0%)	15(75.0%)	0.33	0.09	1.31	0.116
>15,000 Ksh	9(50%)	9(50%)	Ref			
Period of child's hospitalization						
1 - 2 weeks	14(31.8%)	30(68.2%)	1.01	0.40	2.51	0.991
3 - 4 weeks	11(50%)	11(50%)	2.15	0.74	6.24	0.157
5 weeks and above	13(31.7%)	28(68.3%)	Ref			
Child's past hospitalization history						
Yes	22(34.4%)	42(65.6%)	0.88	0.40	1.98	0.764
No	16(37.2%)	27(62.8%)	Ref			

OR= Odds Ratio, CI= Confidence Interval, Ref= Reference

CHAPTER FIVE: DISCUSSION, CONCLUSION AND RECOMENDATIONS

5.1 DISCUSSION

These results support the idea that there is a relationship between the institutionôs structures and care delivery processes and the perception of parents of childhood cancer patients in regard to the quality of care they and their children receive. In this study it had been hypothesized that there is no relationship between the institutionôs structures and care delivery processes and parentsô perception of quality of paediatric oncology care at Kenyatta National Hospital. The null hypothesis stated in this study is therefore rejected since the study findings indicate a relationship between structures and care delivery processes and the parentsô perception of the quality of care received by childhood cancer patients.

5.1.1Characteristics of the study population

This study was conducted among parents of childhood cancer patients at Kenyatta National Hospital. The purpose of the study was to ascertain the parentsô assessment of the quality of pediatric oncology care at the hospital and determine the factors that were contributing to their perception of the care provided. The findings show that the respondents were relatively young with a mean age of 33 years. Almost half 53(49.5%) of the respondents were aged between 30 - 39 years. Many of these parents also had other children who were aged between 6 - 10 years. This indicates that many young families are facing the challenge of having to care for a child with cancer and are faced with the need for the childôs frequent hospitalization. It was also noted that majority of the respondents were casual workers with a monthly income of less than Kshs. 10, 000. This state is likely to lead to parents facing financial hardships related to their childrenôs care and treatment since cancer drugs are expensive and cost as much as fifteen thousand

shillings as had been expressed by one participant in the FGD. Other studies done indicate that families face financial challenges related to their childôs cancer treatment. According to Miedema et al. (2008), families expressed financial hardships associated with caring for a child with cancer. The author further explains that in one study, 37% of families reported that they were forced to borrow money to cover the extra cost of treatment related to the childôs illness.

5.1.2 Overall satisfaction with the care service provided

Sixty two (57.9%) reported satisfaction with the overall care their children had received and were willing to recommend care services at the hospital to others. However, 44 (42.1%) of the parents reported dissatisfaction with the overall care they had received and were unwilling to recommend care services to others. The determinants of overall satisfaction in this study were found to be adequate availability of resources for cancer treatment [OR=3.10; 95%CI=1.39-6.90; P=0.005], sufficient/good care delivery processes [OR=2.87; 95%CI=1.28-6.43; P=0.009] and adequate infrastructure/environment [OR=2.59; 95%CI=1.17-5.74; P=0.018]. As expected there is more satisfaction if resources are adequate, care delivery processes are good and the infrastructure/environment is adequate. Similarly, literature also identifies determinants of perceptions of cancer care to be associated to structures and processes of care within a health care institution. According to a study by Lock et al. (2012), clinical service delivery, availability of drugs, lack of clear instructions to parents and amenities provided for parents and children contributes greatly to parentsôperception of care.

Furthermore, according to the FGDs some of the factors that were attributed to the parentsô dissatisfaction with the care provided and their unwillingness to recommend others to seek care from the hospital include delay in commencement of chemotherapy and radiotherapy treatment,

unavailability of drugs and blood and lack of information about their childrenôs illness and treatment as well as side effects of treatment. Delay in carrying out tests and availing results, as well as congestion and lack of essential amenities such as hot water in the wash rooms also contributed to parentsô dissatisfaction with the care provided. These findings are in agreement with findings from a study by Lis et al. (2009) which show that patient provider relationship, facility setting and information on diagnosis and treatment were major determinants of patientsô willingness to recommend a facility to a friend. In order to provide quality care to patients and achieve high customer satisfaction care ratings, it is therefore important for health care facilities to align the care delivery processes to the patientsô/customersô requirements.

5.1.3 Parents' perception of the infrastructure: Environment

There was no significant association between socio-demographic characteristics and level of parentsô perception on infrastructure**.** About 40.2% of the respondents perceived the infrastructure to be inadequate. This was attributed to congestion, cleanliness of the washrooms, lack of essential amenities such as hot water in the bathrooms and availability of play facilities. The parents and sick children require a comfortable environment in order to facilitate their care and treatment. As a result of the congestion, children were sharing beds. This situation contributes to discomfort among the children and their parents. It also gives rise to the likelihood of children acquiring infections which could have an effect on their treatment outcome and also put more financial burden on the hospital and families of the sick children. Play is important for children because it helps them to understand their world and it promotes learning, growth and development as well as relaxation, fun and socialization. Study findings show that parentsô positive perception is related to their satisfaction with amenities provided (Lock et al., 2012).

5.1.4 Parents' perception of availability of resources

There was no significant association observed between the socio-demographic characteristics and parentsô perception of availability of resources. About 42.1% of the parentsô perceived resources to be inadequate. This was attributed to dissatisfaction with hospital meals, linen, investigations and availability of doctors and nurses. Nutrition plays a great role in cancer care. Lack of adequate nutrition in these patients is likely to expose them to malnutrition which may have effects on the treatment outcomes. This is because they are likely to have greater risk of infection during treatment and also challenges in tolerating the treatment and its side effects. Among the parents whose children had received chemotherapy treatment, 14.9% reported that the drugs were not available. Unavailability of chemotherapy drugs was contributing to treatment delay and inconsistencies as is reflected in the study findings. This eventually affects the treatment outcome in terms of quality of life and mortality rate. Many of the parents were not able to buy the required drugs because of the cost. Others took long before they could eventually buy the drugs due to financial constraints. This may be explained by the fact that many of the respondentsô (64.5%) monthly income level was less than ten thousand shillings. The delay in treatment was also contributing to long stay in the ward while waiting for treatment and this in return was contributing to the congestion in the ward and thus adding to the burden of the strained hospitalôs resources. Study findings show that parentsô positive perception is related to their satisfaction with availability of drugs (Lock et al. (2012). Findings in this study which indicate parentsô dissatisfaction with the availability of drugs is consistent with other studies. Nyongesa et al., (2013) found out that lack of drugs for patients in government hospitals contributes to clientsô perception of low quality of service. There is therefore need for the

hospital to ensure availability of the required resources such as chemotherapy drugs that are needed for childhood cancer treatment.

5.1.5 Parents' perception of care delivery processes

Study findings indicate that majority (54.2%) of the parents had a negative perception of care delivery processes. This dissatisfaction was attributed to information provided by the health care givers in regard to the childôs illness and treatment, response of the nurses and doctors to the parentsô questions and concerns, involvement in decision making and care of the child and their communication with doctors and nurses.

Respondents with negative perception on care delivery processes were significantly more among the age group of 20-29 years (p=0.006) and 30-39 years (p=0.012). This could be associated to the fact that young parents may not have the required skills and knowledge to provide the required care to their children and this is likely to affect their decision making. They therefore require information and guidance to make informed decisions regarding the childôs treatment. Study findings indicate that younger parents expressed need for family involvement in treatment decisions while older parents received and desired to have more input from medical staff members before making the decision (McKenna et al., 2010).

Majority of the parents (59.8%) did not know about their childrenôs illness and treatment. This finding is in agreement with that of a study by Given et al., (2008) which found out that care givers do not have the required skills and knowledge to provide the necessary care. Lack of information about the childôs illness and treatment could have an effect on their involvement in the childrenôs care such as monitoring and management of treatment effects and being involved in decision making concerning their childrenôs care. Parents play a great role as care givers of

these patients, it is important for them to have the required information in order to be able to take care of these children effectively. Parent education is among the duties of nurses. Nurses need to educate the patients and their families. This can help in reduction of challenges such as anxiety in children with cancer and their mothers, which can arise due to inadequate knowledge.

More than half (64.5%) of the parents were satisfied with their involvement in decision making regarding care of their child. There is need for greater recognition of the parent as a care giver for the child during stress of hospitalization. Other studies done found out that increasing parental involvement in the care of children with cancer may improve perceived care quality. Findings from this study further indicate that over 50% of parents of children with cancer would like to be involved more in decision making about the childôs care (Kam et. al, 2008). More than half of the respondents (64.5%) were satisfied with the doctor parent communication whereas 71% were satisfied with the parent nurse communication. These findings of doctor patient communication are low compared to other study findings indicating parentsô 100% satisfaction with physician interaction (Lock, 2012). This indicates that health care giver- parent communication can enhance parentsô positive perception of the care given. There is therefore need to encourage this positive behaviour among the health care givers through seminars that focus on customer care communication. Ineffective communication can be a barrier which can prevent the delivery of appropriate care to childhood cancer patients. According to Kolcaba and Marguerite (2005), the use of comfort theory encourages the family to participate in goal setting and the provision of holistic and proactive care through communication. Through effective communication, parents can be informed about their childrenôs illness, care and treatment and this will enable compliance with treatment and early identification of treatment related problems

for early interventions. Findings from other studies indicate that doctor-patient communication is the main determinant of high quality physician care Mack et al. (2005).

5.1.6 Parents' satisfaction with the health care providers

More than half (57%) of the parents were satisfied with the health care providers (doctors and nurses) whereas 43% were not satisfied with them. The reasons for dissatisfaction with health care providers included lack of a caring attitude, impoliteness, dishonesty and disrespect for parentsô values and beliefs. There was significantly high proportions of respondents with low satisfaction in regard to service providers among parents who had stayed in the hospital for 3-4 weeks (p=0.014) and 5 weeks and above (p=0.025). These findings indicate that dissatisfaction with the health service providers was related to the length of stay in hospital.

The findings demonstrate that parents value efficient services as well as a caring attitude and communication between them and the health care givers. This is in agreement with findings in literature indicating that quality nursing care is regarded as provision of nursing care in a caring as well as a friendly and respectful manner (Izumi et. al 2010). Findings in this study indicate that parentsô satisfaction with the honesty of the doctors and nurses was 72.9% and 68.2% respectively. This indicates that some of the health care providers do not provide honest information to the parents. Health care providersô honesty to the parents regarding information on the childôs care is important because it enables parents to make decisions based on the information given to them.

From the study findings, it is noted that parents would like to be given honest information in order to be aware of what is happening to their child. This is very important to them, given the

fact that they are the primary care givers of these children. It is important therefore for them to have honest information to enable them practice their care giving role effectively.

5.1.7 Parents' awareness about child's care

From the study findings there is no significant association between socio demographic characteristics and awareness about childôs care. Majority (70.1%) of the parents were aware of the side effects of the childôs treatment. Parentsô awareness of their childrenôs illness and treatment as well as the treatment effects is of great importance in providing quality care to paediatric oncology patients. Due to the fact that cancer treatment is long term and has various effects to the child and the family, some of which can be devastating, there is need for the parents to understand the illness and treatment in detail. This information to the parents can help in treatment compliance and management of side effects related to the cancer treatment. Studies indicate that inadequate communication provided to parents by health care providers could lead to abandonment of treatment (Arora et. al., 2010). Information therefore on treatment side effects can help in reducing the rate of treatment abandonment. A Study by Stefanus et al. (2014), found out that 98% of parents would like to receive more information about the side effects of treatment. This is because majority of parents are worried about side effects and would like to receive more information. This is in agreement with findings from the study during one of the FGD session.

Many parents (75.8%) expressed the need to have a support group that would provide emotional and psychological support to them. This indicates that support for parents of childhood cancer patients is important because through support they are able to cope with the cancer treatment and its effects. Studies indicate psychological assessment and intervention can reduce parental stress

by increasing coping hence reducing childrenôs psychological problems because of correlation of distress in parents and children (Azizah et al., 2011). More findings in literature indicate that psychological and sociological support as well as communication between the health care team and parents of children with cancer determines the perceived quality among the parents (Chiaradia et al. (2008). Parents therefore require support related to their childrenôs cancer care such as the required information as well as psychological and emotional support. This could help in ensuring that the quality of life of the sick children is at optimal level in order to improve outcomes.

5.2 CONCLUSION

Majority (57.9%) of the parents were satisfied with the care services their children received whereas 42.1% were dissatisfied. From this it can be concluded that the parents were moderately satisfied with the quality of oncology care services provided to their children at Kenyatta National Hospital. This satisfaction was determined by adequate availability of resources for pediatric cancer treatment [OR=3.10; 95%CI=1.39-6.90; P=0.005], sufficient care delivery processes [OR=2.87; 95%CI=1.28-6.43; P=0.009] and adequate infrastructure/environment [OR=2.59; 95%CI=1.17-5.74; P=0.018]. Moreover, the main reasons attributed to dissatisfaction as mentioned by FGD participants include; delays in commencement of treatment, unavailability of chemotherapy drugs and blood, delays in carrying out tests and availing of results, lack of information about their childrenôs illness and treatment and lack of adequate space in the wards leading to patient congestion.

5.3 RECOMENDATIONS

5.3.1 Operational Recommendations

1. There is need for the hospital management to address the issue of congestion in order to ensure comfort to the patients and their parents.
2. The hospital management needs to ensure that the required resources and amenities for the care of childhood cancer patients are available at all times.
3. Care delivery processes require to be improved in order to deliver timely and efficient care services to paediatric cancer patients.
4. Parents need to be provided with the required honest information regarding their childrenôs illness and treatment for their effective involvement in their childrenôs care.

5. There is need to provide support to the parents in regard to their childrenôs care through counseling and payment of treatment bills through the National Hospital Insurance Fund.
6. There is need to involve parents in support groups for psychological, emotional, educational and physical as well as financial support related to their childrenôs care and treatment.

5.3.2 Research Recommendation

There is need for more studies to be done regarding the effects/impact of the structures and care delivery processes on the quality of life and treatment outcome of childhood cancer patients at Kenyatta National Hospital.

REFERENCE LIST

Aiken, L. H., Sermeus, W. and Kutney- Lee, A. (2012) Patient safety, satisfaction and quality of hospital care: cross sectional surveys of nurses and patients in 12 countries in Europe and the United States*, British Medical Journal,* pp. 344.

Andaleeb, S. (2001) Service quality perceptions and patient satisfaction: a study of hospitals in a developing country, *Social Science & Medicine*, 52 (9), pp. 1359-1370.

Arora, R.S., Pizer, B. and Eden, T. (2010) Understanding Refusal and Abandonment in the Treatment of Childhood cancer, *Indian Pediatrics*, pp. 47.

Azizah, O., Mohamad, N., Hussin, Z.A. and Blunden, S. (2011) Psychological Distress and Associated Factors in Parents of Children with Cancer, *International Journal of Social Sciences and Humanity,* 1 (1).

Blanchard, J. and Lurie, N. (2004) ñR-E-S-P-E-C-T: Patient Reports of Disrespect in the Health Care Setting and Its Impact on Care,ò *Journal of Family Practice*,53(9), pp. 721.

Boutopoulou, B., Petsios, K. and Chrysostomou, A. (2010) 72 Parental Satisfaction Concerning Their Childôs Hospital Care: A Questionnaire Survey, *Paediatric Research*, 68, pp. 39-40.

Chiaradia, G., de Waure, C., Salipante, O., Nocciolini, E., Ricciardi, W. and La Tore, G. (2008) Healthcare quality in paediatric oncology: the role of communication and relational aspects, *Ann Ig*.20(5), pp. 495-502.

Chodzaza, E. and Bultemeier, K. (2010) Service providers perception of the quality of emergency obstetric care provided and factors identified which affect the provision of quality care, *Malawi Medical Journal*, 22 (14).

Copp, G., Caldwell, K., Atwal, A., Brett-Richards, M. and Coleman, K. (2006) Preparation for cancer care: Perceptions of newly qualified health care professionals, *European Journal of Oncology Nursing*.

El Haj Ibn, H., Lamrini, M. and Rais, N. (2013) Quality of care between DONABEDIAN model and ISO 9001 V 2008, *International Journal for Quality Research*, 7 (1), pp. 17-30.

Given, B., Sherwood, P. R. and Given, C.W. (2008) What Knowledge and Skills Do Caregivers Need? *America Journal of Nursing*, 108 (9), pp. 28-34.

Glickman, S. W., Baggett, K. A. and Krubert, C. G. (2007) Promoting quality: the health care organization from a management perspective, *International Journal for Quality in Health Care*, 19 (6), pp.341-348.

Gunawan, S., Wolters, E., van Dongen, J., van de ven P. et al (2014) Parents and Health ï Care Providersô Perspectives on Side ï Effects of Childhood Cancer Treatment in Indonesia, *Asian Pacific Journal of Cancer Prevention*, 15(8), pp. 3593-3599.

Ha, J.F., Longnecker, N. (2010) Doctor ï Patient Communication: A Review, *The Ochsner Journal*, 10 (1), pp. 38-43.

Hess, L. and Gerhardt, P. (2013) Perspectives of Quality Care in Cancer Treatment: A review of literature, *American Health & Drug Benefits,* 6 (6), pp. 321-329.

Hubble, R., Trowbridge, K., Hubbard, C., Ahsens, L. and Ward Smith, P. (2008) Effectively using communication to enhance the provision of pediatric palliative care in an acute care setting, *Journal of Multidisciplinary Healthcare,* 1, pp. 45-50.

Hughes, R.G. (2008) *Patient Safety and Quality: An Evidence- Based Handbook for Nurses*, Rockville (MD) US.

Izumi, S., Baggs, J.G., Knafl, K. (2010) Quality Nursing Care for Hospitalized Patients with Advanced Illness: Concept Development, *Res Nurs Health*, 33 (4), pp. 299-315.

Kam, J., Parepinto, J. A., Brandow, A.M. and Brousseau, D.C. (2008). Parental Perception of Quality of Hospital Care for Children with Sickle Cell Disease, *Wisconsin Medical Journal*, 107 (3).

Kellie, S.J. and Howard, S.C. (2008) Global child health priorities: what role for paediatric oncologists? *European Journal of Cancer*, 44 (16), pp. 2388-2396.

Kieft, R. A.M., de Brounder, B. J.M., Francke, A.L. and Delnoij, D.M.J. (2014) How nurses and their work environment affect patient experiences of the quality of care: a qualitative study, *BMC Health Services Research,* 14, pp. 249.

Knops, R.R. G., Hulschner, M. E. J., Hermens, R.P.M. et al. (2011) High quality care for all children with cancer, *Annals of Oncology*, 23, pp. 1906 ï 1911.

Kolcaba, K. and Marguerite, A. (2005) Comfort Theory and its Application to Paediatric Nursing. *Paediatric Nursing,* 31(3), pp. 187-194.

Lis, C. G., Rodeghier, M. and Gupta, D. (2009) Distribution and determinants of patient satisfaction in oncology: A review of literature, *Patient Preference and Adherence*, 3, pp. 287-304.

Lock, A.L., Bodkyn, C. and Ali, Z. (2012) Parent perception of paediatric oncology services at the Erick Williams Medical Sciences Complex, Trinidad and Tobago, *West Indian Medical Journal*, 61 (1).

Mack, J.W., Hilden, J.M., Watterson, J., Moore, C., Turner, B., Grier, H.E., Weeks J.C. and Wolf, J. (2005) Parent and physician perspectives on quality of care at the end of life in children with cancer, *Journal of Clinical Oncology,* 23 (36), pp. 9155-9161.

Mainz, J. (2003) Defining and classifying clinical indicators for quality improvement. *International Journal for Quality in Health Care,* pp. 523-530.

McDonald, K.M., Sundaram, V., Bravata, D.M. et al. (2007) *Closing the Quality Gap: A Critical Analysis of quality Improvement Strategies (Vol. 7: Care Coordination)*, Rockville (MD) US.

Mckenna, K., Collier, J., Hewitt, M. and Blake, H. (2010) Parental involvement in paediatric cancer treatment decisions, *European Journal of Cancer Care,* 19 (5), pp. 621-630.

Ministry of Health (2013) National Guidelines for Cancer Management Kenya. [Online]. Available at Kehpca.org/wp-content/é /National-Cancer-Treatment-Guidelines2.pdf

Miedema, B., Easley, J., Fortin, P., Hamilton, R. and Matthew M. (2008) The economic impact on families when a child is diagnosed with cancer. *Current Oncology,* 15 (14), 173-178.

Mugenda, O. M. and Mugenda, A.G. (2003) *Research Methods: Quantitative and Qualitative Approaches*. Act Press. Nairobi. Kenya

Muntlin, A., Gunningberg, L. and Carlson, M. (2006) Patientôs perceptions of quality of care at an emergency department and identification of areas for quality improvement, *Journal of Clinical Nursing,* 15 (80), pp. 1045-56.

Ntoburi, S., Hutchings, A., Sanderson, C. et al, (2010) Development of paediatric quality of inpatient care indicators for low ï income countries ï A Delphi study, *BMC Pediatrics*, 10 (90).

Nyongesa, M. W., Onyango, R. and Ombaka, J. (2013) Evaluation of the Level of Quality Health Care Accorded to Patients in Selected Public and Private Hospitals in Kiambu and Nairobi Counties in Kenya, *Primary Health Care* 3, pp. 129.

Patrick, J.T., Ferris, T.G., Marino, B.L., Homer C. and Pervin, J.M. (2003) Are hospital characteristics associated with parental views of paediatric inpatient care Quality? *PEDIATRICS* 111 (2), pp. 308-314.

Pearson, A., Vaughan, B. and FitzGerald M. (2005) *Nursing Models for Practice*, 3rd Edition. Butterworth Heinemann, Philadelphia, USA.

Rodriguez- Galindo, C., Friedrich, P., Morrissey, L. and Frazier, L. (2013) Global challenges in paediatric oncology, *Current Opinion in Paediatrics,*25 (10), pp. 3-15.

Sandoval, G.A., Brown, A.D., Sullivan, T. and Green, E. (2006) Factors that influence cancer patientsô overall perceptions of the quality of care, *International Journal for Quality in Health Care*, 18(4), pp. 266-274.

Shang, J., Friese, C.R., Wu, E. and Aiken, L. H. (2012) Nursing Practice Environment and Outcomes for Oncology Nursing, *Cancer Nursing*, 36 (3), pp. 206-212.

Sheingold, B.H. and Hahn, J.A. (2014) The history of healthcare quality: The first 100 years 1860 ï 1960. *International Journal of Africa NursingSciences,*1, pp. 8- 22.

Stefan, D.C. (2014). Childhood Cancer in Africa: Past, present and future, *African Journal of Cancer,* 6 (3), pp. 127-128.

Stefan, D. C. and Rodriguez ï Galindo, C. (2013) *Pediatric Hematology- Oncology in Countries with Limited Resources: A Practical Manual*, Springer Science & Business Media.

Stefanus, G., Emma, W., Josephine van Dongen, Peter van de Ven et al. (2014) Parents and Health Care Providersô Perspectives on Side Effects of Childhood Cancer Treatment, *Asian Pacific Journal of Cancer Prevention*, 15 (8), pp. 3593-3599.

World Health Organization, Geneva. (2006) Quality of Care: A process for making strategic choices in health systems.

[Online]. Available atwww.who.int./management/quality/assurance/quality care-B.Def.pdf

Ygge, B.M. (2004) *Parental involvement in Paediatric Hospital Care- Implications for Clinical Practice and Quality of Care*, Acta Universitatis Upsaliensis. Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine, pp. 1326 ï 1360, Uppsala. ISBN 91-554-5884-X.

Zamanzadeh, V., Azimzadeh, R., Rahmani,A. and Valizadeh, C. (2010) Oncology patients and professional nursesôperceptions of important nurse caring behaviours, *Biomed Central Nursing*.

APPENDICES

APPENDIX I: GANTT CHART (WORK PLAN)

	Period 2014	 2015								
ACTIVITY	Dec	Jan	Feb	Mar	Apr	May	June	July	Aug	Sep
Problem identification, literature review and proposal writing	■	■								
Presentation to KNH Ethics and Research Committee			■							
Selection and training of Research Assistants				■						
Pretesting of Research Questionnaire				■						
Data collection, processing and Analysis				■	■					
Final report writing and presentation to the school of Nursing						■				
Dissemination to the external examiner						■	■			
Final oral defense								■	■	
Information dissemination										■

APPENDIX II: BUDGET

ITEM	UNIT COST (KSHS)	QUANTITY	COST	TOTAL COST
A. PERSONNEL/HUMAN RESOURCE				
Ethical Committee review fee	2000.00	1	2000.00	
Research Assistants training	1000.00	1	1000.00	
Research Assistants allowance (pretesting)	1000.00	1	1000.00	
Investigator allowance on pretesting	1500.00	1	1500.00	
Allowance for Biostastician for whole period of research	30 000.00	1	30 000.00	
Allowance for investigator for whole period of research	25 000.00	1	25 000.00	
Allowance for research assistants for whole period of data collection	10 000.00	1	10 000.00	
Sub Total				70 500.00
B. MATERIALS AND SUPPLIES				
Foolscap papers	500.00	1	500.00	
Printing paper	500.00	2	1000.00	
USB Flash Disk	1500.00	1	1500.00	
Ball pens	200.00	1 dozen	200.00	
Pencils	100.00	1 dozen	100.00	
Erasers	20.00	2 pieces	40.00	
Stapler and staples	500.00	1 pair	500.00	
Calculator	2000.00	1	2000.00	
Paper punch	300.00	1	300.00	
Envelopes size A4	10.00	110	1100.00	
Sub Total				7240.00
C: PROPOSAL AND THESIS				
Proposal typing and printing	20.00	80 pages	1600.00	
Proposal photocopying	160.00	3 copies	480.00	
Questionnaires photocopying	2.00	110 x 7 pages	1540.00	
Final report typing and printing	20.00	100 pages	2000.00	
Final report photocopying	2.00	3 x 100 pages	600.00	
Report binding	200.00	3 copies	600.00	
Sub Total				6820.00
Total				84 560.00
15 % Contingencies				12 684.00
GRAND TOTAL				**97 244.00**

APPENDIX III: CONSENT TO PARTICIPATE IN A RESEARCH STUDY.

Title of Research study

Determinants of parentsô perception of quality of paediatric oncology care at Kenyatta National Hospital.

Investigator

Mrs. Eunice Keiza, School of Nursing, University of Nairobi.

Study purpose

The purpose of the study is to ascertain parentsô assessment of the quality of paediatric oncology care at Kenyatta National Hospital and determine the factors that contribute to their perception.

Procedure to be undertaken

If you agree to participate in the study:

1). You will be selected at random to participate at your convenient time.

2). You will be required to sign consent.

3). You will be given a questionnaire to fill or you will be interviewed in case you need assistance in answering questions.

4). The questionnaire will take 30-45 minutes to complete.

5). You are not required to indicate your name in the questionnaire.

Benefits

I understand that here are no direct benefits for me. However it will help in understanding of the factors influencing quality of care of paediatric oncology patients at Kenyatta National Hospital and will help in care improvement of paediatric cancer patients.

Risk

I understand there are no potential risks foreseen to be involved as I will only be required to fill in a questionnaire.

Confidentiality

The results of this study will be discussed with me. All other information except for this disclosure will be considered confidential and used only for research purpose. My identity will be kept confidential in as far as the law requires.

Questions

The research assistant or principal investigator will answer my questions.

Right to refuse or withdraw

I understand my participation is entirely voluntary but essential to the success of this study. I am free to refuse to take part or withdraw at any given time without affecting my future relationship with the school of Nursing of the University of Nairobi.

In case you would want to know the results of this study or you have any complaints, dissatisfaction or disagreements, please do not hesitate to contact the following:

1. Eunice Keiza on cell phone number 0716325737
2. Chairman KNH/UON-ERC, Box 20723 Kenyatta National Hospital.Tel 2726300-9, Extension 44102.

Consent

I have been clearly explained and fully understand the nature and purpose of this study and freely consent to participate. Respondentôs signature é é é é é é é é Date é é é é é é é é

I the undersigned have fully explained the relevant details of this study to the person whose signature has been appended above.

Investigatorôs/Research assistantôs signature é é é é é é é é é é Date é é é é é é é .

KIAMBATISHO III: RIDHAA YA KUSHIRIKI KATIKA UTAFITI

Jina la Utafiti

Vigezo vya mtazamo wa wazazi wa ubora wa huduma ya kansa kwa watoto katika Hospitali ya taifa ya Kenyatta

.**Mpelelezi**

Bi.Eunice Keiza, Shule ya Uuguzi, Chuo Kikuu cha Nairobi.

Kusudi la Utafiti

Lengo la utafiti ni kuhakikisha tathmini ya wazazi ya ubora wa huduma ya kansa kwa watoto katika Hospitali ya taifa ya Kenyatta na kuamua sababu zinazochangia mtazamo wao.

Utaratibu

1) Utachaguliwa nasibu kwa kushiriki katika utafiti huu katika hospitali ya taifa ya Kenyatta kwa muda wako rahisi.
2) Utahitajika kutia sahihi ili kushiriki katika utafiti.
3) Utapewa dodosi ujaze au utahojiwa ikiwa unahitaji usaidizi kwa kujaza dodosi.
4) Utatakiwa kujaza dodosi itakayochukua muda wa dakika 30-45.
5) Hauhitajiki kuandika jina lako kwenye dodosi

Faida

Naelewa kuwa hakuna faida ya moja kwa moja kwa ajili yangu. Hata hivyo, itasaidia katika kuelewa vipengele vinavyoathiri huduma bora ya watoto wagonjwa wanaougua saratani waliolazwa katika hospitali ya taifa ya Kenyatta na kusaidia pia katika uboreshaji wa huduma ya wagonjwa hao.

Hatari

Naelewa kuwa hakuna uwezekano wa hatari kuwepo kwani nitatakiwa kujaza dodosi tu.

Siri

Matokeo ya utafiti huu yatajadiliwa pamoja nami. Habari yoyote nyingine isipokuwa hii itazingatiwa siri na kutumika tu kwa madhumuni ya utafiti. Utambulisho wangu utakuwa siri na kutumika tu kwa madhumuni ya utafiti. Utambulisho wangu utakuwa siri kama sheria inavyohitaji.

Maswali

Msaidizi wa utafiti au mkuu wa uchunguzi ndiye atakaye jibu maswali yangu.

Haki ya kukataa au kujiondoa

Naelewa kuwa ushiriki wangu ni kabisa hiari lakini muhimu kwa mafanikio ya utafiti huu. Mimi ni huru kukataa au kujiondoa wakati wowote bila ya kuathiri uhusiano wangu baadaye na shule ya uuguzi ya chuo kikuu cha Nairobi. Kama ungependa kujua matokeo ya utafiti ama una malalamiko yoyote , tafadhali usisite kuwasiliana na wafuatao:

1. Eunice Keiza kupitia nambari ya simu 0716325737.
2. Mwenyekiti KNH/UON-ERC, SLP 20723 Hospitali ya Taifa ya Kenyatta, Nambari ya simu 2726300-9Ugani 44102

Ridhaa

Nimeelezwa kikamilifu na kuelewa asili ya lengo la somo hili na kwa uhuru najipa ridhaa ya kushiriki.

Sahihi ya aliyehojiwa é é é é é é é é é é é é Tarehe é é é é é é é é

Mimi mtafiti, kwa kikamilifu nimeeleza maelezo muhimu ya utafiti huu kwa mtu ambaye saini yake imewekwa juu.

Sahihi ya mpelelezi/msaidizi wa utafiti é é é é é é é é é é é é é Tarehe é é é é é é

APPENDIX IV: QUESTIONNAIRE

Questionnaire for the research on determinants of parentsô perception of quality of paediatric oncology care at Kenyatta National Hospital.

Instructions

(1) The questionnaire is intended to obtain information for study purposes only. The information will help in improving quality of care of paediatric oncology patients. Your responses will be held with confidentiality.

(2) The questionnaire contains seven (7) sections. Kindly complete all the sections by answering all the questions as instructed.

(3) Do not write your name or any other form of identification in the questionnaire.

(4) Kindly return the filled questionnaire in the envelope provided to the researcher or research assistant.

Wardé é é Participants code IDé é é é . Researcher/Research Assistantôs nameé é é é

Section 1: (a) Parentôs/childôs sociodemographic data

Tick the appropriate response.

No	Questions and Filters	Coding categories
101	Parentôs gender.	1. Male ☐ 2. Female ☐
102	How old are you?	Years ☐
103	Have you ever attended school?	1. No ☐ 2. Yes ☐
104	If yes, which level of education did you attain?	1. Primary ☐ 2. Secondary ☐ 3. College/University ☐
105	What is your marital status?	1. Never married ☐ 2. Married ☐ 3. Divorced ☐ 4. Widowed ☐
106	What is your religion?	1. Protestant ☐ 2. Catholic ☐ 3. Muslim ☐ 4. Traditional ☐ 5. No religion ☐ 6. Others. specify é é é é .
107	What is your occupation?	1. Professional ☐ 2. Businessperson ☐

		3. Farmer ☐ 4. Casual worker ☐ 5. Others. Specify é é é é é
108	What is your average monthly income?	Kshs.
109	Where do you reside?	1. Urban ☐ 2. Semi Urban ☐ 3. Rural ☐
110	How old is the child?	Years ☐
111	What is the number of the childôs siblings?	☐
112	How old is the first child on line?	Years ☐
113	How long has the child been hospitalized?	1.1 ï 2 weeks ☐ 2. 3 ï 4 weeks ☐ 3. 5 ï 6 weeks ☐ 4. 7 ï 8 weeks ☐ 5. Above 8 weeks ☐
114	Has the child been hospitalized in the past?	1. Yes ☐ 2. No ☐

Section 2: Infrastructure: Environment

Tick the appropriate response.

201	Are you satisfied with the space in the ward?	1. Yes ☐ 2. No ☐
202	If no, to No. 201, please explain why? é é é é é .. é é é é é é é é é é é é é é é é	
203	Are you satisfied with the cleanliness of the ward?	1. Yes ☐ 2. No ☐
204	If no, to No. 203, please explain why? é é é é ..... é	
205	Are you satisfied with the size of the bed/cot for your child?	1. Yes ☐ 2. No ☐
206	If no, to No. 205, please explain why? é . é	
207	Are you satisfied with ventilation of the ward?	1. Yes ☐ 2. No ☐
208	If no, to No. 207, please explain why? é é é é é é . é	

209	Are you satisfied with the wash room facilities for your child?	1. Yes ☐ 2. No ☐
210	If no, to No. 209, please explain why? é . é .	
211	Are play facilities for the child available?	1. Yes ☐ 2. No ☐

Section 3: Availability of resources

Tick the appropriate response.

301	Are you satisfied with the hospital meals provided?	1. Yes ☐ 2. No ☐
302	If no, to No. 301, please explain why? é ..	
303	Are you satisfied with availability of linen?	1. Yes ☐ 2. No ☐
304	If no, to No. 303, please explain why? é	
305	Has the child ever received chemotherapy treatment?	1. Yes ☐ 2. No ☐
306	If yes, to No. 305, were the chemotherapy drugs available?	1. Yes ☐ 2. No ☐
307	Has the child ever received radiotherapy treatment?	1. Yes ☐ 2. No ☐
308	If yes, to No. 307, were you satisfied with the radiotherapy treatment?	1. Yes ☐ 2. No ☐
309	If no to No. 308, please explain why? é .	
310	Has the child experienced pain related to the illness at any given time while in the ward?	1. Yes ☐ 2. No ☐
311	If yes, to No. 310, was the pain relieving drug available?	1. Yes ☐ 2. No ☐
312	If yes to No. 311, were you satisfied with the childôs pain relieve?	1. Yes ☐ 2. No ☐
313	Has the child ever received blood/blood products transfusion?	1. Yes ☐ 2. No ☐
314	If yes, to No. 313, were the blood/blood products available on time?	1. Yes ☐ 2. No ☐
315	Are the investigations required for the child done on time after they are requested for?	1. Yes ☐ 2. No ☐

316	Are investigation results for the child availed on time?	1. Yes ☐ 2. No ☐
317	Are doctors available when needed? Give reasons for your response é . é	1. Yes ☐ 2. No ☐
318	Are nurses available when needed? Give reasons for your response é . é ..	1. Yes ☐ 2. No ☐

Section 4: Care delivery processes

Tick the appropriate response.

401	Have you been informed about the childôs illness and treatment?	1. Yes ☐ 2. No ☐
402	Are you satisfied with the information provided to you about the childôs illness and treatment?	1. Yes ☐ 2. No ☐
403	If no, to No. 402, please explain why? é	
404	Are you satisfied with the response of the doctors to your questions and concerns?	1. Yes ☐ 2. No ☐
405	If no, to No. 404, please explain why? é	
406	Are you satisfied with the response of the nurses to your questions and concerns?	1. Yes ☐ 2. No ☐
407	If no, to No. 406, please explain why? é	
408	Are you involved in decision making in regard to the childôs care?	1. Yes ☐ 2. No ☐
409	If yes, are you satisfied with your involvement in decision making and care of the child?	1. Yes ☐ 2. No ☐
410	If no, to No. 409, please explain why? é .é é é é é é é é é é é . é .	
411	Are you satisfied with the explanation from the nurses/doctors about any procedure and test done to the child?	1. Yes ☐ 2. No ☐
412	If no, to No. 411, please explain why? é	

413	Are you satisfied with the doctor-parent/child communication?	1. Yes ☐ 2. No ☐
414	If no, to No. 413, please explain why? é	
415	Are you satisfied with the nurse-parent/child communication?	1. Yes ☐ 2. No ☐
416	If no, to No. 415, please explain why? é	

Section 5: Satisfaction with the service providers

(a) Doctors

Tick the appropriate response

501	Are you satisfied with the caring attitude of the doctors? Give reasons for your response. é . é	1. Yes ☐ 2. No ☐
502	Are you satisfied with the friendliness of the doctors? Give reasons for your response. é é é é é é é é é é .. é ..	1. Yes ☐ 2. No ☐
503	Are you satisfied with the politeness of the doctors? Give reasons for your response. é é é é é é é é é é é . é ..	1. Yes ☐ 2. No ☐
504	Are you satisfied with honesty of the doctors? Give reasons for your response. é é é é é é é é é .. é ..	1. Yes ☐ 2. No ☐
505	Are you satisfied with the respect for your values and beliefs by the doctors? Give reasons for your response. é é é é é é é é é . é ..	1. Yes ☐ 2. No ☐

(b) Nurses

Tick the appropriate response

506	Are you satisfied with the caring attitude of the nurses? Give reasons for your response. é é é é é é é é é .. é ..	1. Yes ☐ 2. No ☐
507	Are you satisfied with the friendliness of the nurses? Give reasons for your response. é é é é é é é é é é . é .	1. Yes ☐ 2. No ☐

508	Are you satisfied with the politeness of the nurses? Give reasons for your response. é é é é é é é é é é é . é .	1. Yes ☐ 2. No ☐
509	Are you satisfied with honesty of the nurses? Give reasons for your response. é é é é é é é é é .. é .	1. Yes ☐ 2. No ☐
510	Are you satisfied with the respect for your values and beliefs by the nurses? Give reasons for your response. é é é é é é é é é . é ..	1. Yes ☐ 2. No ☐

Section 6: Care giver (parent) empowerment

Tick the appropriate response.

601	Are you aware of the side effects related to the childôs treatment?	1. Yes ☐ 2. No ☐
602	Have you been adviced on the types of food the child needs to take?	1. Yes ☐ 2. No ☐
603	Is there any information you would like to know about your childôs illness and care? Please explain. é	1. Yes ☐ 2. No ☐
604	Do you/child receive counseling support in relation to the illness and treatment?	1. Yes ☐ 2. No ☐
605	Are you aware of any support group related to your childôs illness?	1.Yes ☐ 2.No ☐
606	If no, to No. 605, do you think you require to be involved in a support group?	1. Yes ☐ 2.No ☐
607	If yes, to No 606, please explain why? é é é é é é é .. é	

Section 7: Satisfaction with the care given

Tick the appropriate response.

701	Are you satisfied with the overall care you have received?	1. Yes ☐ 2. No ☐
702	If not satisfied, to No. 701, please give reasons for your response. é ..	

703	Would you recommend others to seek care from KNH?	1. Yes ☐ 2. No ☐
704	Please give your suggestion as to what you would wish to be improved in your care? é . é . é . é .	

The end.

Thank you for sparing time to participate in this study

KIAMBATISHO IV: DODOSI YA MZAZI

Maswali kwa ajili ya utafiti juu ya vigezo vya mtazamo wa wazazi wa ubora wa huduma ya kansa kwa watoto waliougua saratani katika hospitali ya taifa ya Kenyatta.

Maelezo

1) Dodosi ina nia ya kupata habari kwa madhumuni ya utafiti tu. Habari itasaidia katika kuboresha huduma ya watoto wagonjwa waliougua saratani.
2) Dodosi ina sehemu saba (7). Tafadhali kamilisha sehemu zote kwa kujibu maswali yote kwa kufuata maelekezo.
3) Usiandike jina lako au aina nyingine yoyote ya utambulisho katika dodosi.
4) Tafadhali rudisha dodosi baada ya kujazwa katika bahasha zinazotolewa na mtafiti au msaidizi wa utafiti.

Wodi.....Kificho cha mshiriki.....Jina la mtafiti/msaidizi wa utafitié é é é é .

Sehemu ya Kwanza: Habari binafsi ya mzazi/mtoto. Weka alama (✓) kwa taarifa sahihi.

Nambari	Maswali na vichujio	Makundi
101	Jinsia ya mzazi.	1. Kiume ☐ 2. Kike ☐
102	Uko na miaka mingapi?	Miaka ☐
103	Umewahi hudhuria shule?	1. Ndio ☐ 2. La ☐
104	Kama ndio, ulifika kiwango gani cha elimu?	1. Msingi ☐ 2. Upili ☐ 3. Chuo/ Chuo Kikuu ☐
105	Hali ya ndoa yako?	1. Kamwe sijaolewa ☐ 2. Nimeolewa ☐ 3. Nimetalakiwa ☐ 4. Mjane ☐
106	Je, dini yako ni?	1. Kiprotestanti ☐ 2. Katoliki ☐ 3. Muislamu ☐ 4. Za Jadi ☐ 5. Sina dini ☐ 6. Nyinginezo. Taja é é é é é é ..

107	Je, kazi yako ni?	1. Mtaalamu ☐ 2. Mfanyabiashara ☐ 3. Mkulima ☐ 4. Mfanyakazi wa vibarua ☐ 5. Nyinginezo Tajaé é é é é ..
108	Je, mapato yako ya kila mwezi ni nini?	Shillingi ☐
109	Je, unaishi wapi?	1. Mjini ☐ 2. Mji mdogo ☐ 3. Kijijini ☐
110	Je, mtoto ana miaka mingapi?	Miaka ☐
111	Je, mtoto ana ndugu wangapi?	☐
112	Mtoto wa kwanza yu na miaka mingapi?	☐
113	Mtoto amekuwa hospitalini kwa muda gani?	1. Wiki 1-2 ☐ 2. Wiki 3-4 ☐ 3. Wiki 5-6 ☐ 4. Wiki 7-8 ☐ 5. Zaidi ya wiki 8 ☐
114	Mtoto amewahi lazwa hospitalini zamani?	1. Ndio ☐ 2. La ☐

Sehemu ya Pili: Miundombinu- Mazingira Weka alama (✓) kwa taarifa sahihi.

201	Umeridhika na nafasi katika wodi?	1. Ndio ☐ 2. La ☐
202	Kama la kwa nambari 201, tafadhali eleza kwa nini?..... é	
203	Umeridhika na usafi wa wodi?	1. Ndio ☐ 2. La ☐
204	Kama la kwa nambari 203, tafadhali eleza kwa nini?..... é .	
205	Umeridhika na ukubwa wa kitanda cha mtoto wako?	1. Yes ☐ 2. No ☐

206	Kama la kwa nambari 205, tafadhali eleza kwa nini?..... é .	
207	Umeridhika na uingizaji wa hewa katika wodi?	1. Ndio ☐ 2. La ☐
208	Kama la kwa nambari 207, tafadhali eleza kwa nini? é . é ...	
209	Umeridhika na vifaa vya choo na kuoga kwa mtoto wako	1. Ndio ☐ 2. La ☐
210	Kama la kwa nambari ya 209, tafadhali eleza kwa nini? ..... é	
211	Je, vifaa vya kuchezea vya watoto vipo?	1. Ndio ☐ 2. La ☐

Sehemu ya Tatu: Upatikanaji wa rasilimali

Weka alama (✓) kwa taarifa sahihi

301	Je, umeridhika na vyakula vya hospitali?	1. Ndio ☐ 2. La ☐
302	Kama la kwa nambari 301, tafadhali eleza kwa nini? é .	
303	Je, unaridhika na upatikanaji wa nguo?	1. Ndio ☐ 2. La ☐
304	Kama la kwa nambari 303, tafadhali eleza kwa nini?..... é	
305	Je, mtoto amewahi kupokea tiba ya dawa ya saratani zamani?	1. Ndio ☐ 2. La ☐
306	Kama ndio kwa nambari 305, dawa za tiba ya saratani zilikuwepo?	1. Ndio ☐ 2. La ☐
307	Je, mtoto amewahi kupokea tiba ya mionzi?	1. Ndio ☐ 2. La ☐
308	Kama ndio kwa nambari 307, uliridhika na matibabu hayo?	1. Ndio ☐ 2. La ☐
309	Kama la kwa nambari 308, tafadhali eleza kwa nini?..... é ..	
310	Je, mtoto amepitia maumivu yanayohusiana na ugonjwa wakati wowote katika wodi?	1. Ndio ☐ 2. La ☐

311	Kama ndio kwa nambari 310, dawa za kupunguza maumivu zilipatikana?	1. Ndio ☐ 2. La ☐
312	Kama ndio kwa nambari 311, uliridhika na maumivu ya mtoto kupunguka?	1. Ndio ☐ 2. La ☐
313	Je, mtoto amewahi kupokea damu/bidhaa za damu?	1. Ndio ☐ 2. La ☐
314	Kama ndio kwa nambari 313, je damu/bidhaa za damu zilipatikana kwa wakati unaofaa?	1. Ndio ☐ 2. La ☐
315	Je, uchunguzi unaohitajika kwa mtoto ulifanyika kwa wakati baada ya kuuliziwa?	1. Ndio ☐ 2. La ☐
316	Je, matokeo ya uchunguzi yalitolewa kwa wakati?	1. Ndio ☐ 2. La ☐
317	Je, madaktari wanapatikana wakati wanahitajika? Toa sababu kwa majibu zako? é é é é é é é é é é é é é é é é é .é é é é é é é é é é é é é é é é é ..	1. Ndio ☐ 2. La ☐
318	Je, wauguzi wanapatikana wakati wanahitajika? Toa sababu kwa majibu yako? é é é é é é é é é é é . é	1. Ndio ☐ 2. La ☐

Sehemu ya Nne: Michakato ya utoaji huduma

Onyesha kiwango cha kuridhika kwa kuweka alama (✓) kwa taarifa sahihi.

401	Je, umeelezewa habari kuhusu ugonjwa na matibabu ya mtoto wako?	1.Ndio ☐ 2.La ☐
402	Je, umeridhika na taarifa ulizoambiwa kuhusu ugonjwa na matibabu ya mtoto?	1. Ndio ☐ 2. La ☐
403	Kama la kwa nambari 402 tafadhali eleza kwa nini?..... é . é .	
404	Je, umeridhika na upatikanaji wa madaktari kujibu maswali yako na wasiswasi?	1. Ndio ☐ 2. La ☐
405	Kama la kwa nambari 404 tafadhali eleza kwa nini?..... é .	
406	Je, umeridhika na upatikanaji wa wauguzi kujibu maswali yako na wasiswasi?	1. Ndio ☐ 2. La ☐
407	Kama la kwa nambari 406 tafadhali eleza kwa nini?..... é . é .	

408	Je, unashiriki katika kufanya maamuzi na kufanya huduma ya mtoto?	1. Ndio ☐ 2. La ☐
409	Kama ndio, je, umeridhika na ushiriki katika kufanya maamuzi na kufanya huduma ya mtoto?	1. Ndio ☐ 2. La ☐
410	Kama la kwa namari 409, tafadhali eleza kwa nini?..... é . é .	
411	Je, umeridhika na maelezo kutoka kwa wauguzi na madaktari kuhusu utaratibu wowote, matibabu na vipimo vinavyofanyika kwa mtoto?	1. Ndio ☐ 2. La ☐
412	Kama la kwa nabari 411, tafadhali eleza kwa nini?..... é	
413	Je, umeridhika na mawasiliano kati ya daktari na mzazi/ mgonjwa?	1. Ndio ☐ 2. La ☐
414	Kama la kwa nambari 413, tafadhali eleza kwa nini?..... é . é .	
415	Je, umeridhika na mawisiliano kati ya muuguzi na mzazi/mgonjwa?	1. Ndio ☐ 2. La ☐
416	Kama la kwa nambari 415, tafadhali eleza kwa nini?..... é	

Sehemu ya tano: Kuridhika na watoa huduma

(a) Madaktari

Weka alama (✓) kwa taarifa sahihi.

501	Je, umeridhika na tabia ya kujali ya madaktari? Toa sababu kwa jibu lako..... é .	1. Ndio ☐ 2. La ☐
502	Je, umeridhika na urafiki wa madaktari? Toa sababu kwa jibu lako..... é .	1. Ndio ☐ 2. La ☐
503	Je, umeridhika na upole wa madaktari? Toa sababu kwa jibu lakoé .	1. Ndio ☐ 2. La ☐

504	Je, umeridhika na uaminifu wa madaktari? Toa sababu kwa jibu lako..... é ..	1. Ndio ☐ 2. La ☐
505	Je, umeridhika na kuheshimiwa kwa maadili na imani yako na madaktari? Toa sababu kwa jibu lakoé é é é é é é é é é é é .. é .. é ..	1. Ndio ☐ 2. La ☐

(b) Wauguzi

Weka alama (✓) kwa taarifa sahihi.

506	Je, umeridhika na tabia ya kujali ya wauguzi? Toa sababu kwa jibu lako..... é .	1. Ndio ☐ 2. La ☐
507	Je, umeridhika na urafiki wa wauguzi? Toa sababu kwa jibu lako..... é .	1. Ndio ☐ 2. La ☐
508	Je, umeridhika na upole wa wauguzi? Toa sababu kwa jibu lakoé .	1. Ndio ☐ 2. La ☐
509	Je, umeridhika na uaminifu wa wauguzi? Toa sababu kwa jibu lako..... é ..	1. Ndio ☐ 2. La ☐
510	Je, umeridhika na kuheshimiwa kwa maadili na imani yako na wauguzi? Toa sababu kwa jibu lakoé é é é é é é é é é é é .. é .. é ..	1. Ndio ☐ 2. La ☐

Sehemu ya sita: Uwezeshaji wa mtoaji huduma (mzazi)

Weka alama (✓) kwa taarifa sahihi.

601	Je, unafahamu madhara yanayohusiana na matibabu ya mtoto wako?	1. Ndio ☐ 2. La ☐
602	Je, umeelezwa aina ya vyakula mtoto anafaa kula?	1. Ndio ☐ 2. La ☐

603	Je, kuna taarifa ungependa kujua kuhusu ugonjwa wa mtoto wako na huduma? é é é é é é é é é é é é é é é é . é	1. Ndio ☐ 2. La ☐
604	Je, wewe/mtoto mnapata huduma ya ushauri kuhusiana na ugonjwa na matibabu?	1. Ndio ☐ 2. La ☐
605	Je, unafahamu kikundi chochote cha msaada kinachohusiana na ugonjwa wa mtoto?	1. Ndio ☐ 2. La ☐
606	Kama la kwa nambari 605, je unafikiria kikundi cha msaada kitakusadia?	1. Ndio ☐ 2. La ☐
607	Kama ndio kwa nambari 606, tafadhali eleza kwa nini? é .	

Sehemu ya Saba: Kuridhika na huduma ya matibabu uliyopewa

Weka alama (✓) kwa taarifa sahihi.

701	Je, umeridhika na huduma za jumla umepokea?	1. Ndio ☐ 2. La ☐
702	Kama hujaridhika kwa nambari 701, tafadhali eleza kwa nini? é . é	
703	Je, ungependekeza wengine kutafuta huduma kutoka hospitali ya taifa ya Kenyatta?	1. Ndio ☐ 2. La ☐
704	Tafadhali toa maoni yako kwa yale ungependa yaboreshwe kwenye huduma yako. é ëé ..	

Mwisho.

Asante kwa kutafuta muda wa kushiriki katika utafiti.

APPENDIX V: CONSENT FORM FOR FOCUSED GROUP DISCUSSION

My name is Eunice Keiza. I am a student at the University of Nairobi, school of Nursing Sciences, undertaking a masterôs degree course in paediatric nursing. I am conducting a research study on determinants of parentsô perception of quality of paediatric oncology care at Kenyatta National Hospital. This study is for the award of the degree of Master of Nursing Sciences (Paediatric). I encourage you to participate freely and contribute your views and ideas as much as possible. The information gathered will be treated as a group contribution and will be strictly confidential. The information will be highly valuable to the research and will help in improving the quality of paediatric cancer care. The will to participate is absolutely voluntary without any compulsion or inducement. All rights will be guaranteed. In case you would like to know the results of this study or you have any complaints, please do not hesitate to contact the following:

1. Eunice Keiza on cell phone number 0716325737.
2. Chairman KNH/UON-ERC, Box 20723 Kenyatta N. Hospital. Tel 2726300-9, Ext 44102.

We do hereby provide informed consent to take part in this study. We have been explained the nature of the study and its purpose.

Participantsô signature,

1 é é é é é é é é .. 6 é é é é é é é é é é .

2 é é é é é é é é é ..

3 é é é é é é é é é ..

4 é é é é é é é é é ..

5 é é é é é é é é é ..

Principle investigator/Research assistantôs name é é é é é é é é Signature é é é é ..

KIAMBATISHO V: FOMU YA IDHINI KWA AJILI YA MAJADILIANO YA VIKUNDI

Jina langu ni Eunice Keiza. Mimi ni mwanafunzi katika chuo kikuu cha Nairobi, shule ya uuguzi. Nasomea shahada ya uzamili katika uuguzi wa watoto. Nafanya utafiti juu ya vigezo vya mtazamo wa wazazi wa ubora wa huduma ya kansa kwa watoto katika hospitali ya taifa ya Kenyatta. Utafiti huu ni kwa ajili ya tuzo ya shahada ya uzamili katika uuguzi wa watoto. Nakuomba ushiriki kwa uhuru na uchangie maoni na mawazo yako iwezekanavyo. Habari itakuwa yenye thamani kwa utafiti na itasaidia katika kuboresha ubora wa huduma ya kansa kwa watoto. Mapenzi ya kushiriki ni kwa hiari yako bila kulazimishwa au kushawishiwa. Haki zako zitahakikishwa. Kama ungependa kujua matokeo ya utafiti ama una malalamiko yoyote , tafadhali usisite kuwasiliana na wafuatao:

1. Eunice Keiza, nambari ya simu 0716325737
2. Mwenyekiti KNH/UON-ERC, SLP 20723 Hospitali ya taifa ya Kenyatta. Nambari ya simu 2726300-9 Ugani 44102

Tunatoa ridhaa ya kushiriki katika utafiti huu. Tumeelezewa asili ya utafiti na madhumuni yake.

Sahihi ya washiriki

1.é é é é é é é é é é é é 6 é é é é é é é é é é é .

2.é é é é é é é é é é é

3. é é é é é é é é é é é

4.é é é é é é é é é é é

5. é é é é é é é é é é é

Mtafiti mkuu/msaidizi wa utafiti

Jinaé é é é é é é é é

Sahihié é é é é é é ....

APPENDIX VI: PARENTS' FOCUSED GROUP DISCUSSION GUIDE

Introduction

In this session, we will discuss about determinants of parentsô perception of quality of paediatric oncology care at Kenyatta National Hospital. This discussion is intended to obtain information for study purposes only. The information will help in improving quality of care of paediatric oncology patients. Information from this discussion will be held with confidentiality and at no time will this information be used against you.

Feel free to share your opinions on this topic. You are free to stop participation in this discussion at any time. During the discussion, notes will be taken for the purpose of transcribing the information. Feel free to ask questions at any stage during the session.

1. What are your views on the structures and care delivery processes at Kenyatta National Hospital in regard to the quality of care of children with cancer?
2. What are your views towards the health care providers in regard to the quality of childhood cancer care provided at Kenyatta National Hospital?
3. What is your satisfaction level with the childhood cancer care services at Kenyatta National Hospital?

The end.

Thank you for sparing time to participate in this study

KIAMBATISHO VI: MAJADILIANO MAKINI YA KIKUNDI CHA WAZAZI

Utangulizi

Katika kikao hiki, tutajadili uamuzi wa wazazi kuhusu vigezo vya mitazamo yao ya ubora wa huduma ya kansa kwa watoto katika hospitali ya taifa ya Kenyatta. Mjadala huu una nia ya kupata habari kwa madhumuni ya utafiti tu. Habari hii itasaidia katika kuboresha huduma ya watoto wanaogua ugonjwa wa saratani. Habari kutoka mjadala huu itakuwa ya siri na hakuna wakati wowote habari hii itatumika dhidi yako.Jisikie huru kuchangia maoni yako katika mjadala huu.Unaweza kuacha kushiriki katika mjadala huu wakati wowote. Katika mjadala huu, maandiko yatachukuliwa kwa lengo la kunukuu habari. Una uhuru wa kuuliza maswali yoyote katika kikao hiki.

1. Je maoni yako ni yapi kuambatana na miundombinu na michakato ya huduma katika hospitali ya taifa ya Kenyatta kwa watoto wanaougua saratani?
2. Je maoni yako ni yapi kuambatana na watoa huduma wa watoto wanaougua saratani katika hospitali ya taifa ya Kenyatta?
3. Je, umeridhika kiwango gani na huduma ya kansa kwa watoto katika hospitali ya taifa ya Kenyatta?

Mwisho.

Asante kwa kuchukua wakati wako kushiriki katika utafiti huu.

APPENDIX VII: DATA ANALYSIS DUMMY TABLES

Examples of dummy tables for analysis of descriptive data

Table 1: Parentsô perception of quality of care delivery processes

Characteristics	Frequency (n)	Percentage (%)
Satisfaction with information provided about the childôs illness and treatment		
Satisfaction with availability of doctor/nurse to answer questions and concerns		
Satisfaction with involvement in decision making and childôs care		
Satisfaction with explanations from nurses/doctors about treatment, procedures and tests done to the child		
Satisfaction with doctor-parent/child communication		
Satisfaction with nurse-parent/child communication		

Table 2: Parentsô views regarding the health service providers

Characteristics	Frequency (n)	Percentage (%)
Satisfaction with the caring attitude of the nurses/doctors		
Satisfaction with the friendliness of the nurses/doctors		
Satisfaction with the politeness of the nurses/doctors		
Satisfaction with honesty of the nurses/doctors		
Satisfaction with respect for values and beliefs by the doctors/nurses		

Table 3: Parentsô overall satisfaction with the care given

Characteristics	Frequency (n)	Percentage (%)
Satisfaction with overall care received		

Example of dummy tables for analysis of inferential data

Table 4: Parentsô perception of care delivery processes

Variable	Parentsô perception High, n (%)	Parentsô perception Low, n (%)	χ^2 value	P. value
Information provided about childôs illness and treatment				
Parentôs involvement in decision making and care of the child				
Doctor-parent communication				

APPENDIX VIII: LETTER TO KENYATTA NATIONAL HOSPITAL RESEARCH AND ETHICS COMMITTEE

Eunice Mmbone Keiza,

School of Nursing Sciences,

University of Nairobi.

P.O. Box 19676,

Nairobi.

The Chairperson,

KNH/UON Research and Ethics Committee,

P. O. Box 20723 - 00202
Nairobi.

Dear Sir/Madam,

RE: REQUEST FOR AUTHORIZATION TO CONDUCT A RESEARCH

I am a second year post graduate student at the University of Nairobi, School of Nursing Sciences pursuing Master of Nursing Sciences (Paediatric) degree. I hereby request for your approval to conduct a study on determinants of parentsô perception of quality of paediatric oncology care at Kenyatta National Hospital. The study will be carried out in the paediatric wards. The study is in partial fulfillment of the requirements for the award of Master of Nursing Sciences (Paediatric) degree. Your consideration will be highly appreciated. The research findings will be utilized in provision of quality care to childhood cancer patients. Thank you.

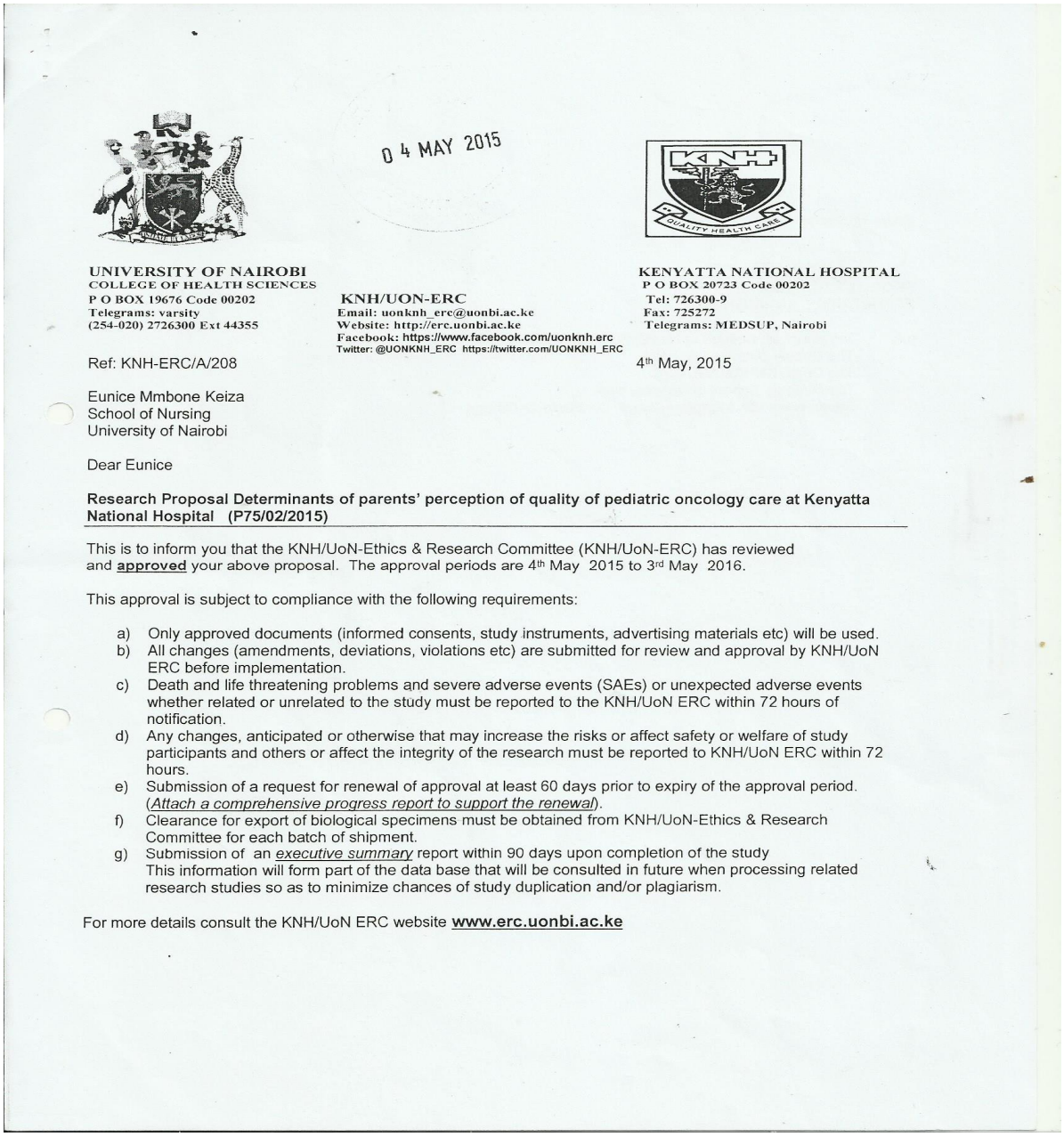
Yours Faithfully

Eunice M. Keiza

APPENDIX IX: OVERVIEW OF KENYATTA NATIONAL HOSPITAL

Kenyatta National Hospital is in Nairobi County and is located off Ngong Road along Hospital Road. It covers an area of 45.7 hectares and within its complex is the college of Health Sciences of the University of Nairobi (UON), the Kenya Medical Training College (KMTC), Kenya Medical Research Institute (KEMRI) and the National Laboratory Service (Ministry of Health). Kenyatta National Hospital is the largest National referral, teaching and research hospital in Kenya with a bed capacity of about 1800. Out of the total bed capacity, 209 beds cater for prime care centre (private wing) which is located on the ninth and tenth floors as well as first floor (ward 1C). Founded in 1901, Kenyatta National Hospital is the largest in Eastern and Southern Sahara. The hospitalôs mandate is to provide specialized quality health care, facilitate medical training and research and participate in National health policy. It is the primary teaching hospital of the University of Nairobi and Kenya Medical Training College - Nairobi. It receives patients from various parts of the country as well as from East and Central Africa. It has 50 wards, 22 outpatient clinics, 24 theatres (16 specialized) and an Accident and Emergency department. Administratively, the hospital is divided into various departments according to the different specialities. Paediatric oncology care is one of the specialized health care provided by Kenyatta National Hospital. The hospitalôs tower block has ten floors with four wards on each floor namely A, B, C, and D. Paediatric oncology is under the department of paediatrics. Oncology ward 1E is located on the first floor of the old hospital building while wards 3A, 3B, 3C and 3D are located on the third floor of the hospitalôs tower block. The paediatric oncology wards admit patients aged 0 - 12 years. The patients are admitted through the paediatric outpatient clinic (POPC) and the pediatric emergency unit (PEU).

APPENDIX X: KNH/UON-ERC PROPOSAL APPROVAL LETTER



0 4 MAY 2015

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

KNH/UON-ERC
Email: uonknh_erc@uonbi.ac.ke
Website: http://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/208

4th May, 2015

Eunice Mmbone Keiza
School of Nursing
University of Nairobi

Dear Eunice

Research Proposal Determinants of parents' perception of quality of pediatric oncology care at Kenyatta National Hospital (P75/02/2015)

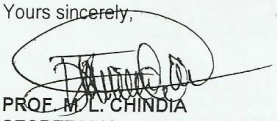
This is to inform you that the KNH/UoN-Ethics & Research Committee (KNH/UoN-ERC) has reviewed and **approved** your above proposal. The approval periods are 4th May 2015 to 3rd May 2016.

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 severe 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) 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*).
f) Clearance for export of biological specimens must be obtained from KNH/UoN-Ethics & Research Committee for each batch of shipment.
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.

For more details consult the KNH/UoN ERC website **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 Deputy Director CS, KNH
The Chair, KNH/UoN-ERC
The Director, School of Nursing, UoN
Supervisors: Dr. Margaret Chege, Dr. Blasio O. Omuga

APPENDIX XI: MAP OF NAIROBI COUNTY

APPENDIX XII: MAP OF KENYATTA NATIONAL HOSPITAL