

KENYATTA UNIVERSITY

SCHOOL OF HUMANITIES AND SOCIAL SCIENCES

DEPARTMENT OF PSYCHOLOGY

**FAMILY CAREGIVERS' PERCEPTIONS OF COMPASSION AMONG PEDIATRIC
HEALTH CARE PROVIDERS IN KENYATTA NATIONAL HOSPITAL, KENYA:
IMPLICATIONS FOR TREATMENT COMPLIANCE**

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**A RESEARCH PROJECT SUBMITTED TO THE SCHOOL OF HUMANITIES AND
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DECLARATION

This project is my original work and has not been presented for a degree in any other university or for any other award.

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This project has been submitted for review with my approval as a university supervisor

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DEDICATION

I dedicate this work to my late parents Mr. and Mrs. Jenesio Wanjohi who never had a chance to see me become the person I am today despite their investment in my life. May they continue resting in peace.

ACKNOWLEDGEMENT

I acknowledge the efforts of my supervisor Dr Lydia Maingi for her unending support towards the completion of this work. I am very grateful for your patience and encouragement and may God bless you. I thank the management of Kenyatta National Hospital for allowing me to carry out my study there. Finally, I thank all the caregivers who participated in this study.

ABSTRACT

Compassion is viewed as a hallmark of quality of care by patients, health workers, health care administrators and policy makers. Despite this, there is a lack of understanding of what patients and their care givers perceive as compassion of health care workers. The purpose of this study was to establish family caregivers' perceptions of compassion among paediatric health care providers (PHCPs) in Kenyatta National Hospital (KNH) and the implications of the perceptions on compliance with treatment. The study was based on Phenomenology theory by Edmund Husserl. Phenomenology captures views of people who have lived through an experience using rich descriptions with the aim of understanding what the experience means to them. Ethical approval was sought from Kenyatta University Ethics Review Committee (KUERC) and Kenyatta National Hospital- University of Nairobi Ethics Review Committee (KNH-UoN-ERC. Authority to conduct the research was sought from the National Council for Science, Technology and Innovation (NACOSTI) and KNH. Ethical standards were observed through voluntary participation and anonymity. Participants were selected through multi-stage sampling. This included purposive sampling for KNH, simple random sampling for the paediatric units and individual interviewees. Participants for focus group discussions (FGDs) and one narrative per FGD were purposively selected. A demographic questionnaire was filled by the interviewees. A pilot study was done prior to the actual study to test the study instruments and no major challenges were identified. Similar questions were used in different instruments to ensure reliability. Structural and content validity were ensured by including questions that addressed each of the objectives for the study. The demographic characteristics were summarized descriptively through frequencies and percentages while the qualitative data was summarized and analysed thematically using predetermined themes. A total of 45 caregivers took part in the study. The findings revealed that caregivers interpret PHCP compassion as love and friendliness, timeliness in treatment, adequate consultation time and receiving adequate information concerning their children. Compassion varied among different PHCPs depending on possession of these qualities. Majority of the caregivers preferred the PHCPs who had these qualities. While compassion was relevant for compliance with treatment, other factors such as motivation to see the children get better and finances influenced the caregivers' compliance. The study recommended formulation of policies that promote education on compassion among PHCPs especially through in-service capacity building in health institutions.

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ABBREVIATIONS

BO:	Burn out
CF:	Compassion Fatigue
FGD:	Focus Group Discussion
IV:	Intravenous
KNH:	Kenyatta National Hospital
KUERC:	Kenyatta University Ethics Review Committee
NHIF:	National Hospital Insurance Fund
NICU:	New born Intensive Care Unit
PHCP:	Paediatric Health Care Provider
PICU:	Paediatric Intensive Care Unit

DEFINITION OF TERMS

Below is a definition of major terms used in the study

Burn out: Physical and mental tiredness resulting from a health care provider's ability to cope with a stressful work environment.

Family Caregiver: An adult family member accompanying a child during the period of hospitalization or spending more time with the admitted child. In this study the terms family caregiver and paediatric caregiver are used interchangeably

Compassion Fatigue: Marked negative physical, social, emotional, spiritual and intellectual changes in health care providers due to prolonged contact with traumatized patients.

Compassion Satisfaction: The pleasure and motivation a health care provider feels when they are able to use their skills to help a patient.

Compassion: Ability of a health care provider to show concern to a sick child and their caregiver, show respect and acceptance of the child and caregiver and being able to listen to the caregiver's concerns.

Paediatric Health Care Provider (PHCP): Different categories of health care providers attending to children admitted in the ward.

Treatment Compliance: Ability of the caregiver to follow the instructions given by their paediatric health care providers, keep appointments and give medicines prescribed

CHAPTER ONE

INTRODUCTION

1.1 Background to the Study

Compassion is an empathic feeling by an individual for the distress being experienced by another person. It compels the individual to try to alleviate the other person's distress and it's considered the basis of health care professions (Meadors&Lamson, 2008). In clinical settings, compassion demonstrates healthcare providers' ability to provide care that focuses on a patient's humanity and uniqueness (Sinclair, S., Russell, L.B., Hack, T.F. *et al.*, 2017). It has been identified by patients, their family members, health care providers and health care organizations as an endorsement of quality care. Compassion of health care providers has been deemed to be beneficial to both patients and health care workers. To patients, it increases trust in the patient– physician relationship, improves patient satisfaction, symptoms and quality of life, and enhances recovery. To the health workers, compassion affects clinician outcomes positively through increased job satisfaction and reduced turnovers (Sinclair, S., Russell, L.B., Hack, T.F. *et al.*, 2017; Sinclair S, Hack TF, Raffin-Bouchal S, *et al.*, 2018)

Compassion and the ability to show compassion by health workers have been identified as a necessity in several studies. A systematic review by Sinclair S, Norris JM, McConnell SJ, *et al.*, (2016) identified compassion as a patients' right and as such it is key to the health care professionals' codes of ethics. Frampton 2013 identified compassion as the foundation of patient centered care while the Canadian researchers Heyland, Dodek, &Rocker (2006) noted that to patients, it was what mattered most in end of life care. Despite being very essential element of

health care, there is evidence that lack of compassion is a contributing factor to health care system failures (Willis,2015, Maclean, 2014,) and an observed unmet need of many patients (Heyland, Dodek, &Rocker, 2006, Crowther , Wilson , Horton & Lloyd-Wiliams 2013). Despite compassion being referenced as a hallmark of quality of care by patients, health workers, health care administrators and policy makers, there is a lack of understanding of what patients and their care givers perceive as compassion among health care workers (Sinclair S, McClement S, Raffin Bouchal S, et al 2016, Sinclair S, Norris JM, McConnell SJ, et al, 2016)

Various themes and perceptions of compassion and compassion ability have been cited in studies. These include; i) Acknowledgement of the patient, where the health care provider is expected to call the patient by name, make eye contact and ask what they can do for the patient. ii) Self-introduction by the health care provider by skill and experience. iii) An estimate of the duration that the medical procedure being undertaken may take such as a medical, test or treatment. iv) An explanation of what is to happen, step by step and being available to answer questions including leaving a contact where the professional may be reached and v) Thanking the patient and the caregiver for choosing the hospital, cooperation and especially the family for supporting the patient (Lerwick, 2016, Sinclair S, Hack TF, Raffin-Bouchal S, *et al.*, 2018)

Other studies reveal that effective communication is a health care provider's primary tool for showing respect, empathy and compassion to patients and their families. Research further reveals that skilful communication expressed through use of appropriate language and nonverbal signals results in patient satisfaction and leads to improvement in patient adherence to medical procedures which translates to greater clinical outcomes and fewer malpractice claims (Palazzi, Lorin, Turner,

Ward & Cabrera, 2015). Skills such listening, confronting, involvement, helping, presence and understanding; virtues including relational space, virtuous response, seeking to understand, relational communication and attending to patients needs to relieve suffering have also been cited as key dimensions of compassion . Paediatric caregivers view health care providers as competent when they show them respect, genuineness, approachability, ability to connect, ability to listen, are timely and informative (Davies, Baird & Gudmundsdottir, 2013; Sinclair S, Hack TF, Raffin-Bouchal S, *et al.*, 2018)

Effective communication between a health care provider and a child or their caregiver is essential in the management of the child. It forms the cornerstone of care as it is centred on the patient and family, responding to their needs. It helps in decision making between the doctor-patient-caregiver in that they become partners in making relevant medical decisions leading to a great clinical outcome. When there is proper communication, the caregivers are more likely to comply with treatment schedules (Marginean, Melit, Chinsesan.....&Azamfirei, 2017). Caregivers also perceive health care providers as competent and caring when they show compassion on the sick child and are responsive to their feelings. Using a language that the caregivers understand and continued contact are perceived as signs of caring (Brooten, Youngblut, Seagrave....& Roche, 2013). This is associated with greater caregiver satisfaction and adherence to medical advice.

Parents also value health care providers who value their opinion regarding the child's illness and respond to the child's feelings and concerns. Parental satisfaction is positively related to further active communication and their perception to health care providers' interpersonal sensitivity leads to partnership building with good clinical outcomes (Rider, Volkan&Hafler, 2008). In paediatric health care settings, markers of quality care range from clinical outcomes, caregiver satisfaction,

caregiver adherence to the doctor's instructions and caregiver perception of quality communication. Caregivers who associated a positive emotion to a clinical visit experience had better recall for instruction given by the doctor (Lee, Cui, Rosario...& Lin, 2020).

A study carried out in Ghana defines Family Centred Care (FCC) as a concept in pediatric health care that embraces family members of a sick child as care recipients. This concept recognizes that care needs to be planned around the whole family and not just the sick child. The study was conducted in two different government hospitals in Ghana that admit children involved in road traffic accidents. 19 participants were involved in face to face in-depth interviews using semi-structured guides. The study sought to understand FCC in a sub Saharan African context. The study findings revealed that parents play a critical role of helping children cope in stressful clinical environments. Due to this they sometimes experience high stress levels due to unfulfilled information needs from their children's health care providers. Parents expect respect and dignity from the health care providers, involvement and information sharing between them and the health care providers. Other needs identified by parents include negotiation for quality care and effective communication from the health care providers. The study found that health care institutions lack policies on parental participation and involvement in care recommending further research and policies that consider family as integral in pediatric health care (Ohene, Power & Raghu, 2019). Lack of parental involvement may lead to discrepancies in the treatment of a child occasioned by misunderstanding between the caregivers and the PHCPs.

Lack of parental involvement was also identified by Keiza, Chege and Omuga (2017) who did a study in the oncology department of Kenyatta National Hospital among 107 caregivers to evaluate their perception to care of children being treated for cancer. The study found that 54.2 % of the

caregivers were dissatisfied with information provided concerning the child's illness, the manner the doctors and nurses handled their questions and issues about involvement in decision making. This study recommended further research to evaluate enhancement of care among children. These studies reveal that paediatric health care is yet to recognize the important role played by paediatric caregivers. This results in a disconnect in parental acknowledgement and involvement in care by health care providers. To the caregivers this is interpreted as lack of compassion. This can lead to failure to carry out proper instructions either due to lack of information or failure to understand the importance of some of the instructions given.

Although working in the medical field can be rewarding and personally fulfilling, it can also be demanding and stressful for primary health care providers. This can lead to burn out which affects one's professionalism through emotional exhaustion, cynicism and depersonalization. This has the potential to lead to lowered quality of care to patients, higher chances of making medical errors and eventual premature retirement from the profession (Shanafelt, Boone, Tan ...&Oreskovich, 2012). The burn out unique to health care professions is described as compassion fatigue and interferes with a health care provider's ability to form a therapeutic relationship with their clients. A therapeutic relationship is a pre-requisite to provision of quality care (van Mol, Kompanje, Benoit, Bakker & Nijkamp, 2015). The ability of a health care provider to form a therapeutic relationship with a patient or caregiver and being responsive to their concerns is deemed as compassion.

In Kenya, the national hospital insurance fund has continued to offer universal health coverage thereby increasing the number of patients seeking help especially in the public health sector. In Kenya children account for 43% of the total population according to Society for International

Development making them a significant focus in matters of health (Pyone, Smith & van den Broek, 2017). Most of the services in the 0-5 years age-group are free in the public hospitals. Despite the increase in numbers of patients, the number of paediatric health care providers has not increased at the same rate. This means the paediatric health care providers handle huge workloads with potential risk for compassion fatigue and this may affect the quality of care that they give to their patient. Lack of compassion among PHCPs may interfere with mutual trust with caregivers leading to suspicion of medical procedures hence poor compliance with instructions given to paediatric caregivers. Compassion in view of increasing number of paediatric patients has not been studied locally. This study sought to establish the caregivers' perceptions of compassion among the paediatric health care providers at Kenyatta National hospital and whether these views had any implications on compliance with treatment.

1.2 Statement of the Problem

Compassion is an essential component of quality health care and is not only rarely studied but is also lacking in many healthcare institutions. Compassionate care is dependent on the ability of a health care provider to form a therapeutic relationship with his/her patients which ultimately affects patients and their caregivers' compliance with the treatment. Failure to comply with treatment regimens can lead to poor health outcomes. It is not clear however how patients perceive or interpret their HCPs' compassion. Although a few studies have investigated the health care providers' perceptions of compassion, it is essential to establish if their perceptions are consistent with those of their patients and their family caregivers.

Recently in Kenya there has been an increase in paediatric patients accessing health care through universal health coverage. There has also been a lot of focus on children under five years of age

especially with the presidential big four agenda. However, the impact of rising numbers of patients on paediatric health care provider's ability to offer compassionate care has not been well established. Studies on the area such as (Sinclair, Norris, Mc Connell *et al.*, 2016; Sinclair, Russell, Hack *et al.*, 2017) have focused on the self -reports of the health care professionals and have been conducted mainly in the developed countries with little focus on sub Saharan Africa. In Kenya a studies conducted on compassion fatigue among paediatric caregivers in KNH recommended further research in the area (Kokonya, Mburu & Kathuku...et al 2005; Maingi, Mathai, Warutere & Farquhar 2020). Studies that have been conducted on perceptions among the patients or their caregivers (Heyland, Dodek, Rucker *et al* 2006; Parikh& Odejide, 2018) have not established the implications of those perceptions on treatment compliance.

The current study sought to address this gap by establishing the perceptions family caregivers have concerning PHCPs' compassion and if these perceptions had any implications on their compliance with treatment.

1.3 Purpose of the Study

The purpose of this study was to establish family caregivers' perceptions on the compassion of paediatric health care providers in Kenyatta National Hospital, Nairobi. and the implications of those perceptions on treatment compliance.

1.4 Objectives of the Study

Broad Objective-To establish family caregivers' perceptions of compassion among paediatric health care providers and the implications the perceptions had on compliance with the treatment given to their children in Kenyatta National Hospital, Nairobi. Kenya.

Specific Objectives

- I. To explore family caregivers' perceptions of compassion among paediatric health care providers in Kenyatta National Hospital.
- II. To assess the family caregivers' compliance to treatment in Kenyatta National Hospital
- III. To find out the implications of the family caregivers' perceptions of compassion among PCHPs on compliance to treatment.

1.5 Research Questions

- i. What are the family caregivers' perceptions of compassion among paediatric health care providers in KNH?
- ii. What is the state of treatment compliance among family caregivers in KNH?
- iii. What are the implications of the family caregivers' perceptions of compassion among PCHPs on their compliance with treatment?

1.6 Justification and Significance

The recent focus on universal health coverage, free medical health for children under five years and the current presidential big four agenda in Kenya have led to increased numbers of paediatric patients. There is need for evidence based findings on the effect of this increase on paediatric health care providers in order to initiate interventions or programs that can foster quality of health care services. Limited studies have focused on health care providers' compassion locally and few have sought this information from the recipient of health care services. The current study focused on a rarely studied group, the caregivers of paediatric patients. Given that compassion has been identified as key component of quality care, understanding how it is manifested is essential. This may guide future training programs as well as interventions addressing the same.

KNH being the largest referral hospital in the region has the largest paediatric capacity including four medical paediatric wards, oncology ward, PICU, the new born unit amongst other paediatric services. The hospital receives many referral cases of chronic illnesses among children posing a high potential for compassion fatigue and hence justifying its selection for the study. Findings from the study may be used to develop programs that improve paediatric health care by informing PHCPs, hospital administrators and policy makers in the health care system.

1.7 Scope and Limitations

The study focused on perceptions of the caregivers of the pediatric patients and not on the health care providers' views. Since the study sought subjective experiences, it wasn't possible to discount or verify the participants' views because they were borne out of experience and the interpretation of whatever occurred was very subjective. The study was limited only to perceived lack of compassion and not any other factors that may hinder compliance with treatment. A study on other factors affecting treatment compliance may be carried out. Qualitative research is time consuming at data collection and data analysis. A quantitative research may be carried out to assess perceptions of compassion among paediatric caregivers. The study was carried out at Kenyatta National Hospital, Nairobi, Kenya which is a large teaching and referral hospital and hence may limit generalization of findings to similar hospitals. Other studies focusing on PHCPs may need to be carried out to get their perceptions on services provided.

1.8 Assumptions of the Study

The study made the following assumptions:

1. Family caregivers of pediatric patients perceive compassion of the HCP differently.
2. Perceptions held about PHCPs' compassion have implications on treatment compliance

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This study focused on compassion among pediatric health care providers as perceived by caregivers of children to whom they offer their services. It also sought to find out if these perceptions influenced treatment compliance. This chapter includes the theoretical framework of the study, review of related literature and finally the conceptual framework

2.2 Theoretical Framework

This study was anchored on phenomenology theory. This theory was advanced by Edmund Husserl (1859-1938). Other proponents of the theory include Martin Heidegger, Maurice Merleau-Ponty Jean-Paul *et al.* It is the study of phenomena, the appearance of things or the meanings attached to experience. According to this theory, meaning is made through examining views of people who have been through an experience. It involves describing a lived experience with the aim of exploring meaning and trying to make sense of it. This is done through rich descriptions or narratives that bring out the lived experience. Phenomenology studies the structure of various types of experiences ranging from perceptions, thought, memory and imagination (Klettlinger, Wirfel, & Bielak, 2015); (Davidsen, 2013). According to Welman and Kruger (1999, p. 189) “phenomenologists are concerned with understanding social and psychological phenomena from the perspectives of people involved” (Groenewald, 2004). The aim of using phenomenological qualitative research is to capture as closely as possible how people experience phenomena and the context in which they experience it. In this study, caregivers explained in their own words, their experience of compassion by the health care providers attending to their children. To an observer, the interpretation may be different but for the caregivers it was a very subjective experience.

2.3 Review of Related Literature

This section includes a review of related studies as guided by the objectives of the study and a conceptual framework showing interrelationship of the study variables.

2.3.1 Perceptions of Compassion

Compassion is an empathic feeling by an individual for the distress being experienced by another person. It compels the individual to try to alleviate the other person's distress and it's considered the basis of health care professions (Meadors&Lamson, 2008). It is characterized by empathy, respect, genuineness, effective communication and being readily available for consultation. Empathy can be described as having both an affective and a cognitive component. The affective component is concerned with sharing of emotions with another person, emotional contagion, which is an automatic response and essential for empathic encounters. Sharing of emotions for the one offering empathy can either lead to empathic concern or personal distress when the emotions are over aroused. Both empathic concern and personal distress lead to empathic action. If the empathizer experiences personal distress, the goal of their empathic action will be to relieve their own distress and not the distress of the other person. Since for health care providers compassion is concerned with relieving a patient's distress, failure to take action may indicate inability to provide compassionate care.

The cognitive component of empathy is the ability to understand another person's internal state. This requires a voluntary process to take place such as self-regulation and cognitive flexibility. This allows the empathizer to manage and regulate their own emotions in relation to the other person's distress. This means that empathy can only occur when a person has the ability to regulate

their own emotions and can differentiate whose emotions belong to whom in empathic encounters (Hunt, Denieffe, & Gooney, 2017). This means that the health care provider needs to identify their own emotions and deal with them so as to be in a position to deal with emotions emanating from caregiving roles. Unless this happens, offering compassionate care will not be possible.

Themes illustrating compassion among paediatric health care providers' have been classified into three categories in this review. These include observable behavior, time taken for consultation with the patients and adequacy of information relayed to the caregivers about the patients' condition and treatment.

Observable PHCPs behaviour that displays compassion include active listening, attentiveness, confronting, involvement, helping, presence and understanding. This is according to Sinclair, Norris and McConnell *et al.*, (2016) who did a study among a patient cohort where patients were asked to describe the associations and situations that came to mind when compassion was mentioned. The findings also revealed that that compassion is an outcome of a process of intuition and communication grounded on a response to suffering. It is also evident that most people tend to gauge their health care standards based on non-technical aspects such as a healthcare provider's ability to communicate and possess soft skills (Bari, Khan, Jabeen&Rathore, 2017). According to Salmani, Hasanvand, Bagheri and Mandegari (2017) caregivers expect health care providers especially nurses to have age appropriate baby talk which would help children to cheer up reducing emotional stress and promoting relaxation. Several studies have reported that the most important predictive factors for effective communication between a paediatrician and a child/caregiver are showing interest, caring, warmth and responsiveness. (Marginean *et al.*, 2017). Humanized care during hospitalization is evidenced by holistic and equality in provision of services while non-

humanized care is displayed by attitudes valuing hospital rules, inattention and lack of compassion by healthcare professionals according to Salmani *et al.*, (2017).

A study done to evaluate how caregivers perceive nursing behaviors elicited varied reports. The study was done among 18 caregivers in both private and government hospitals in Iran. The outstanding theme was fluctuation in care. A caregiver reported how some nurses made several attempts to insert an intravenous line (IV) and kept missing it causing pain to her child. The caregiver was relieved when a particular nurse came and fixed it in one attempt. Observed behaviour such as undertaking medical procedures like gaining IV access without talking to the child or caregiver was interpreted as disrespectful. Some caregivers would have liked to be with their children during such procedures but the child was taken away to a different room without explanations and they found this as rude and uncaring. One caregiver reported that she kept on calling the nurse to check on her child with a fever but she kept delaying and only came to check the patient after one hour. This distressed the caregiver and was interpreted as lack of compassion. However, some of the caregivers expressed satisfaction with nursing behaviors which they said were respectful to their children. They felt valued when a nurse explained what they wanted to do with their child such as inserting an Intravenous (IV) line or administering medicine (Salmani, *et al.*, 2017). This study sought to find out if caregivers face similar challenges from health care providers in Kenya.

This shows that caregivers may interpret inflicting pain on a child as lack of compassion and avoiding causing pain as being compassionate to the child. It also reveals that parents want to be involved in the management of their sick children through explanation of medical procedures.

When they are involved they feel respected and accepted and when the health care provider assumes their presence, they feel rejected. Caregivers are not just interested in the treatment of their children but also in how the treatment is administered.

In North Carolina, a study was performed to assess caregiver ratings of participatory decision making styles and child and caregiver satisfaction among children with asthma. 327 children as well as their caregivers were interviewed. The study found that when children and caregivers were involved in decision making during hospital visits for asthma treatment, there was more satisfaction with the treatment. The health care providers were perceived positively when they listened carefully, interacted actively and inquired about how the client was being managed at home. Children reported being more satisfied when the health care providers knew them better as a person, by name rather than as a patient. On the other hand, the caregivers were more satisfied when they were involved in the decision making of their children's asthma treatment (Sleath, Ayala, Washington.....& Gillette, 2011). According to Salmani *et al.*, (2017) behaviors such as politeness in asking questions and greeting caregivers was perceived as respectful. This shows that being humane and treating caregivers respectfully are perceived by caregivers as a sign of respect and acceptance. The study also found that health care providers need to be more sensitive when talking about a sick child in front of relatives. Lack of sensitivity to the caregiver and the family can mean lack of compassion which is a sign of poor health care.

Similar findings were identified by a study conducted among 63 caregivers in four hospitals in Florida, USA. The study sought to assess the perceptions of caregivers towards the health care providers of children in the ICU around the time of death. The study found that caregivers

perceived health care providers who called them to be with their child near the time of death as compassionate and caring. They also found the staff to be understanding when they were patient with the caregiver's questions, explaining the child's illness at their level of understanding and were willing to repeat over and over until the caregiver understood. The study also found health care providers as insensitive and non-supportive when they were abrupt, unfriendly and they laughed and joked outside the room of the dying child (Brooten *et al.*, 2013). This study informs on what caregivers of children at the end of life expect from their health care providers. Health care providers may become insensitive to patients and their caregivers due to emotional detachment occasioned by compassion fatigue. When they have not dealt with their emotional distress, health care providers will not be capable of showing compassion through empathizing with their patients.

Chinawa, Obu, Manyike, Obi and Chinawa (2016) conducted a study among 227 caregivers of children admitted in three major teaching and referral hospitals in Nigeria to assess their perceptions of the attitude and skills of paediatricians. Over half of the respondents felt that paediatricians were competent because they treated the children in a caring humane way, not technically. 34.4 % of the respondents were not aware of the cadre of doctors treating their children because they did not introduce themselves during the ward rounds. The study also found that interaction between a patient and the doctor is affected by length of contact and the workload of the doctor. Caregivers were more comfortable with paediatricians who approached their children with gentleness. They also regarded good communication to be when the paediatricians were unhurried despite their busy schedules. Good communication also meant taking time to create rapport with caregivers, listening to them and explaining medical conditions in lay man terms.

These studies show that caregivers observe PHCPs looking for cues of compassion such as gentleness, respect as shown by self-introduction, ability to listen and sensitivity such as calling them to be with children at the verge of death. Good communication and appearing unhurried are also regarded as compassionate care. Explanation of medical procedures and timeliness in checking on a child were rated as compassionate behaviours among nurses. On the other hand joking and laughing outside the room of a dying child, delays in responding to caregiver needs and hurried consultations revealed lack of compassion to the patients and caregivers. The current study sought to find out whether similar expectations exist among pediatric caregivers in KNH.

Time spent by HCPS on a patient is another major theme used to interpret the level of compassion. Research reveals that caregivers of sick children would like to spend adequate time with their health care providers so as to gather as much information as possible concerning their children's illness. However most of the health care providers appear hurried and this deters the caregivers in expressing their concerns (Chinawa, Obu, Manyike, Obi & Chinawa, 2016).

In a study carried out in the USA among 6 caregivers to assess the perceptions of caregivers of children with Autism Spectrum Disorder (ASD) to health care providers, one participant reported that she did not mind the doctor taking a lot of time with her child because it meant he was spending quality time with her (Klettlinger, Wirfel, & Bielak, 2015). This reveals that adequate time with a patient translates to quality care to a caregiver. Marginean *et al.*, (2017) carried out a study in Romania among 100 participants who were divided into 25 paediatricians, 25 caregivers, 25 children and 25 other health care staff. The study sought to assess communication skills between

paediatricians and children. It was identified that paediatricians tend to ask close ended questions during consultation to avoid lengthy consultations. This tends to hinder the patients/caregivers chance to express their concerns, sometimes not even explaining the actual reason for consultation. Both the children and paediatricians pointed out that time spent in consultation actually needs to improve. The study recommended that trainee undergraduates need to be taught about the importance of communication between themselves, children and their caregivers right from the time they are in school.

Similar findings were reported in a study done in Iran among caregivers in both private and government hospitals. Caregivers reported that when they asked questions, the nurses were brief in response and they seemed too busy to address their concerns. This deterred the caregivers from asking questions when they realized their questions were unwelcome. This was interpreted as lack of compassion among the nurses (Salmani *et al.*, 2017). These studies reveal that adequate time between a patient or a caregiver and a health care provider is essential as it allows the caregiver to express all their concerns. Adequate time and communication also allows the patient or a caregiver to ask questions and clarify information from the health care provider. In this way there is mutual understanding of the illness, treatment procedures and likely outcomes of treatment. When a health care provider looks too busy to address the patient or caregiver's concerns, this can create anxiety and dissatisfaction with the whole clinical experience. This may affect how well a caregiver follows through with the instructions given concerning treatment.

Adequacy of information concerning the patient was deemed as a key indicator of compassion.

When proper information about a child's illness is explained in a language that the caregiver can understand, the stress and anxiety of the illness is greatly reduced in a caregiver. When caregivers are allowed to participate in their child's care through communication, they face less anxiety, become more autonomous, adhere to treatment schedules and cope better with the stress of a sick child. Caregivers value and desire to have all the relevant information concerning their child and future implications of the disease. When paediatric health care providers do not respond to these needs, they predispose the caregivers to distress and insecurity about the treatment which can lead to non-compliance (Melo, Ferreira, Lima & Mello, 2014). This reveals the importance of collaborative approach to treatment between the health care providers and caregivers of sick children. Some of the factors which could cause health care providers to treat their patients as well as caregivers with indifference could be detachment from their jobs, unexpressed emotions, and cumulative insensitivity to patient stories occasioned by compassion fatigue.

According to Marginean *et al.*, (2017) it's important for a health care provider to provide information to caregivers concerning the diagnosis, treatment and complications which can occur when treatment given to their children is not adhered to. This was identified in a study among 100 participants comprising children, their care givers, health care providers and other hospital staff to evaluate perceptions of caregivers to services offered. The study reported that where the patient or their caregiver does not speak the language of the health care provider, the latter needs to devise ways of communicating this information in the best way possible essentially 'talking the patient's language'.

The study also identified that health care providers struggle to communicate news of a severe condition with a poor prognosis concerning a child to a caregiver. This is despite the need to ensure that the caregivers fully understand the implications of such a diagnosis. The health care provider needs to have nonverbal skills because at such a time the caregiver may seem like they do not understand due to the pain of the diagnosis. They need to empathize without giving false hopes and without crushing the child or the caregiver. The child should not be ignored despite the young age but the paediatrician can explain some details taking into account the age of the child (Marginean *et al.*, 2017). The study also identified that between 35% and 70% of medicolegal issues arise out of failure of paediatric health care providers to understand the conceptions and opinions of the child's family, poor delivery of information and failure to include the patient's values in the medical strategies.

Hendricks-Ferguson, Sawin, Montgomery.....&Haase (2015) conducted a study in three major paediatric hospitals in Midwest USA on 14 nurses with less than 1 year experience in paediatric oncology. The study sought to explore the ability to engage the family on discussion of children undergoing palliative and end of life care. The study found that nurses struggle to communicate news of death and sometimes do not know what to tell the parents or where to start after a child's death. Some of the participants recommended that a skilled model for communication be put in place to make communication easy for the health care providers. This brings out a gap in the training of health care providers. What is perceived as refusal to give information may actually be a struggle for the health care provider that can be addressed in basic training.

Similar findings were found in the Kenyatta National hospital among 107 caregivers of children in the paediatric oncology unit. More than half of the parents reported that they had inadequate information about their children's illness and treatment and desired to know more. Half of the parents said that they were counseled in relation to their children's illness and treatment. Some respondents from the Focused Group Discussions indicated that they had inadequate information about their children's illness and treatment and would want to know more about their children's illness, type of treatment, and side effects (Keiza, Chege & Omuga, 2017). This reveals how important it is for the health care provider to give adequate information to the caregiver. It reduces anxiety and improves adherence to treatment schedules, factors which are likely to improve the overall outcome of treatment. Though the health care provider may have all the information, he/she may lack the skills to communicate this information to the caregiver or may have unresolved emotions related to other patients they have dealt with in the past. They may be afraid to tell the caregiver the actual diagnosis and implications of the disease. They may be afraid of giving false hopes especially in terminal illness. This calls for communication skills training in delivering difficult news to caregivers as the caregivers need this information no matter how difficult it is. Regular psychological debriefing to help health care providers deal with cumulative stress arising from caregiving may also improve communication of difficult news.

2.3.2 Family Caregivers' Compliance with Treatment

Treatment compliance is the extent to which the patient's behaviour mirrors agreed recommendations from the prescriber. Non-compliance on the other hand occurs when for many varied reasons the prescriber instructions are not adhered to. In children with chronic illnesses, non-compliance is estimated to be between 30-50%. The rates of non-compliance when compared to adults with chronic illnesses were higher among children and adolescents. In a paediatric setting

compliance is much more complex compared to the adult population as it heavily relies on the caregiver. The therapeutic relationship involves a triad, the professional, the parent and the child. Health professionals are viewed as a source of advice on treatment regimens and help in communicating with the child on importance of being compliant on medication (Santer, Ring, Yardley, Geraghty & Wyke, 2014).

In a study done in Australia among 26 general practitioners and registered nurses dealing with parents who decline vaccinating their children, it emerged that health care workers experience an internal conflict and belief that they are health advocates whose professional roles and moral authority is meant to protect the child. This often posed a communication breakdown between them and parents. Many participants reported experiencing frustration as well as anger during such encounters with parents. To them the parent was questioning their credibility as health care advocates and existing medical establishments (Berry, Henry, Danchi & Leask, 2017). The feeling of challenged authority and mistrust could possibly contribute to the health care providers' decline in engaging caregivers of children. This could originate from the health care providers lack of effective communication skills which would consider the parents point of view probably leading to a fruitful dialogue that convinces the parent to accept a certain medical procedure or form of treatment. These studies reveal that communication skills need to be enhanced among health care providers. They need to be receptive to the paediatric caregivers' concerns and avoid feeling like they are losing their positions of authority when approached for discussion of their patients. Locally no studies have focused on treatment compliance and possible contributing factors hence the need for the current study.

2.3.3 Compassion and Treatment Compliance

Studies on paediatric patients and their parents reveal that treatment related discomfort is more than just discomfort from the disease itself. Difficult medical procedures may interfere with children's adherence to other aspects of their treatment leading to a psychological distress to them and their caregivers. The ability to manage pain and distress associated with medical treatment therefore becomes essential for paediatric health care professionals. The distress a child manifests is related to how a parent behaves before and during the medical procedure. If the parent is anxious, the child is also likely to become anxious (Penner, Cline.....&Ruckdeschel, 2008). This reveals that engaging and involving the parent of a sick child during treatment is likely to have positive outcomes for both the child and the parent leading to better compliance and greater clinical outcomes.

Family centred care is a concept that can be used to improve compliance with treatment. It recognises participation of the family especially parents as vital in the treatment of their children. Parents are recognized as natural caregivers and also decision makers in the lives of their children. It beliefs in supporting the family as well as the child through the journey of hospitalization in a professional way. This involvement results to good clinical outcomes. However, it has some challenges where the professionals feel like their identity is threatened and may not encourage full participation of the parents as they feel intimidated and like they are losing control (Crawford, 2014).

In a literature review of 648 articles related to compassion in clinical settings, patients reported that compassionate care from clinicians improved recovery including a sense of responsibility and

control over their health. In such cases the patient felt heard and understood. This deepened a patient's sense of their illness experience leading to an improvement in their symptoms. Compassionate care was also found to enhance a patient's trust towards their clinicians as well offer hope to the patient. On the other hand compassion was related to positive clinician outcome such as job satisfaction and retainment. The study reported that compassion among clinicians was an effective medium to elicit patient information through patient compliance and disclosure. In contrast a hostile attitude limited accuracy in diagnosis and led to poor medical decision making (Sinclair, Norris, McConnell.....& Bouchal, 2016). In paediatric health care settings, markers of quality care range from clinical outcomes, caregiver satisfaction, caregiver adherence to the doctor's instructions and caregiver perception of quality communication. Caregivers who associated a positive emotion to a clinical visit experience had better recall for instruction given by the doctor (Lee, Cui, Rosario....& Lin, 2020). PHCPs need to understand the importance of effective communication as an important aspect of caregiver satisfaction ultimately leading to adherence to their instructions. The current study sought to find out if caregivers' perception among PHCP compassion had influence on treatment compliance in KNH.

2.3.4 Summary of Literature Review

The reviewed literature concerning caregivers' perceptions of compassion reveals that some non-verbal and observable behaviors among PHCPs can display compassion. This includes smiling, showing warmth and responsiveness. Explaining medical procedures in lay man terms , requesting to take away a child for a procedure and calming down a child are all interpreted as ability to show compassion (Salmani *et al.*, 2017). However the study did not show the influence of these perceptions on treatment compliance. This study was conducted among nurses in Iran while the current study seeks to find out if similar expectations exist in KNH among all cadres of PHCPs.

Participatory decision making that involves parents, politeness in asking questions and self-introduction were important aspects of compassion according to Chinawa *et al.*, (2016). Inadequate time and scanty information given to caregivers during interaction with PHCPs caused distress to caregivers and suspicions about treatment. Keiza, Chege and Omuga (2017) found that over half of the respondents in the study were dissatisfied by the amount of information they had concerning their children's treatment. The current study sought to find out if paediatric caregivers had similar perception and whether they influenced compliance with treatment.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Introduction

This chapter details the methodological steps that were undertaken to describe paediatric caregivers' perceptions of compassion among paediatric health care providers and their implications for treatment compliance. It describes the research design, study variables, site of the study, target population, sampling techniques and sample size, research instruments, validity and reliability, pilot study, data collection procedures, data analysis and presentation and data management and ethical considerations.

3.2 Research Design

The study was qualitative in nature and was conducted according to phenomenological research design. Phenomenological design aims at capturing subjective experiences of respondents. The study captured the perceptions of caregivers on compassion among paediatric health care providers.

3.3 Study Variables

Family caregivers' perceptions of compassion among paediatric health care providers was the independent variable while compliance to treatment was the dependent variable. The variables were derived from the title of the study. Compassion was measured using caregiver observations, caregiver perception of adequacy of time spent and information received from their paediatric health care providers. Treatment compliance was measured using ability of the caregivers to follow instructions/advice of their PHCP, attending scheduled appointments and ability to administer prescribed medications.

3.4 Site of the Study

The study area was Kenyatta National Hospital Nairobi. The hospital is located in the upper hill region of the Nairobi City, 3.5km west of the central business district. It sits on 45.7 acres of land. This is the largest public tertiary referral and teaching hospital in Kenya with a total bed capacity of 1800. The hospital was selected purposively because of its high paediatric capacity. The study focused on all the paediatric units-medical, surgical, renal, PICU, NICU, oncology, burns unit. Perceptions of caregivers of patients hospitalized within the sampled paediatric units were assessed.

3.5 Target Population

All caregivers with children admitted in Kenyatta National Hospital paediatric wards during the period of study formed the target population for this study (330). 45 participants were sampled from the all paediatric units through multistage sampling. The paediatric units included four medical wards, a surgical ward, orthopaedic ward, renal unit, private ward, ophthalmology ward, New Born Unit, NICU, PICU, oncology and burns unit.

3.6 Sampling Techniques and Sample Size

First, all the paediatric units were sampled according to type of patients that is, medical, surgical, orthopaedic, renal, ophthalmology and private wing. Out of these, three units were selected through simple random sampling for individual interviews. Participants for focused group discussions were selected purposively from caregivers of children with similar illnesses that is oncology, PICU and NBU. Out of each focused group, one narrative was purposively selected. At least 10 participants were randomly selected from each sampled paediatric unit for individual interviews and 15 participants for focused group discussions and narratives.

Table 1: Participant Sampling Frame

Paediatric Unit	Number of Patients per unit	Sampled Participants
Orthopaedic	50	10
Surgical Ward	50	10
Medical	50	10
Oncology for FGD	50	4
PICU/NICU for FGD	10	3
NBU for FGD	120	5
Narratives	12 (FGD participants)	3
Total	330	45

3.7 Research Instruments

A triangulation of data collection methods was employed to minimize bias from participants' self-reports of their perceptions of the PHCPs compassion. This also helped to validate the data collection instruments. The instruments include; demographic questionnaires, interview and FGD schedule and use of narratives. Each of them has been explained below;

3.7.1 Demographic Questionnaires

These were used to collect quantitative data from the individual interview participants and of their admitted children. These included age, sex, and period of hospitalization among others. It was self-constructed by the researcher.

3.7.2 Interview Guide

This is a tool that the researcher /research assistants used to guide the individual interviews to capture the study objectives. It consisted of unstructured questions so that it could assist the researcher collect subjective experiences of the participants. One interview lasted 45-60 minutes.

3.7.3 Focused Group Discussion Schedule

These are questions that the researcher used to guide focused group discussions. The FGDs were meant to generate a discussion concerning the study objectives. Three focused groups were formed. The oncology group had four participants, the NBU had 5 participants while the PICU had 3 participants. These are the ones who gave consent to participate in the study. The FGDs were conducted by the researcher assisted by one research assistant. Out of each focused group one participant was purposively selected for a narrative which lasted 45 minutes-1hour. The sequence of interviews was individual, focused groups and narratives. All interviews were preceded by a written informed consent.

3.7.4 Narratives

These were narrations involving a single participant from each of the discussion groups. The participant was identified through their desire to want to share more but hesitating due to lack of a conducive sharing atmosphere or one who seemed very emotional for further sharing in a private setting. The researcher used their counselling skills to pick out the participant. Some interviews were audio recorded with informed written consent from participants and later transcribed. The identifiable details of the participants were not recorded for anonymity purposes.

3.8 Validity and Reliability

Validity is the ability of an instrument to measure what it is intended to measure while reliability is the ability of an instrument to yield similar results in a repeat study. The researcher ensured that questions used in the unstructured interviews and focused group discussions were easy to understand and that they captured the study objectives so as to gather adequate and relevant information. The researcher by using triangulation in data collection was able to validate information obtained from participants using different instruments. The researcher with the help of two trained research assistants conducted all the interviews and the FGDs to ensure the questions were asked in the same way to enhance reliability.

3.9 Pilot Study

The researcher carried out a pilot study one month prior to the actual study in Thika level 5 hospital. Sample size was 10 participants. The purpose of the pilot study was to test the study instruments and address any emerging gaps on the instruments. The different interview schedules had similar questions which were varied to ensure they addressed the same situations. No major challenges emerged.

3.10 Data Collection Procedures

After relevant authority to collect data was granted, written consent was obtained from the participants, the sociodemographic questionnaire was administered to sampled participants scheduled for individual interviews. Thereafter individual interviews followed in a private setting within the hospital. Interviews were audio-recorded for those who gave consent. Each individual interview was coded anonymously e.g. Participant 001 June 2019 while FGD and narratives were coded as FGD 001 and narrative 001 respectively. Focused group discussions were conducted for

participants with similar experiences. Three FGDs were formed one each from PICU, NBU and oncology wards. From each focused group a participant was selected purposively for a narrative. This was to gain more information concerning their experiences in that particular unit and for each of the study objectives. Two research assistants were recruited to assist in data collection. They were trained for two days, a week prior to data collection. They were involved in conducting both the individual interviews and focused group discussions. The latter took place in the presence of the researcher.

3.11 Data Analysis and Data Presentation

The sociodemographic data was analyzed using frequencies and percentages and presented in tables. Information from individual interviews, FGDs and narratives was first put in tables, sub themes picked and the main themes later picked. These were presented in line with qualitative studies quoting verbatim some of the responses of the respondents. Themes such as listening, communication and love and friendliness were identified.

3.12 Data Management

All information was kept secure in lockable cabinets and saved under codes. The questionnaires and audio records were kept in a safe place and will be destroyed after five years.

3.13 Ethical Considerations

The researcher sought approval from Kenyatta University Ethics Review Committee and KNH-UoN Ethics Review Committees. Authority to conduct the research was sought from National Council for Science, Technology and Innovation (NACOSTI) and KNH. The researcher obtained written consent from the participants in the study and maintained confidentiality and anonymity

by using codes for the participants rather than names. Participants were informed that participation was voluntary and one was free to exit at any point. Risks were minimal as the study sought the participants' opinions on the quality of care accorded to their children.

CHAPTER FOUR

DATA ANALYSIS, PRESENTATION AND DISCUSSION OF FINDINGS

4.1 Introduction

This chapter presents the study findings and discussion on caregivers' perceptions of compassion among paediatric health care providers in Kenyatta National Hospital and their implications for treatment compliance. The presentation of the research findings was based on the demographic characteristics and objectives of the study. The research objectives were as follows:

- i. To explore caregivers' perceptions of the compassion among paediatric health care providers in Kenyatta National Hospital.
- ii. To assess paediatric caregivers' treatment compliance in Kenyatta National Hospital.
- iii. To find out the implications of caregivers' perceptions of PCHP compassion on treatment compliance in Kenyatta National Hospital.

4.2 Response Rate

Data for this study was collected through demographic questionnaires, unstructured interviews and focused group discussions. The target population was 330 participants. Out of the 51 participants sampled, 6 participants opted out of the focused group discussions leaving 45 participants. Out of these 45, 30 respondents participated in the individual interviews while 15 respondents participated in focused group discussions and narratives representing a response rate of 88%.

4.3 Demographic Characteristics of Respondents

The demographic characteristics of the caregivers in individual interviews together with those of the patients were collected. These included age, gender, marital status, residence, relationship to the child and period of caregiving for caregivers. On the other hand, the demographic characteristics of the children included the period of hospitalization, ward, and their diagnosis. Table 2 and 3 shows the demographic characteristics of the caregivers and the children respectively.

Table 2. Demographic Characteristics of Caregivers

Age	Frequency	Percentage
21-30	20	66.70%
31-40	7	23.30%
41-50	2	6.70%
51+	1	3.30%
Total	30	100%
<hr/>		
Gender		
Female	30	100%
Total	30	100%
<hr/>		
Marital Status		
Married	25	83%
Separated	2	6.7%
Single	3	10%
Total	30	100%
<hr/>		
Residence		
Urban	14	46.7%
Semi urban	5	16.7%
Rural	11	36.7%
Total	30	100%
<hr/>		
Relationship to the Child		
Mother	29	96.7%
Others (Grandmother)	1	3.3%
Total	30	100%
<hr/>		
Period of Caregiving		
0-6 weeks	22	73.3%
>6-12 weeks	4	13.3%
12 weeks and above	4	13.3%
Total	30	100%

Table 2. Above shows that two thirds of the respondents were aged between 21-30 years while those aged 51 and above formed only 3.3%. All the caregivers were females. More than three quarters (83%) were married and 6.7% separated. Nearly half (46.7%) lived in urban centres while 16.7% lived in semi-urban settings. Almost all the caregivers (96.7%) were mothers to the children while the rest (3.3%) were grandmothers. Nearly three quarters (73.3%) had been caregiving for a

period of 0-6 weeks and 13.3% for more than 12 weeks. This shows that the participants in the study had spent some significant time in the ward and were able to give the required information sought by the study.

Table 3. Demographic Characteristics of Children

Age	Frequency	Percentage
< 0- 6 months	14	46.7%
>6 month -1 year	1	3.3%
>1 - 5 years	7	23.3%
>5- 10 years	6	20%
>10-15 years	2	6.7%
Total	30	100%

Period of Hospitalization	Frequency	Percentage
0-4 weeks	19	63.4%
>4 – 8 weeks	4	13.3 %
>8 -12 weeks	3	10%
>12 weeks -1 year	3	10%
>1year	1	3.3%
Total	30	100%

Ward	Frequency	Percentage
NBU	8	26.7%
Paed medical	22	73.3%
Total	30	100%

Diagnosis	Frequency	Percentage
Preterm	5	16.7%
Respiratory	5	16.7%
Liver	2	6.7%
Renal	2	6.7%
Congenital illnesses	4	13.3%
Tropical	1	3.3%
Cancer	3	10%
Total	30	100%

Table 3 shows that about half of the children (46.7%) were aged between 0 – 6 weeks of age while those aged 6 months to 1 year were the least at 3.3%. Those aged between 1-5 years were 23%. This indicates that most of the paediatric patients were 5 years and below. Those above 5 years were 26.7% with the highest age being 15. This is likely to be because of free health services for children 5 years and below. Out of these, the majority (63.4%) had been hospitalized for 0-4 weeks. Almost three quarters of children (73.3%) were in the paediatric medical wards and over a quarter

(26.7%) from the New Born Unit. Less than a quarter (16.7%) were born preterm and a similar number had respiratory conditions while 3.3% had tropical diseases. Over half of the patients were in 0-5 years age bracket and are likely to have been beneficiaries of the NHIF universal coverage which offers selective free services for this age group.

4.4 Presentation of Research Findings According to Study Objectives

4.4.1 Caregivers' Perceptions of Compassion among Paediatric Health Care Providers in KNH

Study Objective I: To explore caregivers' perceptions of compassion among PHCPs in KNH.

The first objective sought to explore how caregivers perceived compassion of paediatric health care providers. The objective was measured in terms of caregiver observations, time taken during consultation with PHCP and amount of information given by the PHCP. Their observations were conceptualized in different themes which included the following, love and friendliness, communication, timeliness and listening.

Participants perceived love and friendliness as an important aspect of compassion. Some perceived love and friendliness in terms of warm reception, polite communication and timely treatment while others saw it as the way in which PHCPs cared or assisted the children, and how they related with children and assisted with meals. Some excerpts on love and friendliness are listed below.

Participant LF 1: "For me compassion means love, warm reception, polite communication and timely treatment."

Participant LF 2: "Compassionate care means how one cares for the child, plays with the child and assists with meals.

Participant LF 3: "Compassionate care means showing love".

Participant LF 4: "Compassionate care is when a PHCP talks politely to you and teaches you how to take care of the baby (NBU caregiver).

Participant LF 5: "Compassionate care is based on how a PHCP treats a caregiver and her child. So far compassionate care here is low."

These views demonstrate that apart from medical treatment, caregivers are looking for health care providers who possess soft skills such as the ability to show warmth, approachability and generally humane behaviour towards them and their children.

This is consistent with findings by Salmani, Hasanvand, Bagheri and Mandegari (2017) that caregivers expect PHCPs especially nurses to have age appropriate baby talk which would help reduce emotional distress and promote relaxation in children. Similar views were elicited by a study conducted among nurses who deal with children in needle related medical procedures. It found that parents were an extension of the children and were required to help a child relax during a medical procedure. Nurses also needed to know how to interact with children at different age groups. Some conversation was necessary before a needle procedure and it depended on how anxious the child was, whether the child had been exposed to needles before and age of the child. If a child was anxious minimal information was given concerning injections while more was offered to a curious child (Karlsson, Rydstrom, Enskar&Englund, 2014). When the children are relaxed, their parents are more likely to relax and follow through with the treatment procedures. The findings also agree with a study by Palazziet *al.*, (2015) who found that communication that is patient-centred portrays empathy and uses language and non-verbal signals effectively leading to patient satisfaction. This reveals that caregivers are looking for signs that their PHCPs care even as they entrust their childrens' care to them. PHCPs should be aware that caregivers are reading their non-verbal behavior as they attend to their children and interpreting it as either compassionate or uncompassionate. This observation affects how their services are rated and accepted.

Communication as an observed behavior

The theme of communication featured prominently in the responses of the participants. Good response from nurses and doctors, politeness in communication, service without delay and service with kindness were presented as the indicators of good communication which according to them manifested compassion. On the other hand, lack of compassion was indicated by use of harsh language when communicating to caregivers and the patients. Below are some of the responses given by the participants.

Participant C1: “Compassionate care means a good response from the nurses and doctors”

Participant C2: “Compassionate care means service with kindness and mercy. Uncompassionate care is when the PHCP is harsh, uses harsh language, or is not humble.”

Participant C3: “Compassionate care is politeness in answering questions.”

The study findings on communication are in tandem with the study by Salmani *et al.*, (2017) which found fluctuation of care in Iranian hospitals where nurses would fail in communicating with patients and caregivers when carrying out basic procedures. PHCPs who involved the caregivers in the treatment procedures through communication were found to be compassionate while those who did not, only distressed them. Involving caregivers in their children’s treatment communicates respect as well as empathy. PHCPs who understand this will know that they are not dealing with a child alone but an entire family hence will take time to explain what needs to be done to a child to a caregiver first with the intention and willingness to hear their concerns and address them. Similar findings were reported by several studies which found that the most important predictive factors for effective communication between a paediatrician and a child/caregiver are showing interest, caring, warmth and responsiveness (Marginean *et al.*, 2017). Showing interest means being ready to hear the viewpoint of the parents and finding out what the treatment being offered means to them. If anything needs to be clarified, this should be done politely keeping in mind that

parents may not fully understand some medical procedures. Only when questions are fully addressed do parents/caregivers feel comfortable with the treatment being offered to their children. When caregivers are relaxed, the children are more likely to be relaxed making the work of the PHCPs easier.

Timeliness

Timeliness was also reported by the participants as an aspect of compassion. Responding on time and noticing changes in symptoms of the patients was considered an indicator of compassion. Giving the right treatment as required was seen as compassion just as receiving help when in need. Quick response and giving the right information were deemed to indicate compassion. Some of the responses are sampled below.

Participant T1: “Compassionate care means responding on time and being able to notice when the baby’s condition changes.”

Participant T2: “Compassionate care means being helped when you ask for help”

Participant T3: “Compassionate care is shown by good communication, quick response giving the right information and remembering various patients’ needs even when they are many.”

Listening

A few respondents considered compassion as being listened to by the doctor. To them listening was a way of communicating empathy which gave a sense of relief and being understood. Some felt that the PHCPs were in a hurry even during the ward rounds and did not have time to listen to their concerns about their children. Listening therefore proves to be a beginning point for effective treatment as indicated by two respondents below.

Participant L1: “Compassionate care means being listened to, attended to on time. It is having someone backing you up.”

Participant L2: “When the doctor listened to me, I felt relieved, and understood. Compassionate care to me is having someone take time to hear you out rather than rushing you in the process of consultation.”

Participant L3: “ I don’t have sufficient information because the doctors are always in a hurry. Again they come in a group because of the trainees so one can’t say everything

about the baby due to embarrassment. It would be good if the doctor came to see the patient alone.”

The findings on listening partly agree with Marginean *et al.*, (2017) who observed that health care providers asked closed ended questions hindering their listening skill. However, the study did not focus directly on listening but the questioning procedure which involved closed ended questioning. Caregivers considered being listened to rather than being asked questions as compassion on the part of the PHCPs. Time is a precious commodity for all PHCPs hence they may be tempted to rush the patient in order to save it. However this results in miscommunication and lack of satisfaction by the patient. According to Palazzi *et al.*, (2015), listening is an art. The PHCP needs to encourage the patient by inviting him/her to talk and showing that they are listening by leaning forward, nodding or by simply saying ‘‘I am listening.’’ The study proposes a model for enhancing the listening skill. It is Stop, Look and Listen. The PHCP needs to stop thinking about anything else and concentrate on the patient. The PHCP also needs to be aware of their own mood. The PHCP also needs to look whether the setting provides privacy and judge the emotional state of the patient. Finally the PHCP needs to listen to the patient and understand by confirming with patient before acting. This came out in the present study where the caregivers complained that the PHCPs were always in a hurry even during the ward rounds and had no time to listen to them. It also brought out the aspect of privacy during doctor-patient interaction. It matters where the conversations are taking place and so PHCP’s ability to listen may be affected by presence of other distractions in the ward.

Consultation Time

Time taken during consultations between patient/caregiver and the PHCPs was one of the major themes used to measure PHCP compassion.

Generally, the respondents indicated that the time taken by the doctor for consultation depended on different factors. Some of the caregivers indicated that consultation time depended on the condition of the child whereby, a very sick child would get more time compared to one who was not. Another factor found to determine the consultation time was the type of ward. The participants noted that consultation time was longer in the private more than the public wards. Similarly, when a concern was raised or a question asked; doctors would spend more time to address that concern. Finally, consultation time was determined by the whether the doctor was accompanied by other hospital staff like nurses and students. The doctor was more hurried when accompanied by other personnel than when he/she was alone.

Majority of the caregivers considered consultation time as an important aspect of compassion. Most of them were of the opinion that consultation time lasted for 5-10 minutes which was okay for some caregivers but was too short for others. Caregivers who received longer time during consultation (over 10 minutes) and their concerns addressed during the consultation expressed satisfaction with consultation time. However, some caregivers were not at ease to consult the doctor when accompanied by other staff members like medical students. Most of those who were discontented with such consultation felt excluded because doctors would discuss among themselves. Most caregivers took that negatively. The following are some of the excerpts on consultation time.

Participant CT1: "Consultation lasts 5-8 minutes and depends on how sick the child is. It is longer when the child is very sick."

Participant CT2: “Consultation time depends on how sick the child is, if very sick, the doctor takes more time and less when not very sick. Most of the time I am satisfied with time spent. However, sometimes the doctor writes more than he listens.”

Participant CT3: “Consultation time depends on the condition of the patient. I took 20 minutes during admission. The doctor took history, blood from the patient and fixed an IV line for fluids.”

Participant CT4: “The longest consultation time lasts 10 minutes”. I am familiar with daily procedures so no need of the doctor to spend a lot of time. If I have a question after the ward round, I can get another doctor to address my questions. Shortest consultation is 5-10 minutes. There is a complaint book and one can request for change of doctors.”

Participant CT5: “Doctors come for a few minutes during the ward rounds, usually in a group. The amount of time the doctor takes depends on the questions I have. I make sure I ask all the questions before the doctor leaves.”

Participant CT5: “In the private wing consultations took half an hour between the doctor, the nurse and me (mother). It was good but here many professionals come during the ward round and talk among themselves rarely involving the caregiver. The child (13 years) even says they don’t talk to her.”

Participant CT6: “Doctors spend about 5 minutes. It’s not adequate for me.”

The findings agree with Chinawa *et al.*, (2016) who found that caregivers preferred PHCPs who spent time with a patient because it provided room for personal expression. In the current study most caregivers felt their concerns were addressed fully if the doctor spent more than 10 minutes. This shows that spending more time with a patient is interpreted as compassion and goes a long way in reducing the distress of a caregiver. The PHCPs need to engage more with the caregivers and especially during the ward rounds rather than discussing among themselves in medical terms that the caregivers don’t understand. Caregivers feel left out in such conversations and may assume the PHCPs have something to hide and that’s why they exclude them in their interactions. This

can create suspicion among the caregivers. Patient centred care in paediatric settings should recognize caregivers as integral in decision making and treatment of paediatric patients hence allow them enough time for self-expression.

Amount of Information Given by PHCP.

Amount of information was one of the measures of PHCP compassion.

The study found that scarcity of information was a recurring theme in most of the paediatric units. Respondents in individual interviews as well as those in FGDs had similar views. Even those caregivers who had some information still had gaps in most of the areas surrounding their children's treatment. For instance some would know the condition their child was being treated for but miss to know the modalities of treatment, duration, possible complications or the outcome. For others they had not been told anything about their child and only overheard it from different PHCPs while handing over to a different shift. For some caregivers blood would be drawn from their children without proper explanation and when the results got misplaced and more blood was needed, they would now be told what it was all about. Sometimes they would not know their children needed to be transfused until it became urgent. This was especially identified in the NBU and oncology wards where caregivers did not stay with their patients and visited only at specific times. Because of the nature of NBU where mothers went to feed the babies every 3 hours, sometimes the doctors would be gone from the unit by the time they visited or they would be too busy to address their needs. At the time of the current study the population of the babies ranged from 120 to 140 making it almost impossible to meet all the caregivers' information needs. In the oncology ward, the caregivers could meet the professor for updates on their children every Thursday. The doctors in the oncology ward were not always easy to access for information. While

the nurses were easily available in the oncology ward and NBU, the information they could give was limited. A study conducted among nurses taking care of children in palliative care found that nurses spent more time with caregivers than doctors and hence were more accessible for information. However they reported feeling like their role was merely supporting decisions made by doctors. The study also found that the nurses were not trained in communicating difficult news to recipients of palliative care. Their communication was informed by their own values, attitudes and past experiences (Hendricks-Ferguson *et al*, 2015). This therefore shows that since the nurses are easily accessible to the caregivers they can be empowered to engage in information sharing where the doctors are found to be too few or too busy to handle caregiver concerns in the course of a child's treatment. This will bridge the gap of inadequate information by having pediatric teams working more cohesively to meet caregiver needs. Some of the excerpts sampled from the participants are sampled below.

Participant AI 1: "I know my child is on chemotherapy but the doctors have not been able to find the site of primary cancer." (FGD Oncology)

Participant AI2: "Occasionally there is a good doctor like the one working this week. He has explained what is to be done to my baby in theatre and I am contented." (FGD, NBU)

Participant AI3: "The doctor told me it is sometimes hard to tell the outcome of the treatment for the condition." (FGD Oncology).

Participant AI5 "I sometimes get information by overhearing nurses handing over to the next shift." (FGD NBU)

Participant AI6: "Sometimes one gets conflicting information from different doctors or the information a doctor gives varies with what the nurse says. It leaves me confused." (FGD NBU)

Participant AI7: "Sometimes blood is taken from my baby without getting any feedback, then when a situation becomes critical, they start rushing to me to get donors to give blood to the baby." (FGD NBU)

The findings by Keiza, Chege and Omuga (2017) where 54.2% of caregivers reported having inadequate information concur with the current study findings where some caregivers indicated that they lacked adequate information on their children's illness, type of treatment and even the side effects. This study had been conducted in the same hospital among caregivers of children in the oncology ward. The findings also agree with a study by (Melo, Ferreira, Lima & Mello, 2014) which showed that when caregivers receive inadequate information concerning their children, they become anxious and distressed about the treatment given. Receiving adequate information about patients therefore communicates compassion and goes a long way in relieving unnecessary suspicion and distress to paediatric caregivers. Some of the possible reasons that impede PHCPs from sharing information could be past failures in treatment, feeling vulnerable or past patient losses which leave the PHCPs guilty of giving hope especially in the NBU and Oncology wards where the mortality rates are high (Granek, Bartels, Barrera&Scheinemann, 2015). Despite this, PHCPs need to understand how to communicate with caregivers taking into account their emotional states. Communicating difficult news can be incorporated into the basic training for PHCPs. This would ease communication between PHCPs and caregivers making the latter more receptive of whatever the information is relayed by PHCPs.

Difference in the Levels of Compassion

Although health care institutions are meant to promote healing and reduce human suffering, the same institutions have failed to create systems for collaborative relationships between patients and health care providers. The pediatric health care providers have not been positioned to show compassion to their patients. The PHCPs are expected to be stoic, follow data and work like machines. They withhold their vulnerability and humanity yet this is what pediatric caregivers

are seeking for; their kindness, empathy and compassion. It's almost as if the PHCPs are ashamed to show their humanness (Micalizzi, Dahlborg & Zhu, 2015).

The study sought to find out if compassion varied among the different PHCPs. The findings were conflicting. While a large number felt that the nurses were more compassionate, others stated that the doctors were compassionate and still others believed that both doctors and nurses were equally compassionate. Those who felt nurses were the most compassionate indicated that they talked to children, were understanding and were available to the caregivers. This indicates that availability was considered an important indicator of compassion. Elderly nurses were also found to be more compassionate. This could be because elderly nurses have greater experience on how to communicate compassion to both caregivers and patients. They were also found to be more polite and responsive.

On the other hand, those who felt that doctors were compassionate stated that they answered questions from patients, took time with caregivers, responded immediately whenever called upon, they were available when needed, had friendly attitude, and communicated well with the caregivers. This supports the earlier findings on responsiveness of health care providers, availability, communication and friendliness as indicators of compassion. Finally, those who felt that both doctors and nurses are compassionate indicated that all of them took time to listen; they consistently attended to patients and administered medication to children at the right time. Some of the responses are provided below.

Participant LC 1: "Compassion levels differ. Doctors are more compassionate because they respond fast"

Participant LC 2: "Compassion levels differ. Professor is more compassionate because he/she takes time during the ward round to attend to the child."

Participant LC 3: “I consider doctors more compassionate than nurses. They are friendlier to the parent and the child. The fact that they prescribe medications makes them look like they care the most.”

Participant LC 4: “I find the nurses more compassionate because they understand most of us. They also talk to children if the child cries.”

Participant LC 5: “Yes there is a difference. Nurses are more compassionate since they are available whenever I need them”

Participant LC 6: “The physiotherapists give the best care. The nurses are also good and I appreciate the doctor because he has enabled the child to reach where she is.”

Participant LC 7: “The most compassionate is the nurse and doctors who are stationed in the ward. If my child convulses, they are readily available. Compassion is availability

These findings are in agreement with those found by Salmani *et al.*, (2017) who found that nurses who took time to explain a medical procedure such as fixing an IV line were found to be more compassionate than their peers who simply took a child away from the caregiver without explaining what they intended to do with the child. It also concurs with a study done in Nigeria by Chinawa *et al.*, (2016) which found that paediatricians were viewed as compassionate when they appeared unhurried, were willing to create rapport with patients as well as caregivers and had the ability to listen to caregivers’ concerns. Caregivers with children who needed physiotherapy services viewed physiotherapists as most compassionate because this is the PHCP who they interacted with frequently. Availability was interpreted as compassion just as appearing unhurried and addressing caregiver concerns was. This means that compassion means different things to different caregivers. Compassion is a subjective feeling. To some its answering questions, to some its politeness, to others its friendliness while to others its proximity to the caregiver. It’s important for the PHCP to understand their patients and caregivers and what they are looking for as they seek their services so as attain patient satisfaction. A study conducted among Iranian nurses revealed

that several factors affected ability to show compassion. These are an individual's personal interest, religious beliefs, role modeling at the family level and altruism. Due to this, the study found that young nurses could learn how to show compassion from their elder peers. Therefore the study concluded that compassion could be learned and developed through organizational support. It also concluded that hiring organizations could hire nurses who are highly motivated as to offer compassionate care to their patients (Zamanzadeh, Valizadeh, Rahmani, van der Cingel & Ghafourifard, 2018). This means that those who were found to be uncompassionate in the current study could benefit from role modeling by their peers or get in service training to enhance compassion ability.

4.4.2 Paediatric Caregivers' Treatment Compliance

Objective II: To assess paediatric caregivers' compliance with treatment in KNH

The second objective sought to assess paediatric caregivers' treatment compliance in Kenyatta National Hospital. The objective was measured in terms of ability to follow instructions, attending scheduled appointments and ability to administer prescribed medication. Different themes emerged from the interviews with the participants on why they complied with treatment. They included motivation to see improvement in their children, clarity of instructions, written instructions, regular check-up and encouragement, facilitation of treatment, finances and seriousness of the condition.

Motivation for Improvement

Most participants indicated that they followed instructions because they wanted to see their children's condition improve and at the same time to ensure the child benefited from treatment. Others did so because they were afraid of feeling guilty of endangering the life of their children.

This implies that their compliance was not dependent on the compassion of the health care providers for most of the caregivers. Some of their responses are sampled below.

Participant MI 1: “I follow instructions because I want to see my child get better.”

Participant MI 2: “When I notice improvement, I’m encouraged to continue with the instructions given.”

Participant MI 3: “I don’t want to feel guilty of endangering the life of my child by not following instructions.”

These responses point to the fact that compassion of the PHCPs does not necessarily lead to compliance on the part of the caregiver. This may imply that as long as a caregiver has been given the instructions to follow, all they would want to see is improvement of their child rather than the person or the attitude of the PHCP.

Clarity of Instructions

Some participants remarked that they followed instructions when they knew proper treatment procedures were followed, when the instructions were explained to them and when the instructions were helpful to the child. Some of the responses sampled from the participants are provided below.

Participant CI 1: “I also follow if proper procedures are followed. For instance doctors wanted to treat my child for tuberculosis since she wasn’t responding to treatment and I declined until she was tested. She tested negative and hence was not put on treatment which would have been unnecessary.”

Participant CI 2: “I comply especially when they explain and I can also verify what I am being told. One time I was told to reduce the feeds because the baby had an infection and wasn’t retaining feeds. I complied because I could understand what they were telling me.”

These findings indicate that clarity of instructions was significant in enhancing compliance to treatment. If instructions of the PHCP are not clear, some caregivers may decide not to comply simply because they did not understand or they are suspicious of the treatment.

Written Instructions

Some participants indicated that they complied when the instructions were written down and made available. Similarly, when the instructions were written down, it helped them not to forget any procedures. Some excerpts are sampled below.

WI1: “I was instructed on how to mix formula milk and I’m doing it well because it was explained, put in writing and hung on the bedside.”

WI2: “I follow instructions better if they are written down because I cannot forget.”

These findings show that health care providers who write down instructions play a role in the compliance of the caregiver to the given instructions. Accordingly, failing to write down the instruction with the assumption that they have understood may bring about noncompliance on the side of the caregiver which in turn may affect the treatment outcomes of the patient.

Regular Check-up and Encouragement

Another reason for complying with treatment was regular check-up and encouragement of caregivers by PHCPs. Most of them felt that regular check-ups encouraged them to follow up instructions. It was also noted that when doctors took time to explain them, they would feel encouraged and this made them adhere. Some excerpts are provided below.

Participant RC1: “When nurses check up on the baby especially at night, I am encouraged to follow up the instructions.”

Participant RC2: “I follow instructions when the doctor takes time to explain instructions during visits”

The findings show that regular check-up and encouragement communicates compassion to caregivers and may influence their compliance to treatment. This shows that the presence of a

PHCP may provide caregivers with an opportunity to ask for clarifications on the instructions provided.

Facilitating Treatment

The respondents also indicated that they followed instructions in order to facilitate treatment of their children by PHCPs. Some noted that they followed instructions to ensure that nothing was omitted in the process of treatment of a child. Others followed instructions because at one point they will continue with the care at home. There were also caregivers who feared they will be referred to other facilities, and still others did not understand some issues so they had to comply. Some of the responses are provided below.

Participant FT1: “There is need to work hand in hand with doctors and nurses. At one time chemo was given but not entered in the file. The doctor went with my word hence it was included in the treatment already given.”

Participant FT2: “I want to be able to continue doing things right at home after discharge.”

Participant FT3: “To avoid problems such as being referred elsewhere after refusal to comply some are referred and even die out of non-compliance.”

These findings show that the compliance of these respondents did not depend on the compassion of the health care provider but the desire to ensure that the treatment progressed smoothly. This shows that most of these caregivers were ready to play their part as long as it was prescribed by the doctor to prevent any other inconveniences or repercussions they felt would be hard to bear.

Finances

Some of the respondents indicated that finances made them not to follow instructions. Availability meant the instructions will be followed while lack of finances meant they will not follow. One excerpt is given below.

Participant F: “My child has cancer. Sometimes I am asked to buy indigenous foods which are very expensive in Nairobi and I can’t afford, so I don’t buy.”

This shows that economic status of the caregivers also played a role in their compliance rather than the compassion ability of their caregivers.

Seriousness of the Child's Condition

The seriousness of the child's condition was cited as another reason for adhering to instructions. The participants felt that they followed instructions to see if the child's condition will change and others did not know about some medical conditions like cancer. Others were aware that their child's condition is sensitive and needed regular attendance to clinics. There were those who failed to follow instructions when they felt the instructions may worsen the condition of their children. Some of the responses are provided below.

Participant SC1: "I follow instructions when I realize my child's condition is serious and instructions well stipulated."

Participant SC2: "My child's condition is so sensitive so I follow instructions such as coming to the clinic. I was shocked to learn that a certain lady failed to come to the clinic and the child later died."

Participant SC3: "Sometimes I ignore instructions, for example, when my child has fever and I'm told to expose him, if he shivers, I cover him because I think the cold will affect him more."

Participant SC4: "Sometimes they draw blood from my child severally and lose the results, when they come to draw again, I may refuse since he has cancer and is losing blood through multiple injections."

The findings indicate that compliance or noncompliance did not rely on the compassion of PHCPs but on the condition of the patients. Accordingly, the caregivers who complied or failed to comply may have feared that their children's condition would be worsened by some procedures or unnecessary exposures. Generally, the findings indicate that compliance to treatment was influenced by several factors including clear instructions, affordability, seriousness of the child's condition, knowledge of the condition as well as understanding of the implications for the child.

These results partly agree with Berry *et al.*, (2017) who found that most caregivers complied with treatment when the instructions were clear and well explained and declined when the instructions were unclear. However, in the current study, other reasons like written instructions, facilitation of treatment, motivation to see change, seriousness of the condition, and finances were key indicators of the reasons for compliance with treatment. The reason for this discrepancy may be because the study by Berry *et al.*, (2017) used a population of healthcare providers and not caregivers as the current study.

4.4.3 Implications of Paediatric Caregivers' Perceptions of PHCP's Compassion on Treatment Compliance

Study objective III: To find out the implications of paediatric caregivers' perceptions of PHCPs compassion on treatment compliance in KNH.

This objective was measured in terms of caregiver ability to follow instructions given by the provider. For some the motivation to follow instructions was related to PHCP compassion while for others, motivation was by other factors other than compassion.

Treatment Compliance not related to PHCP Compassion

Generally, majority of the respondents did not comply because of compassion shown by PHCPs but because of the motivation to see a child's condition improve and the caregivers' judgment of the intervention. Some of the excerpts are listed below.

Participant CNT1: "Even if the PHCP is not compassionate I'd still follow instructions to help my child."

Participant CNT2: 'I can't follow instructions which would harm my child. I declined an artificial leg because it was too heavy and causing pain to my child'

Participant CNT3: "The doctor was harsh on me because I delayed bringing the child to hospital but her condition has greatly improved since she was put on medication."

Participant CNT4: “I do not mind how the nurses talk to me provided they give the proper medication to my child. I have spent a lot of money in other hospitals for my son to be well and I cannot afford to lose him due to disagreements. I pretend I don’t hear their noise.”

Participant CNT5: “I know doctors understand all sicknesses so I can’t doubt their treatment of the child I usually do whatever they tell me to. If they shout at me, that’s OK, all I want is my child to improve. My child has improved a lot even though some nurses were harsh on me on the first day.”

Compliance Related to PHCP Compassion

A smaller number of caregivers stated that they complied with treatment because PHCPs took time to explain treatment procedures and medication, they listened to them, and they talked politely to them. Those who felt the PHCPs were not compassionate enough would transfer to other facilities or ignore the instructions. Some of the responses are given below.

Participant CRT 1: “The doctor takes time to explain to me what to do especially administering medication and because of this I usually follow the instructions.”

Participant CRT 2: “Whenever the doctor listens to me, I feel that he understands. However, other doctors do not listen and in such cases I feel I should ignore their recommendations.”

Participant CRT 3: “The nurses kept on shouting at me whenever I did not do things right and I paid more money to transfer to the private wing.”

Participant CRT 4: “When the doctors are polite, to me they look genuine and I find it easy to follow instructions.”

The findings on how caregiver perceptions influence compassion seem to partly agree with the findings by Chinawa *et al.*, (2016) who found that 50 percent of caregivers were happy with the provision of services by PHCPs. The reason for this was because the PHCPs spent time with the caregivers and this motivated them to comply with their children’s treatment. Similarly, another study by Rider *et al.*, (2018) showed that most caregivers in the US adhered to treatment when

communicated to in a polite way. The current study, however, found that it did not necessarily matter for most caregivers on whether they were treated well or not, majority believed in the interventions rather than the PHCPs compassion.

This chapter has discussed the findings of the current study. The response rate of the respondents was 88%. The sociodemographic findings of the caregivers were reported where most of them were found to be between the ages of 21-30 years. Majority of the caregivers were mothers and came from the urban set up, most of them were married and had been caregiving for a period of 0-6 weeks. On the other hand, the age of children ranged between 0-15 years with most of them in the 0-6 month age group. Majority had been in hospital for four weeks and below. Paediatric medical wards formed the bulk of the respondents with majority of the children having a diagnosis of prematurity.

Most of the caregivers conceptualized compassionate care as love and friendliness, being listened to, polite communication, adequate consultation time as well as adequate information concerning their children. The study found that it was easier for the caregivers to follow instructions when they were well explained, they were written down or PHCPs followed up to see how they were doing. The study found that most of the caregivers complied with treatment. However the reasons for compliance were diverse and varied. While a majority were motivated to comply with treatment by a desire to see improvement in their children, a good number of caregivers found compassion in the PHCP as a significant motivator for compliance. Those who complied due to compassion valued the time taken by the PHCP in addressing their concerns, polite communication, love and friendliness and adequate information given to them concerning their children. For the rest, it did not matter how the PHCP behaved towards them as long as they gave the necessary treatment.

CHAPTER FIVE

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

This chapter presents the summary of findings, conclusions and recommendations of the study on caregivers' perceptions of compassion among paediatric health care providers in Kenyatta National Hospital and its implications for treatment compliance.

5.2 Summary

The following is a summary of the major findings based on the study objectives

5.2.1 Sociodemographic Characteristics of Caregivers and their Patients

The response rate of the respondents was 88%. The sociodemographic findings of the caregivers were as follows. It was found that they ranged between the ages of 21-30 years. Majority of the caregivers were mothers and came from the urban set up, most of them were married and had been caregiving for a period of 0-6 weeks. Their views of compassion did not vary with age, marital status or residence. On the other hand, the age of children ranged between 0-15 years with most of them in the 0-6month age group. Majority had been in hospital for four weeks and below. Paediatric medical wards formed the bulk of the respondents with majority of the children having a diagnosis of prematurity.

5.2.2 Caregivers' Perception of Compassion among Paediatric Health Care Providers

The first objective aimed at exploring on how caregivers perceived compassion among paediatric health care providers. Majority of caregivers perceived compassion through observations of love and friendliness, polite communication, timeliness in attending to patients, attentive listening as well as adequate consultation time and adequate information given. In addition, nurses especially the elderly were found to be more compassionate compared to their younger peers as they were more friendly and responsive. Doctors were viewed as compassionate when they took time during consultation or ward rounds to address the caregivers' concerns. Those who felt that the doctors were more compassionate cited friendliness to them and their children as an important indicator of compassion. Others felt doctors were more compassionate when they gave them information concerning their children and appeared unhurried when giving them this information. Doctors who gave caregivers adequate time to express their concerns were also found to be more compassionate.

In the NBU these indicators were missing among doctors. The probable reason for this would be the huge numbers of patients compared to the available number of doctors. In the same unit, compassion among nurses varied from caregiver to caregiver. Some caregivers viewed nurses as compassionate when they helped them to feed their babies as well as teaching them how to bathe the children. Being first time mothers with very premature children, some as small as 850g some caregivers struggled in basic handling of the babies. Any nurse who went out of her/his way to teach a first time mother how to handle the baby was viewed as compassionate. Nurses who were able to pass on the information from the doctors to the caregivers during the feeding time were viewed as compassionate as was a nurse who was willing to explain that information to the father of the child when he visited. Some caregivers in the NBU FGD pointed out that there was a male

nurse who was very compassionate at the time of the study. He never forgot the caregivers concerns no matter how many they were. This shows that despite a large number of patients, it's still possible to show compassion to caregivers and their patients. Nutritionists in NBU were rated as very compassionate since they readily taught caregivers how to express breast milk for their babies.

This shows that caregivers are looking for a helping hand and are willing to be taught and involved in the management of their children. On the contrary assuming that they know what they are supposed to do may be interpreted as lack of compassion. In the oncology ward, the Professor was viewed as most compassionate among most of the caregivers mainly because of giving the much needed information. Since cancer is a chronic disease, caregivers were looking for a lot of information. Would their children get healed? What were the side effects of the current treatment? What would they tell their children concerning the illness? What caused the cancer? The doctors in the oncology ward were not readily available to answer these questions hence they were found to be less compassionate than the Professors. The nurses in the oncology ward were mostly found to be compassionate. Although they did not offer a lot of information, being close to the children and addressing their daily needs was viewed as compassion to the caregivers. All the caregivers in the oncology ward said that their children were very comfortable and did not cry as they left after the visiting hour showing that they were well taken care of by the nurses.

In the pediatric medical wards, most of the caregivers were living in with their patients and had better access to doctors and nurses. They would get better information than their peers in the NBU and oncology wards. However the information was delivered in a hurried manner mainly during the ward rounds from the doctors. They had easy access to the nurses and most of them viewed the nurses as most compassionate due to their availability in times of emergency such as a fever

or convulsion. Availability especially among nurses was a strong indicator of compassion. On the contrary, using a harsh language was viewed as uncompassionate among all the PHCPs. One caregiver reported how a doctor in NBU answered harshly when she wanted to inquire the progress of her baby. He complained that he was tired and wanted to go and rest and so asked if the caregiver's issue was urgent. The caregiver shied off and never asked that question again. This shows that doctors were found to be uncompassionate when they appeared unfriendly, were unwilling to address caregivers' concerns especially on information and generally did not have adequate consultation time with caregivers. The perceived lack of attention towards the caregiver was perceived as lack of compassion. Unavailability among doctors was also viewed as lack of compassion. Generally in the NBU and Oncology wards, the doctors were unavailable and this came out clearly as lack of compassion as the caregivers could not access the much sought for information. Some nurses in NBU were also unwilling to talk to the fathers of children who had a lot of questions concerning their babies during the visiting hours. Compassion among nurses was viewed not to be using a harsh language, being impolite and inability to pass on the information about the child to significant others. Being always with the patients in the ward, there was a natural expectation that they had all the information concerning the patient. Failure to relay this information or politely inform the caregivers when they did not have this information was interpreted as lack of compassion.

5.2.3 Paediatric Caregivers' Treatment Compliance

The second objective assessed the paediatric caregivers' treatment compliance. Majority of the caregivers reported that they complied with treatment as advised by their PHCPs. The reasons for compliance were varied. While some complied due to perceiving their PHCPs as compassionate, others complied for other reasons. Some of the reasons given for complying with treatment were

a desire to see improvement in their children, getting clear instructions, having instructions that were written down, being followed up and encouraged by PHCPs and having the financial ability to buy resources needed for treatment. Only a few caregivers reported not following instructions by their PHCPs. They cited reasons such as perceived lack of compassion in their PHCPs, using their own judgment and avoiding harming the child with medical procedures that they deemed harmful.

5.2.4 Implications of Caregiver Perceptions of PHCPs Compassion on Treatment

The third objective aimed at finding out the implications of caregiver perceptions of PHCPs compassion on treatment. It was found that some compliance of caregivers depended on compassion while the other did not. Those who complied because of compassion did so because the health care provider took time to explain treatment procedures and medication, listened to the caregiver and talked politely to them. The respondents who complied due to compassion felt that when they were allowed adequate time for self-expression, were listened to and had enough information, it helped them to make good decisions about the treatment their children were receiving. They had no questions concerning the treatment offered hence it was easy to follow instructions. Failure of the PHCP to have these qualities would make them suspicious of treatment procedures and created unnecessary anxiety. Those who complied with treatment for other reasons cited the desire to see improvement in their children as the major reason for compliance. Other reasons given were clear and written down instructions, seriousness of the child's condition and ability to purchase what was needed for treatment (finances). Lack of medical knowledge among some caregivers was also cited as a reason for compliance as they left the decision solely to PHCPs. A few caregivers complied out of fear of repercussions of failing to adhere to PHCPs advice. This reveals that although some caregivers complied to treatment when PHCPs were deemed more

compassionate, others complied for many varied reasons. However caregivers preferred the most compassionate

5.3 Conclusions

The following conclusions were made from the study findings:

1. Majority of the caregivers felt that adequate consultation time, timeliness, polite communication and responsiveness were important aspects of compassion. Doctors were viewed as compassionate when they appeared unhurried during consultation time as well as during the ward rounds. They were rated as friendlier to the children and caregivers and mostly were rated as polite. However those doctors who were not available for consultation and information on the progress of a child were viewed as uncompassionate. Nurses were rated as compassionate mostly based on their close proximity and availability to the caregivers. Those who were willing to give information about a child in the absence of a doctor were viewed as compassionate especially in the paediatric medical wards. In the NBU, those who went out of their way to train first time mothers how to handle the premature babies were viewed as compassionate. On the other hand, nurses who were harsh, unavailable or unwilling to relay information from the doctors were viewed as uncompassionate. In the NBU, nutritionists who helped caregivers to express milk for their premature babies were rated highly for compassion. Physiotherapists in the paediatric medical wards were rated as compassionate for explaining their procedures to the caregivers. Professors in the oncology ward were rated as compassionate for being available to share information about their patients.

Caregivers also found them to be more compassionate for being reachable on phone for any information they needed.

2. Perception of compassion among the different PHCPs varied from caregiver to caregiver. Perceptions depended mainly on their roles. Since doctors are expected to consult, make a diagnosis and give feedback depending on findings, caregivers rated doctors mainly on friendliness during consultation and ability to answer questions concerning their children when caregivers sought the answers. Nurses on the other hand were mainly evaluated on availability and politeness since they interacted more with caregivers because they were stationed in the wards as opposed to doctors who would come to the ward and leave at various times. As custodians of patients' files in the ward, caregivers expected them to share as much information as possible though it was established some of the information needed to come from the doctors. It would be good for the institutions to brief the caregivers on how to access patient information when it was needed.
3. Paediatric caregivers' treatment compliance was enhanced by giving clear instructions, making regular follow ups, giving adequate information and addressing caregivers' concerns.
4. Most paediatric caregivers complied because their desire was to see improvement in their children rather than due to compassion among the PHCPs. This means that apart from compassion the other factors identified during the study need to be enhanced to promote compliance to treatment.

5.4 Recommendations

The recommendations for policy and suggestions for further research are as follows.

5.4.1 Recommendations for Policy

The study makes the following recommendations for policy:

- i. There is need for for paediatric health care providers especially nurses and doctors to increase their consultation time with paediatric caregivers in order to give them room for expression of their expectations and also ensure proper understanding of the procedures. This implies the need for reduced caregiver-patient ratio and hence employment of more PCHPs
- ii. There may be need for health institutions to formulate practice policies that promote education on compassion among PHCPs which may help to improve compliance with treatment.
- iii. Health care institutions may need to improve and increase dissemination of information to patients and their caregivers as well as utilize the biographical information while prescribing some treatment procedures. The information can be disseminated through mobile phones and apps to ensure caregivers understand instructions from health care providers.
- iv. On top of promoting compassion, health care institutions may need to incorporate psychological professionals who can address any psychological distress experienced by caregivers in the course of their children's treatment.
- v. There is need for in-service capacity building on compassion among the pediatric caregivers

- vi. There is need to educate PHCPs on how patients and their caregivers perceive compassion so that they can deliver care in ways that are more relevant to their clients.

5.4.2 Suggestions for Further Studies

The study makes the following suggestions for further studies:

- i. This study focused on the views of caregivers rather than the health care providers and so another study may need to be conducted to assess the views of the health care providers on their capacity for compassion.
- ii. Quantitative studies employing use of validated measures of compassion can be conducted to give quantitative measures of PCHPs compassion.
- iii. This study was qualitative and relied on the subjective experiences of the caregivers. A quantitative study may need to be conducted to find out the extent to which the identified indicators of compassion influence compliance.
- iv. The study focused on compassion and its implications on treatment compliance. Other studies may be conducted in the other hospitals to determine which other factors may be influential to compliance to treatment.
- v. The study was conducted in a national referral hospital. Other studies may be conducted in other facilities to determine if the caregiver experiences are similar to those reported in the current study.
- vi. Finally, other studies may be carried out in both private and public hospitals to determine if there are significant differences in the levels of compassion in both.

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APPENDICES

APPENDIX I: QUESTIONNAIRE

Participants: Caregivers/Patients

Instructions: Please answer the following questions and tick one box as appropriate

Caregiver's Characteristics:

1. Client Code:

2. Date:

3. Age: 21-30 31-40 41-50 51-60 61-70

4. Gender: Male Female

5. Marital status:

Single Married Separated Widowed Others

6. Residence:

Urban Semi urban Rural

7. Relationship to the child:

Mother Father Brother Sister Others

8. Period of Caregiving:

Children's Characteristics:

9. Age:

10. Period of hospitalization:

11. Diagnosis/Paediatric Unit:

APPENDIX II: UNSTRUCTURED INTERVIEW SCHEDULE

Participants: Caregivers

Date:

I am conducting a research on the above topic. Please share your experience as honestly as possible. Remember any information shared will be confidential and may be used to improve the services you and your child receive during a hospital visit.

1. How would you describe compassionate care in a hospital set up?
2. Based on your observations how would tell that your health care provider is being compassionate to you and your child?
3. How often do you interact with the staff treating your child? Are you happy with the frequency of interaction?
4. How much time does the health care provider spend with you or the child in a single consultation?
5. Do you consider the information you have about your child's condition sufficient?
6. Is there a difference in the way different health care providers handle your child or show compassion? Whom do you think is more compassionate and how do they show it?
7. What do you wish the health care did differently?
8. What is your opinion about the nurses, doctors, or other health care providers' ability to care well enough for patients and their family members?
9. Do you follow the instructions given to you by your child's health care provider?
10. What influences whether or not you comply with instructions concerning your child's treatment?
11. In your opinion, what do you think affects the health care provider's ability to care well enough for patients and their families?
12. Based on your experience, is there need to change how paediatric health care is delivered? If yes, what would be your recommendations?

KIAMBATISHO II: RATIBA YA MAHOJIANO

Washiriki: WaleziTarehe:

Ninafanyautafitijuuyamadahapojuu. Tafadhalishirikiuzoefuwakokwauaminifuiwezekanavyo.

Kumbukataarifazozotezilizoshirikiwazitakuwazasirinazinawezakutumikakuboshahudumaamba zowewenamtotowakohupokeawakatiwaziarayahospitali.

1. Unawezajekuelezeautunzajiwahurumakatikahospitaliiliyowekwa?

2.

Kulingananauchunguziwakoitaelezeajekwambamtoahudumawakowaafyaanakuwanahurumakwa konamtotowako?

3. Ni marangapiunashirikiananawafanyakazikumtibusmtotowako? Je, unafurahiamzungukowamwingiliano?

4. Mtoahudumayaafyaanatumiamudaganinawewe au mtotokatikamashaurianomoja?

5. Je, unazingatiataarifaulizonazokuhusuhaliamtotowakoyakutosha?

6. Je, kunatofautikatikanamnawatoahudumatofautizaafyawanavyoshughulikiamtotowako au kuonyeshahuruma? Unadhanininanimwenyehurumazaidinajinsiganiwanaionyesha?

7. Unatakahudumayaafyaielekeenini?

8. Maoniyakokuhusuwauguzi, madaktari, au

uwezowawatoahudumazaafyakutunzavizuriyakutoshakwawagonjwanawanafamiliawao?

9. Je, unafuatamaelekezouliyopewanamtoahudumayaafyayamtotowako?

10. Ni ushawishiganiunaozingatia au kutozingatiamaelekezokuhusumatibabuyamtotowako?

11. Kwa maoniyako, unafikirikunaathiriuwezowamtoahudumayaafyakutunzavizurivyakutoshakwawagonjwanafamilia zao?

12. Kulingananauzoefuwako, kunahajayakubadilishajinsihudumayaafyayatotoinavyotolewa? Kama ndiyo, mapendekezoyakoyangekuwanini?

APPENDIX III: FOCUSED GROUP DISCUSSIONS SCHEDULE

Participants: Caregivers with similar experiences

Date.....Group Code:

As caregivers of children having similar illnesses I assume you have some similar experiences and that is why I put you together. Kindly share as honestly as possible. I would like to emphasize that whatever we discuss is confidential. Please respect each other's opinions. The information you share is meant to help improve paediatric health services.

1. What does compassion in a hospital set up mean to you?
2. What are some of the observations you have made of your health care providers as they treat your child? How would you tell by observing that they care for your child?
3. How much time do you spend interacting with your health care provider concerning the child's illness? Is it adequate in your view? Is there anything you think could be done differently?
4. What do you know about your child's condition and treatment? Do you consider it adequate? If it's not, what else would you want to know?
5. When a health care provider gives you instructions concerning your child's treatment what determines if you follow them fully or not?
6. What in your opinion affects health care providers' ability to give quality care and what changes would you recommend towards this?7. Is there a difference in the ability to show compassion among the doctors, nurses, students or other professionals? Describe these differences.

KIAMBATISHO III: RATIBA YA MAJADILIANO YA KIKUNDI INAYOLENGA

Washiriki: Walezi wenye uzoefusawa Tarehe

Kama

walezi wawatoku wanamagonjwa kamahayonadhani unauzoefu kamahuonandiomaananinawawek apamoja. Shiriki kwaukarimuiwezekanavyo.

Ningependakusisitizakwambachochotetunachojadilinisiri. Tafadhali heshimumaoniyakilammoja. Maelezo unayoshiriki yanakusudiwakusaidiakuboreshahudumazaafyayatoto.

1. Hurumakatika hospitali ili yowe kwainamaanishaninikwako?

2. Ni zipiba adhi ya chunguzi uliofanyawato ahudumazako zaafyawanapomtibumtotowako?

Unawezajekumwambiakwakuchunguzakwambawanamhudumiamtotowako?

3. Unatumiamudaganikuingiliananamtoto ahudumawakowaafyaku husuugonjwawamtoto? Je, inatoshakatika mtazamowako? Je, kuna chote unachodhanika inawezakufanywatofauti?

4. Unajuanika kuhusu halinamatibabuyamtoto wako? Je, unaichukuliaku wainatosha? Kama sivyo, niki tunganika ingine unependakujua?

5.

Mtoahuduma anapokupama elekezo kuhusumatibabuyamtoto wako ninini huamukama utayafuataki kamilifu au la?

6. Ni ninikwama oniyako kuna athiri uwezowawato ahudumazaafyakuto ahuduma bora nani mabadiliko gani unependekewahili?

7. Kuna tofauti katika uwezowakuonyeshahurumamiongonimwamadaktari, wauguzi, wanafunzi au wataalamu wengine? Eleza tofauti hizi.

APPENDIX IV: INFORMED CONSENT FORM

My name is Wanjohi Grace Wambui. I am a masters student at Kenyatta University, Department of Psychology. I am conducting a study on ‘Caregivers’ Perceptions of Paediatric Health Care Providers’ Compassion Ability in Kenyatta National Hospital, Nairobi, Kenya.’ The information obtained will be used to improve paediatric health care services.

Procedures to be followed

Participation in this study may require you to answer a questionnaire that will be provided, participate in a face to face interview or be enrolled in a group. The information will only be used for the intended research purposes and will bear no identifying information. Please remember the participation in the study is voluntary. You may ask questions related to the study at any time. You may refuse to respond to any questions and may stop responding at any time. You may also stop being in the study at any time without any consequences.

Discomforts and risks

The study involves no known risk to you and contains no deception. However if any of the questions make you uncomfortable, you may refuse to answer these questions if you so choose.

Benefits

Participation in this study is voluntary and if you choose to participate, you will help us know more about compassion ability among pediatric health care providers and how caregivers of their patients perceive their services in Kenyatta National Hospital.

Rewards

There are no rewards for participating in this study.

Confidentiality

Privacy and confidentiality will be ensured. You are not required to write your names on the questionnaire to ensure anonymity. The questionnaires and information obtained from participants will be kept in a private office in order to ensure privacy.

Contact information

If you have any questions you may contact me on 0722483254. For more information about your rights as a research participant you may contact the Chairperson, Kenyatta University Ethics Review Committee at kuerc.chairman@ku.ac.ke

Participant’s statement

The above information regarding my participation in the study is clear to me. I have been given a chance to ask questions and my questions have been answered to my satisfaction. My participation in this study is entirely voluntary. I understand that my records will be kept private and that I can leave the study at any time.

I understand that I will still get the same care and the same services whether I decide to leave the study or not and my decision will not change anything.

.....

Signature.....

Date.....

Investigator’s statement

I, the undersigned have explained to the volunteer in a language that he/she understands, the procedures to be followed in the study and the risks and benefits involved.

Name of the investigator

Investigator’s signature.....

Date.....

FOMU YA KUSHIRIKI KATIKA UTAFITI

Kichwa cha Funzo: MAONI YA WAJALI WATOTO KUHUSU UWEZO WA MADAKTARI WA WATOTO KUWAPOKEZA MATIBABU YENYE HURUMA KATIKA HOSPITALI YA KITAIFA YA KENYATTA, NAIROBI, KENYA: UHUSIANO NA KUFUATA MAAGIZO YA MADAKTARI.

Mtafiti Mkuu na ushirikiano wa taasisi: GRACE W WANJOHI, UNIVERSITY KENYATTA, Idara ya PSYCHOLOGY

Wachunguzi wa ushirikiano na ushirika wa taasisi:

Utangulizi:

Ningependa kukuambia juu ya utafiti unaofanywa na watafiti waliotajwa hapo juu. Kusudi

ya fomu hii ya idhini ni kukupa taarifa unayohitaji ili kukusaidia kuamua kama la

kuwa mshiriki katika utafiti. Jisikie huru kuuliza maswali yoyote kuhusu madhumuni ya utafiti, kinachotokea ikiwa unashiriki katika utafiti, hatari na faida iwezekanavyo, haki zako kama kujitolea, na kitu kingine chochote kuhusu utafiti au fomu hii ambayo haijulikani. Tunapojibu maswali yako yote kwa kuridhika kwako, unaweza kuamua kuwa katika utafiti au la. Utaratibu huu unaitwa 'kibali cha habari'. Mara unapoelewa na kukubali kuwa katika utafiti, nitawaomba kusaini jina lako kwenye fomu hii. Unapaswa kuelewa kanuni za jumla zinazotumika kwa washiriki wote katika utafiti wa matibabu:

- i) Umuzi wako wa kushiriki ni kikamilifu kwa hiari
- ii) Unaweza kuondoka kwenye utafiti wakati wowote bila ya kutoa sababu ya kuondolewa kwako
- iii) Kukataa kushiriki katika utafiti hautaathiri huduma unazostahili katika afya hii

kituo au vifaa vingine. Tutakupa nakala ya fomu hii kwa rekodi zako.

Naweza kuendelea? NDIO /LA

Utafiti huu una kibali na Hospitali ya Taifa ya Kenyatta-Chuo Kikuu cha Maadili ya Nairobi na

Natiba ya Kamati ya Utafiti No _____

HUU UTAFITI UNAHUSU NINI?

Watafiti waliotajwa hapo juu ni kuhojiana na watu wanaojali watoto waliokiri katika kitengo cha watoto wa Hospitali ya Taifa ya Kenyatta. Kusudi la utafiti ni kujua jinsi wasaidizi wanaona huruma kutoka kwa watoa huduma ya afya ya watoto wao na jinsi hii inathiri matibabu ya kufuata. Washiriki katika utafiti huu wa utafiti wataulizwa maswali kuhusu uzoefu wao mikononi mwa watoa huduma ya afya ya watoto. Kutakuwa na washiriki takriban 40 katika utafiti huu kwa nasibu waliochaguliwa. Tunaomba ridhaa yako kufikiria kushiriki katika utafiti huu.

NINI ITAFANYIKA UKIKUBALI KUSHIRIKI KATIKA HUU UTAFITI?

Ikiwa unakubali kushiriki katika utafiti huu, mambo yafuatayo yatatokea:

Utashughulikiwa na mhojiwaji mwenye ujuzi katika eneo la kibinafsi ambako unasikia vizuri

kujibu maswali. Mahojiano yataendelea dakika 45 hadi 60 kwa moja kwenye mahojiano moja, na masaa 1-2 kwa ajili ya majadiliano ya kikundi. Mahojiano yatashughulikia mada kama vile watunza huduma wameona, uzoefu mzuri na mbaya kutokana na hospitali ya watoto wao pamoja na matarajio yao. Baada ya mahojiano kukamilika, ushauri wa ushauri unaweza kutolewa kwa washiriki ambao wanaweza kuwa na wasiwasi baada ya kugawana uzoefu mbaya. Tutaomba namba ya simu ambapo tunaweza kuwasiliana na wewe ikiwa ni lazima. Ikiwa unakubali kutoa maelezo yako ya kuwasiliana, itatumiwa tu na watu wanaofanya kazi kwa ajili ya utafiti huu na kamwe hawatashirikiwa na wengine. Sababu zinazotaka tu kuwasiliana na wewe ni pamoja na: kufafanua habari fulani ulizoshiriki wakati wa utafiti.

JE, KUNA BAADHI YA MAADILI, MAGONJWA YANAYOTOKANA NA UTAFITI HUU?

Utafiti wa kisaikolojia una uwezekano wa kusababisha dhiki ya kisaikolojia kwa kukumbuka uzoefu usiofaa. Kujibu maswali katika mahojiano pia inaweza kuwa na wasiwasi kwako. Ikiwa kuna maswali yoyote unayotaka kujibu, unaweza kuruka. Una haki ya kukataa mahojiano au maswali yoyote yaliyoulizwa wakati wa mahojiano. Wafanyakazi wa utafiti watawashauri kwa usumbufu mdogo au kukupeleka ushauri zaidi wakati wa lazima.

JE, KUNA FAIDA YOYOTE KUWA KATIKA UTAFITI HUU?

Unaweza kufaidika kwa kupata ushauri wa bure. Tutakutaja kwa usaidizi zaidi wa kisaikolojia ikiwa ni lazima. Pia, maelezo unayoyotoa itatusaidia kuelewa vizuri uzoefu wa mlezi na watoto huduma ya afya ya watoto. Taarifa hii ni mchango wa huduma za afya ya watoto na kisaikolojia.

HUU UTAFITI UTAKUGHARIMU NINI?

Kuwa katika utafiti huu hauna gharama ya fedha lakini inaweza kukupoteza muda wako.

UKIWA NA MASWALI BAADA YA UTAFITI?

Ikiwa una maswali zaidi au wasiwasi juu ya kushiriki katika utafiti huu, tafadhali piga simu au tuma ujumbe wa maandishi kwa wafanyakazi wa kujifunza kwa namba iliyotolewa chini ya ukurasa huu. Kwa habari zaidi kuhusu haki zako kama mshiriki wa utafiti unaweza kuwasiliana na Katibu / Mwenyekiti, Kenyatta National Hospital-Chuo Kikuu cha Nairobi Maadili na Utafiti Kamati Namba Namba 2726300 Ext. 44102 au barua pepe uonknh_erc@uonbi.ac.ke.

Wafanyakazi wa kujifunza watawalipa malipo yako kwa idadi hizi ikiwa wito ni kuhusiana na utafiti huu.

HAKI ZAKO ZAIDI NI GANI?

Uamuzi wako wa kushiriki katika utafiti ni wa hiari. Wewe ni huru kupungua ushiriki katika kujifunza na unaweza kujiondoa kwenye utafiti wakati wowote bila udhalimu au kupoteza faida yoyote.

FORM YA SHAHILI (MAELEZO YA KUTIKA)

Taarifa ya Mshiriki

Nimesoma fomu hii ya idhini au nilisoma habari. Nimekuwa na fursa ya kujadili utafiti huu wa utafiti na mshauri wa utafiti. Nimekuwa na maswali yangu akajibu kwa lugha ambayo mimi

huelewa. Hatari na faida zimeelezwa kwangu. Ninaelewa kuwa ushiriki wangu katika utafiti huu ni hiari na kwamba nipate kuchagua kuchagua wakati wowote. Ninakubali kwa hiari kushiriki katika utafiti huu wa utafiti. Ninaelewa kwamba jitihada zote zitafanywa kuweka taarifa kuhusu utambulisho wangu binafsi.

Kwa kusaini fomu hii ya kibali, sijaacha haki yoyote ya kisheria ambayo nina kama mshiriki katika utafiti wa utafiti.

Nakubali kushiriki katika utafiti huu wa utafiti: Ndio/ Hapana

Nakubali kutoa taarifa ya mawasiliano kwa kufuatilia: Ndio /Hapana

Jina _____ la _____ kuchapishwa _____ la _____ mshiriki:

Sawa saina / Thumb ya mshiriki _____ Tarehe _____

Jina la mtoto

Taarifa ya Mtafiti

Mimi, nimeelezea kikamilifu maelezo muhimu ya utafiti huu wa utafiti kwa mshiriki jina lake hapo juu na kuamini kwamba mshiriki ameelewa na amepewa kwa hiari na kwa uhuru kibali chake.

Jina la Mtafiti: Grace Wanjohi: _____ Tarehe _____

Sahihi _____

Jukumu katika utafiti: Mtafiti Mkuu / Msaidizi wa Utafiti

Kwa habari zaidi wasiliana nami juu ya 0722483254 / _____ kutoka 8am hadi 5pm

Jina la Kuchapishwa la Mashahidi

Jina _____ Maelezo ya mawasiliano _____

Sahihi / kitambulisho: _____ Tarehe; _____

APPENDIX VI: KNH AUTHORIZATION LETTER



KENYATTA NATIONAL HOSPITAL
P.O. BOX 20723, 00202 Nairobi

Tel.: 2726300/2726450/2726550
Fax: 2725272
Email: knhadmin@knh.or.ke

Ref: KNH/PAEDS-HOD/48 Vol.II

Date: 26th April 2019

Grace W. Wanjohi
Dept. of Psychology
School of Humanities and Social Sciences
Kenyatta University

Noted
SAEN gwp
13/5/19

Dear Grace

RE: AUTHORITY TO COLLECT DATA IN PAEDIATRICS DEPARTMENT

Following approval by the KNH/UON-Ethics & Research Committee for your Research Proposal and subsequent filing of the Study Registration certificate, this is to inform you that authority has been granted to collect data in *Paediatrics Department*, on your study titled "*Caregivers' perceptions of paediatric health care providers compassion ability in Kenyatta National Hospital, Nairobi, Kenya: Implications for treatment compliance*".

Kindly liaise with the Senior Assistant Chief Nurse Paediatrics for facilitation.

You will also be required to submit a report of your study findings to the Department of Paediatrics after completion of your study.

DR. ADELAIDE KITUYI
AG. HEAD OF DEPARTMENT, PAEDIATRICS

Cc. Senior Assistant Chief Nurse, Paediatrics



APPENDIX VII: INTRODUCTORY LETTER



KENYATTA UNIVERSITY GRADUATE SCHOOL

E-mail: dean-graduate@ku.ac.ke

Website: www.ku.ac.ke

P.O. Box 43844, 00100
NAIROBI, KENYA
Tel. 8710901 Ext. 57530

Our Ref: C50/37936/2016

DATE: 20th May, 2019

Director General,
National Commission for Science, Technology
and Innovation
P.O. Box 30623-00100
NAIROBI

Dear Sir/Madam,


RE: RESEARCH AUTHORIZATION FOR GRACE W WANJOHI – REG. NO. C50/37936/2016.

I write to introduce Grace W. Wanjohi who is a Postgraduate Student of this University. The student is registered for MA degree programme in the Department of Psychology

Grace intends to conduct research for a MA Project Proposal entitled, “Caregivers’ perceptions of compassion ability among paediatric health care providers in Kenyatta National Hospital, Nairobi, Kenya”. Subject to clearance with the office of the Director, Ethical Committee Kenyatta University.

Any assistance given will be highly appreciated.

Yours faithfully,


PROF. ELISHIBA KIMANI
AG. DEAN, GRADUATE SCHOOL

AM/ik