

**NURSES EXPERIENCES AND PERCEPTIONS
OF PROVIDING FUTILE CARE TO PATIENTS
IN THE CRITICAL CARE UNIT AT KENYATTA
NATIONAL HOSPITAL**

OWITI TERESA

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DECLARATION

I, Teresa Owiti, declare that this is my original work and that to the best of my knowledge, it has not been presented for the award of any other degree in any other institution of higher learning.

Signed.....

Teresa Owiti.

H56/89445/2016

SUPERVISORS APPROVAL

This dissertation has been submitted by our approval as University of Nairobi supervisors.

1. Dr Eunice Omondi

Lecturer, School of Nursing Sciences,

University of Nairobi

Signature.....

Date.....

2. Dr. Emmah Matheka

Lecturer, School of Nursing Sciences,

University of Nairobi

Signature.....

Date.....

DEDICATION

This research is dedicated to my loving parents Mr. Hippolytus and Mrs. Florence Owiti for their support, my wonderful babies Pearl, Linsey and Aileen for their patience and understanding during my academic journey, my brother and sisters for encouraging me to keep going.

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LIST OF ABBREVIATIONS

CCU	Critical Care Unit
CPR	Cardiopulmonary Resuscitation
DNR	Do Not Resuscitate
EOL	End of Life
GCS	Glasgow Coma Scale
HCP	Health Care Provider
ICU	Intensive Care Unit
KNH	Kenyatta National Hospital
LOS	Length of Stay
MV	Mechanical Ventilation
NBI	Non Beneficial Interventions
NBT	Non Beneficial Treatment
TADA	Texas Advance Directive Act
TBI	Traumatic Brain Injuries
USA	United States of America

DEFINITION OF TERMS

Critical care unit- this is a specialized unit within a hospital that caters for patients with severe life-threatening conditions, which require constant, close monitoring and support from specialized equipment and medication.

Critically ill patient-this is a patient who requires specialized care and constant monitoring, usually in the ICU, due to life-threatening conditions resulting from severe trauma, organ failure or post major surgery.

Futile care- provision of medical care that does not meet the physiological goals of treatment and thereby does not benefit the patient.

Multiple organ failure- also known as multiple organ dysfunction syndrome, total organ failure or multisystem organ failure is altered organ function in acutely ill patient requiring medical treatment to achieve homeostasis.

Perception- critical care nurses view regarding the level and type of care that they are giving to the critically ill patient.

Terminally ill patient- these are patients with incurable diseases that cannot be adequately treated and there is reasonable expectation of death within a short period of time.

ABSTRACT

Background: Intensive care is meant for patients who are likely to benefit from the limited and expensive resources. However, sometimes patients in the intensive care unit receive care that is ultimately not beneficial to them. Nurses are the majority care givers and consequently give care to these patients. Studies done in the developed world have reported the existence of futility of care in the Intensive Care Unit and how nurses perceive futile care as useless, time wasting and prolonging suffering. In our setup, futile care is provided but nurse's experiences and perceptions regarding futility of care have not been explored.

Main objective: To explore the nurses experiences and perceptions of providing futile care to patients in the critical care unit at Kenyatta National Hospital.

Methods: The study utilized a descriptive qualitative approach and was conducted in the intensive care unit at Kenyatta National hospital. Purposive sampling technique was used to select ten nurses who met the inclusion criteria. In-depth individual interviews and participant observation by the researcher were used to collect data. The interviews were audio-recorded and transcribed verbatim. Data was inductively analyzed through the manual coding process and codes condensed into themes and sub themes.

Results: Three themes emerged from the analysis of the data: non beneficial treatment, wastage of resources and distress, under these major themes there were six sub themes. Nurses considered futile care as non-beneficial to the patient in relation to their physiological conditions. The nurses also expressed that since futile care was not beneficial to the patients, this amounted to wastage of resources. It was also established that providing futile care to patients lead to distress among the nurses and patients families because of unclear admission criteria and lack of DNR protocols.

Conclusion: Nurses in KNH ICU perceived futile care as non-beneficial and felt that continued provision of the same was a waste of resources and lead to distress among the nurses and patients' families.

Recommendations: There is need to review the admission policies in the unit, to develop and implement DNR protocols, to train the nurses on end of life care and to institute supportive measures to the nurses so as to mitigate the moral distress that they experience as a result of providing futile care to patients.

CHAPTER ONE: INTRODUCTION

Intensive care units are departments in the hospital that provide specialized care for patients with severe life-threatening conditions, which require constant, close monitoring and support from specialized equipment and medication. However it is observed that there are ICUs that also provide futile care. Futile care is the provision of treatment that does not meet the physiologic goals in a patient thus the patients does not benefit from such treatment. Nevertheless it is observed that provision of futile care is a common occurrence in the critical care units in developed countries (Carter et al., 2017). This study aims to explore the experiences and perceptions of futility of care among nurses working in the critical care unit at Kenyatta National Hospital. This chapter discusses the background information about futile care, statement of the problem, study justification and significance and the research objectives.

1.1 BACKGROUND INFORMATION

Within the medical fraternity a universal consensus on the definition of futility of care has been a challenge. Various countries, institutions have different criteria for defining when the care being provided is futile. Alexander & Shepard (2016) defined futile care as the treatment that cannot accomplish the intended physiologic goal. They agreed that futility is a complex concept associated with the accomplishment of goals. An act is considered futile if its goals are not achievable or its degree of success is empirically implausible (Kon et al., 2016). Providing aggressive therapy in the intensive care unit that is not beneficial to the patient is considered to be futile care. The provision of treatment perceived to be futile is a major problem in the intensive care units leading to burdens for patients and families as well as health care providers (Anstey, Adams & McGlynn, 2015). . In this study the concept of futile

care will be defined as the provision of medical care that does not meet the physiological goals of treatment and therefore does not benefit the patient as defined by Armstrong (2014).

In a USA study, 'Nurses perception of futile medical care,' the common factors identified while describing cases perceived as futile were comorbidities, poor quality of life, bleak prognosis, pain and suffering, brain death and prolonged stay in the ICU (Sibbald, 2007). Furthermore, the reasons that were given for why care was considered futile included patients in the dying process, patient had no meaningful quality of life, use of considerable resources to no benefit as well as pain and suffering. The participants suggested strategies to avoid or limit futile care in the ICU which were education of the nurses, early discussion of resuscitation status with families and assistance of clinical ethicists (Sibbald, 2007).

A study done in Iran indicated that nurses regarded futile care as ineffective care, aimless care, waste of time and money, patients suffering as well as tormenting to the nurses. The nurses reported that patients suffering during invasive procedures was also painful for them. In addition, the interventions that they considered futile included futile medical orders, futile diagnostic procedures and futile admissions to the ICU (Yekefallah, 2015).

Feelings of emotional exhaustion leading to burnout among critical care nursing staff are greatly influenced by the frequency with which nurses are involved in life-sustaining interventions that conflict with the nurses' values and standards in terms of what the nurses think are ethically appropriate (Meltzer & Huckabay, 2004). Furthermore, experiencing feelings of emotional exhaustion can lead to staff conflicts, absenteeism, lowered morale, and decreased productivity, ultimately culminating in burnout and compromising patients' care (Meltzer & Huckabay, 2004).

There is need to carry out a study in Kenyatta national hospital to explore the experiences and perceptions of futile care among critical care nurses. KNH is a public hospital in the

developing world meaning it has different institutional values, infrastructure, policies and protocols of admitting patients to the ICU, different staff culture, and institutionalized protocols of intensive care.

1.2 PROBLEM STATEMENT

Futility of care is a common occurrence in the critical care units (Piers, 2011). Medical technology has helped physicians to prolong the lives of many terminally ill patients without having any hope of successful treatment (Aghabarary & Nayeri, 2016). In the ICU in KNH, statistics from the health information department shows that severe head injury patients occupy approximately 60% of the beds with a mortality rate of about 45%. Provision of futile care occurs whereby patients with severe head injury including brain stem involvement still receive the intensive therapy including mechanical ventilation, routine radiographic tests and unwarranted laboratory tests. These patients continue to receive the aggressive medical therapy offered in the ICU despite the bleak prognosis. A patient with motor neural disease can stay in the ICU for over 200 days with no hope of ending the dependence on the ventilator.

Nurses may regard futile care as useless, time wasting, costly, tormenting both to the patient, family as well as the nurse (Yekefallah, 2015). Anecdotal evidence suggests that nurses working in the ICU in KNH often feel demoralized and frustrated when providing intensive care to patients who have nil chances of survival. There are many patients in the wards who require intensive care but due to lack of beds in the ICU, they end up dying in the wards while awaiting ICU beds. It is therefore necessary to carry out this study to explore the experiences and perceptions of futility of care among nurses working in the ICU at KNH since they are the people most often in contact with the patients.

The nurses reported that patients suffering during invasive procedures was also painful for them. In addition the interventions that they considered futile included futile medical orders, futile diagnostic procedures and futile admissions to the ICU(Yekefallah, 2015).

This study will give an insight into how nurses perceive the concept of futile care in the critical care unit and the findings may be a useful step for designing effective care protocols in the intensive care unit and offer full support to the nurses in terms of counselling and educational programs.

1.3 STUDY JUSTIFICATION/ SIGNIFICANCE

The intensive care unit is an important part of the health care system that provides resource intensive and specialized medical and nursing care to the critically ill patients with the hope of recovery. It also offers a pathway for close monitoring and support of organs to sustain life during instances of life threatening organ system dysfunction. Critical care resources are not only limited but are also expensive therefore appropriate utilization of ICU resources is essential.

Studies done in the USA, Europe and the Middle East show negative experiences and perceptions on provision of futile care. Besides there are no studies on nurses perceptions of futile care in Africa. Anecdotal reports in KNH demonstrate discouraging experiences and perceptions. KNH was the first public hospital to establish an ICU in Kenya and has the largest ICU with a bed capacity of 21 ant a total of 108 qualified nurses. It is therefore important to get first-hand information on experiences and perceptions on futility of care from those caring for the patients twenty four hours a day, optimally the nurses.

Futility of care in the intensive care unit has not been studied in Kenyatta National Hospital yet it occurs. Patients with irreversible illnesses continue to receive aggressive therapy

offered in the unit. Nurses are involved with the provision of futile care in the ICU in KNH, their perceptions and experiences should therefore be studied.

This study will provide an insight into how nurses perceive the futile interventions they administer to patients who they perceive to have very poor prognoses and how this affects their wellbeing. Nurses spend most time with patients at the end of life than any other health care provider in the hospital, yet there is limited empirical evidence regarding their experiences and perceptions on futility of care. . The findings of this study will contribute to the existing body of knowledge on nurses' perception futile care of knowledge on the perceptions and experiences of futile care in the ICU. The findings may also be used to inform policy on admission and discharge of patients in ICU.

1.4 STUDY BENEFITS

It is anticipated that the findings of this study will enhance the understanding of the meaning of the concept of futile care from the perspective of the critical care nurses. The ICU stakeholders may use these findings to guide institutional policy formulation regarding decision making on care modalities at the end of life in the ICU.

The findings may also be used to design supportive measures to the critical care nurses like trainings and counselling.

1.5 STUDY OBJECTIVES

1.5.1 Broad objective

To explore the nurses' experiences and perceptions on providing futile care to patients admitted to critical care unit at Kenyatta National Hospital.

1.5.2 Specific objectives

1. To determine the understanding of futile care among critical care nurses at KNH.

2. To establish the type of interventions considered as futile by the critical care nurses in KNH ICU.
3. To determine the effects of providing futile care on the critical care nurses at KNH.

1.6 RESEARCH QUESTIONS

1. What do critical care nurses in KNH ICU understand about futile care?
2. What interventions do critical care nurses consider as futile?
3. Does providing futile care affect the critical care nurses in any way?

1.7 THEORETICAL FRAMEWORK

Phenomenology

This study applied the theoretical framework of phenomenology by Edmund Husserl. This is a broad discipline and a method of inquiry in philosophy based on the principle that realism consists of objects and events as they are perceived or understood in the human perception. It studies the structures of conscious experiences as experienced from a first person point of view as well as how we experience those events. It also focuses on the perception of the world by human beings or the perception of how things appear and is often defined in terms of the study of phenomena as they are experienced. As a methodology, the researcher collects data, analyses them and reports on their findings while following a series of steps. The findings are therefore a collection of descriptions of meanings for individuals of their lived experiences (Sloan and Bowe, 2014).

Basically, phenomenology studies the structure of various types of experience ranging from perception, thought, memory, imagination, emotion, desire, and volition to bodily awareness, embodied action, and social activity, including linguistic activity. The structure of these forms of experience typically involves what Husserl called “intentionality”, that is, the directedness of experience toward things in the world, the property of consciousness that it is

a consciousness of or about something. According to classical Husserlian phenomenology, our experience is directed towards things only through particular concepts, thoughts, ideas and images. These make up the meaning or content of a given experience, and are distinct from the things they present or mean (Sloan, Bowe and Bowe, 2014). Futility of care is a complex concept associated with accomplishment of goal (Wilkinson & Savulescu, 2011). In the Webster dictionary futile is defined as serving no useful purpose and completely ineffective. the definition is relative to the goals of each stakeholder, the patient prognosis, the burden to benefit ratio perceived by each stakeholder (patient, family, physician, hospital), and the limits of medical technology, clarity among involved parties is paramount since what is considered futile is relative (Armstrong, Poku & Burkle, 2014). This implies that futility of care in the ICU will have different meanings to the nurses and they may also have varied experiences. Use of phenomenology as a theoretical framework enables the researcher to explore the different experiences and perceptions of medical futility.

The concept of medical futility has been criticized in the medical realm with some critics calling it an empty, indefinable and useless concept while others think it is only the patient and/or his family who should decide what is futile. Others believe that only the physician can determine futility (Pope, 2010). It was therefore appropriate to use phenomenological approach to elicit the meaning of medical futility from the nurses' perspectives through exploring their perceptions and experiences.

In this study the researcher explored the nurses' experiences and perceptions of providing futile care by asking them to describe and give an account of how providing futile care was. Each participant defined futile care as he understood it in her own words and what his or her experiences were with regards to provision of futile care.

CHAPTER TWO: LITERATURE REVIEW

2.1 INTRODUCTION

Literature search was done to provide an overview of theories, ideas and other significant literature currently published on the topic. Literature review is important because it enables the researcher to learn from previous theories, show where the study fits into the existing body of knowledge, illustrate how the topic has been studied and also to provide context to the research.

2.2 SEARCH STRATEGY

Literature review was done using data bases such as PubMed, Google Scholar and Hinari. The key search words were futile care, medical futility, futility of care in the ICU, perception of futile care. The search focused on studies that were done between 2005 and 2018. Search was done on studies published in the English language only. Sixteen articles were found but only 11 were included in the literature review because they were more relevant in relation to the study objectives. These studies had been carried out mostly in the USA, Europe and the Middle East. There were no studies on futility of care that had been carried out in Africa. The following themes were created from the reviewed articles: concept of medical futility, understanding and perception of futile care, futile care experiences and types of futile care.

2.3 CONCEPT OF MEDICAL FUTILITY

Futility of care is a complex concept associated with accomplishment of goal (Wilkinson & Savulescu, 2011). In the Webster dictionary futile is defined as serving no useful purpose and completely ineffective. Futility in medicine is an ancient concept and Hippocrates stated that physicians should “refuse to treat those who are overmastered by their illness” because in such cases medicine is considered powerless (Kasman, 2004). Technological advancement and innovations have reshaped the treatment preferences and decisions surrounding end of

life care such that it is now possible to prolong the life of a patient rather than allowing the natural process of dying.

In an article 'When medical intervention is futile and who decides', Bagheri (2014) argued that medical futility is an acknowledgement of human mortality, an inescapable clinical reality that is vague in definition and a clinically unpleasant connotation while Kasman (2014) suggests that medical futility occurs when there is absolute certainty that any action geared towards a goal, an action, or an activity will fail in achieving this goal. However, it is not possible to be certain that an action will fail to achieve the goals therefore there should be a clear cut difference between resource intensive management and provision of palliative care for comfort, pain control, respect for dignity and reassurance from the medical team (Kasman, 2004).

The determination of medical futility can only be made within the context of the individual clinical situation. For instance, it would be considered a futile act to perform cardiopulmonary resuscitation to a patient with multiple organ, and CPR may be withheld on these grounds because the probability of full recovery is nil, however, resuscitating a patient with chances of survival that are small, but existent, would not be considered to be futility of care (Lilia et al.,2004).

There is controversy on whether heroic treatments in cases such as the first example are to be viewed as prolongation of life or prolongation of dying. This issue has no easy or correct answer. Lilia(2004) defined futile care as life-sustaining interventions and treatments that have no medical benefit for a patient because the interventions and treatments cannot end dependence on intensive medical care (Meltzer and Huckabay, 2004a).

In the clinical setting, interventions that are labelled as medically futile refer to the unfortunate situation in which continued therapy will not benefit the patient and, therefore,

should not be used. Expanding this definition is difficult, particularly when applied to complex patient situations. Some classifications use the term strictly to refer only to the absence of physiologic effects and situation rarely encountered in clinical medicine (Armstrong, Poku & Burkle, 2014). Interventions can have some physiologic action but do not achieve the patient's goals. Individual goals, inaccurate statements regarding prognosis, or a miscalculation of the burden to benefit ratio can cause nearly any therapy to seem futile in the loose sense. Because the definition is relative to the goals of each stakeholder, the patient prognosis, the burden to benefit ratio perceived by each stakeholder (patient, family, physician, hospital), and the limits of medical technology, clarity among involved parties is paramount since what is considered futile is relative (Armstrong, Poku & Burkle, 2014).

Health care providers should however be careful so as not to abuse the concept of futility. Some proponents believe that it's not the care that is futile but some medical interventions that are considered futile. Pain relief, comfort, relief from suffering as well as attention to personal needs are all mandatory until the time of death (Ba et al, 1997).

Apparently the concept of medical futility has been criticized in the medical realm with some critics calling it an empty, indefinable and useless concept while others think it is only the patient and/or his family who should decide what is futile. Others believe that only the physician can determine futility (Pope, 2010).

Swetz et al., (2014) argue that the term medical futility is often invoked when an otherwise curative or disease-averting intervention is geared towards a seriously ill patient has a low chance of recovery. He further notes that medical writers, clinicians and ethicists have realized that the definitions of medical futility can be confusing, inconsistent and controversial but is often slanted to reflect the definers' point of view.

The reasons for providing futile care are varied. Willmott et al (2016) stated that issues of communication among patients and their families is a driver of futile treatment because of avoidance and discomfort with a conversation related to dying. The doctors said it often took several conversations to reach an agreement on withdrawing futile treatment from dying patients and that they were comfortable providing futile treatment for a limited duration to allow this to occur.

2.4 NURSES UNDERSTANDING AND PERCEPTION OF FUTILE CARE

Deciding on the futility of a certain treatment is among the most sensitive health care issues that can result in making the most unethical decision mainly because futile treatment is widely used in clinical reasoning as a strong reason for avoiding treatment of a patient. Doctors and nurses working in the critical care unit frequently perceive that patients under their care sometimes receive non beneficial treatment and in most cases these health care providers feel powerless to change the situation. However doctors are more likely than nurses to perceive care as futile (Anstey, Adams and McGlynn, 2015). Nurses working in the critical care unit often encounter a great deal of pain and suffering as they journey with patients through days and weeks of life support and treatment they perceive as non-beneficial/ futile to these patients (Meltzer & Huckabay, 2004).

ICU care providers throughout Europe more or less agreed on the main issues of what inappropriate care are. Nurses, junior and senior physicians indicated that a mismatch between level of care and prognosis was the most common cause of inappropriate care in the ICU. Furthermore, it was remarkable that factors inside the ICU were the most important reasons for perceived disproportion which was more often ascribed to prognostic uncertainty (Piers et al, 2014).

Understanding and perception of futile care varies among health care providers and a study done in Iran showed that nurses' definition of futile care may depend on the patient's condition and the personal perspectives of the nurses rooted in one's emotions, personal beliefs and cultural values (Rostami et al, 2016). Nurses may perceive futile care as useless and ineffective, care associated with waste of resources and torment of patients as well as the nurses themselves (Rostami et al, 2016). In another study nurses believed that futile care is aimless and least effective in improving the health of the patient since care that is effective should meet the patient's physical, mental, emotional, social and spiritual needs Yekfallah et al, (2015).

Several factors are associated with nurses' perception of futile care such as the feeling that the intensive care unit is not the appropriate setting for some particular patients. They acknowledge that the amount of care provided is disproportionate to the patient's expected prognosis or wishes. In addition there is fear of litigation and when there is prognostic uncertainty (Anstey, Adams and McGlynn, 2015).

A study done in Iran reported that mechanical ventilation and intubation, comorbidities hence poor quality of life, poor prognosis, suffering and pain, brain death and prolonged ICU stay as the common factors associated with futility (Sibbald, 2007).

In some cases nurses feel that they are just extending a painful life and describe the patient as really suffering (Sibbald, 2007). Therefore, nurses are more likely to perceive care as non-beneficial because they have been found to have the least decision making power in the ICU, they spend most of the time at the bedside and also have the greatest emotional involvement with the suffering patient Piers et al, (2011).

2.5 FUTILE INTERVENTIONS

When determining if intensive care interventions are appropriate for a particular patient, Kon et al (2016) suggested that health care providers should evaluate the prognosis in regard to possible survival without ICU care, and the recovery of cognitive ability of the patient, adequate enough to perceive the benefits of the treatment. However they argued that this can prove to be difficult and suggested objective scoring systems which can be used in some specific disease or injury states.

Futile care can be categorized as futile admission, futile diagnostic procedures, futile medical orders, futile nursing interventions as well as irrelevant duties for nurses (Yekefallah et al., 2015). In the acute care settings specific interventions that can be considered futile are the following actions when performed on terminally ill patients with bleak prognosis and probability of survival has been declared zero by the clinicians. These include resuscitation attempts, dialysis, radiotherapy, transfusion, life support. Others include non-beneficial medication use, like the use of cardiovascular and endocrine drugs at the end of life Kim et. al. (2016).

A review article of futility studies came up with several examples of treatment that are considered futile (Aghabarary and Nayeri, 2016). These include use of antibiotics for viral infections, treatment not effective in reversing physiologic deterioration, terminal medical diagnosis. For example, defibrillation on asystole, sustaining life of a terminally ill patient using mechanical ventilation and vasopressor support (Aghabarary and Nayeri, 2016).

2.6 MANAGING MEDICAL FUTILITY

Many institutions world over have unilateral DNR policies which allow clinicians to withhold CPR in the event of cardiopulmonary arrest against the wishes of patients and surrogates. Some of these policies allow unilateral DNR orders before the arrest occurs with the involvement of an interdisciplinary ethics consultation team. It has been found that

hospitals and critical care societies have expressed a growing interest in these policies as a mechanism for protecting the critically ill patients on an irreversible trajectory from unnecessary harm (Courtwright et al, 2015).

Ba et al, (1997) agrees an understanding between judges and doctors would ensure the evolution of a sensitive and sensible legal framework in the interest of the patient for their treatment and care. Juki et al (2016) states that end-of life conflicts often arise from inadequate communication among stakeholders and therefore the most effective resolutions aim to improve communication, clarify values and align goals, values and prognosis. In the study it was also noted that open and clear communication at the end of life may be difficult and health practitioners often lack the training for these types of discussions.

Jukic (2016) states that TADA (Texas advanced directive agreement) legally permits physicians to refuse life-sustaining treatment without consent, for whatever reason, as long as an institutional committee agrees. A hospital must give the surrogate forty-eight hours' notice before the institutional committee meeting occurs. If the committee agrees with the attending physician that life-sustaining treatment is inappropriate, the hospital must give the surrogate ten days after the meeting to find a facility that will provide the treatment desired. If the clinician follows these procedures, the statute provides civil, criminal, and disciplinary immunity to providers who stop life-sustaining treatment on the eleventh day. TADA offers a clear, unambiguous legal safe harbour. Physicians in most U.S. jurisdictions are afraid to refuse surrogate-requested treatment that they deem inappropriate or even cruel. In contrast, TADA has proven effective at allowing physicians to avoid providing such treatment (Juki 2016).

(Bosslet et al, 2015) suggests that when responding to requests for futile interventions, clinicians should seek to understand the reasons for such requests, empathically correct

misperceptions, provide emotional support, and explain why the requested interventions may not be provided. If disagreement persists, clinicians should obtain expert consultation to assist with the conflict resolution. Clinicians should consider seeking expert consultation to provide intensive psychosocial support to the surrogates. Clinicians should not be required to administer futile interventions during the time period in which communication consultants are being involved.

According to Malone (2014), the creation of a medical futility policy on the part of a health care institution is only as good as it is enforceable, and implementation should be a two-step process which must occur simultaneously. The initial part requires a large-scale effort on the part of the institution to make sure that the policy is well publicized, understood, accepted by its stakeholders which include the people utilizing that institution's services, and its employees. Besides, there must be a recognition on the part of the institution that adopting a medical futility policy may leave the institution vulnerable to litigation.

Malone also highlights that there are ethical issues to address specifically with regard to respect for patient autonomy that needs to be reconciled with a physician's duty of beneficence and non-maleficence, as well as professional standards and integrity. There are also legal implications. Hospitals and other health care institutions are encouraged to adopt a medical futility policy, but also accept that the application of such a policy may expose them to the threat of litigation should family members disagree with physicians' and/or ethics committees' decisions (Malone, 2014).

2.7 EFFECTS OF PERCEPTION OF FUTILE CARE AMONG NURSE

In a USA study, Meltzer et al (2004) concluded that sustained exposure to clinical situations in which conflicts arise about treatment goals for critically ill patients may lead nurses to act contrary to their values leading to moral distress and generalized stress which may in turn

lead to emotional and spiritual exhaustion. Some of the occupational sources of stress that may cause burn out in nurses working in ICU are conflict amongst themselves and with the administration, inadequate resources and poor staffing, huge workload, emotional demands of patients and patients' families, ethical dilemmas regarding use of life-sustaining technology and exposure to death and dying. Nurses working in critical care units are faced with complex ethical issues as compared to nurses in other acute care settings. Working in such emotionally charged environments where life and death issues are encountered on a daily basis could be extremely stressful and could contribute to the experience of moral distress.

Moral distress results when a person perceives that institutional constraints prevent the right course of action to be followed. It is a stress response experienced when ethical challenges of critical care are faced by nurses, such as withholding chest compressions or intubation while giving pharmacological treatment during a cardiac arrest (Meltzer and Huckabay, 2004). Nurses have now and again identified issues related to futile treatment as among the most stressful aspects of critical care. Disagreement over following advance directives of dying patients, actions that prolonged the suffering of patients, and physicians who avoided discussions with the family members were among the most common obstacles to good end-of-life care identified. Among family-related factors, nurses identified the most common obstacles to good end of life care as lack of understanding about care, not accepting poor prognoses and overriding patients' advance directives (Beckstrand, Kirchhoff and Brigham, 2005).

A study in Iran showed that ICU nurses experience a high level of moral distress, which has a positive correlation with ICU work experience as well as perception of futile care. Moral distress may lead to low levels of collaboration with the other health care providers, exhaustion as well as burnout (Asayesh et al, 2018). Some authors suggest that palliative care should be part of the ICU management to provide relief from pain and other symptoms,

provide spiritual and psychosocial support related to end of life and bereavement as an established a care philosophy (Mitchell, 2016). Palliative care aims at offering family support while reducing stressful symptoms, establishing clear and sensitive communication and aligning treatment with patient preferences.

2.8 NURSES COPING STRATEGIES

Nurses working in high-stress areas such as critical care, paediatrics, and oncology report high levels of burnout which includes emotional exhaustion, depersonalization, and reduced personal accomplishment. This emotional exhaustion has the greatest validity as a predictor of burnout. Burnout is associated with adverse health outcomes, increased turnover of nurses, and decreased patient satisfaction (Ettings et al, 2015).

Factors that contribute to burnout include stressors associated with physical and psychological sources, emotional and spiritual demands creating the perception of excessive workload, and moral distress.

Resilience can help individuals prevent moral distress and burnout, it is the ability to adapt coping strategies to minimise distress. It involves activities such as art, play and physical exercise, developing problem-solving skills or engaging in work and prayer. There is no empirical evidence that internal resilience by critical care nurses decrease the psychological well-being of these nurses. Coping behaviours can be categorized into 2 broad groups, effective and ineffective behaviours (Hour, 2017).

2.9 SUMMARY OF LITERATURE REVIEW

Futility of care has no universal definition and its definition depends on several factors and situations. There are several situations where nurses feel that the care they are giving their patients is futile, for instance when the level of care does not match the patient's prognosis and when they feel that other patients would benefit more from ICU services. Nurses often experience moral distress when faced with ethical dilemmas surrounding medical futility and

it has been found out that various coping mechanisms are employed to mitigate these feelings of distress. Futile interventions in the ICU are varied and include routine examinations and tests, CPR, mechanical ventilation, dialysis, surgeries, inotropic support all when performed on patients whose prognoses are poor and will not benefit physiologically from such interventions.

There is need to carry out research on futility of care in the critical care in Kenya being a third world country with different challenges from those experienced in the critical care units in the developed world.

CHAPTER THREE: METHODOLOGY

3.1 INTRODUCTION

This chapter discusses the study methodology as follows: the choice of study design, study site and target population, sampling and recruitment process, inclusion and exclusion criteria, the research instrument and data collection procedure, ethical considerations of the study, data management, analysis and strategies to ensure rigor of the study. Finally it gives an account of dissemination plans of the study results and the study limitations.

3.2 STUDY DESIGN

The researcher utilized the descriptive qualitative approach to explore the experiences and perceptions of providing futile care to patients in the critical care unit in KNH. Qualitative methodology is used when the research topic is poorly understood or unknown, or the boundaries of its context are ill-defined, the phenomenon under investigation is not quantifiable, or when the researcher suspects that the phenomenon needs to be re-examined or it's not clear (Klopper, 2008) .

Qualitative research designs are suitable for understanding views and perceptions and help to discover new thoughts and individual views. The approach is also used to extrapolate experiences, meanings and perspectives of the study participants (Hammarberg, Kirkman & Lacey, 2018). The goal of qualitative research is to produce a rich description and in depth understanding of the phenomenon of interest, the cultural or lived experience of people in their natural settings (Khan, 2014).

Qualitative method was appropriate for this study because individual perceptions are experiences are varied and in-depth individual interviews provided rich information regarding the nurses' experiences and perceptions of providing futile care to patients in admitted in ICU.

3.3 STUDY SITE

The study was conducted in the main ICU in KNH. This is the largest teaching, referral and research hospital in Kenya. It is situated in the capital city of Nairobi along hospital road in upper hill. It has a bed capacity of 1800 and receives patients from within and outside Nairobi, as well as from east and central Africa. KNH has one main critical care unit with a bed capacity of 21. It also has 5 other subsidiary ICUs namely NICU, PICU, medical ICU, neurological ICU and cardiology with an additional total bed capacity of 20.

The main ICU admits all patients who require intensive therapy except neonates who go to NICU. Traumatic brain injury constitutes approximately 60% of patients admitted to the main ICU. In addition, other conditions include multiple organ failure, severe sepsis, post cardiac surgical patients, obstetric emergencies, motor neural diseases. Overall mortality averages 35% mostly from traumatic brain injury.

3.4 TARGET POPULATION

The target population for this study were all the nurses working in the main ICU in KNH and those who were providing direct patient care at the time of data collection. There were a total of 108 nurses who worked in the unit.

3.5 SAMPLING TECHNIQUE

Descriptive qualitative approach can utilize any sampling method though it most often involves maximum variation technique so as to obtain a broad insight into the phenomenon being studied (Kahkle 2014). For this study, purposive sampling technique was used to identify study participants. Purposive sampling is a non-probability sampling technique whereby the sample is selected based on the characteristics of a population and the objectives of the study. The characteristics included the ages of the participants, gender, number of years of ICU experience and CCN specialization. The guidelines for sampling in qualitative research studies propose a sample size of between 7 to 50 participants (Gentles et al, 2015)

because the intention of qualitative research is not generalization but achieving saturation. The researcher introduced the study title, objectives and methodology to the ICU manager thereafter with her assistance, critical care nurses who met the inclusion criteria were identified from among the 108 nurses working in the critical care unit. . In this study saturation was achieved after interviewing 10 nurses. Therefore sampling ceased because there was no new data being generated.

3.6 ELIGIBILITY CRITERIA

3.6.1 Inclusion criteria

- All nurses who are on permanent and pensionable terms of employment and working in ICU at the time of the study.
- All qualified nurses who have worked in ICU for more than least years.
- All qualified nurses performing direct patient care in the ICU.

3.6.2. Exclusion criteria

- All nurses working in the ICU on locum basis at the time of the study.
- All student nurses on clinical placement in the ICU at the time of the study.
- All qualified nurses who have worked in ICU for less than two years.
- All qualified nurses on annual, maternity or study leave during the study period.
- Critical care nurses who did not voluntarily consent to participate in the study.

3.7 RECRUITMENT PROCESS

The intention to carry out this study was made known to the nurses verbally during the morning and afternoon shifts for a period of one month, between 2nd august 2013 to 29th august 2018. Study introduction was done to the identified nurses to enquire if they would be

willing to take part in the study. Thereafter, an agreement was made between the researcher and the willing participants about the most appropriate time for the interview considering that the ICU is a busy unit with very sick patients who require close monitoring. Their contacts were taken for the purposes of communication concerning the scheduled interview. However because of the iterative relationship between sample and data analysis, recruitment continued until there was data saturation (Zhang & Wildemuth, 2005).

The researcher reported to the unit each morning at 7.00 am during the weekdays for a period of one month from 2nd august 2018 to 29th august 2018. An average of 20 nurses report to work in the ICU each morning. On the first day, 2nd august 2018, three nurses were recruited but only one was interviewed on that day due to the busy nature of the unit. The interviews could only be done during lunch break and early afternoon. The remaining 2 nurses were scheduled for interviews on various dates when they would be on shift. Their contacts were taken and interview date and time scheduled at their convenience. The researcher continued the recruitment process every morning after the nurses' report until a total of 20 nurses were identified for possible interview. However, after conducting a total of ten interviews the researcher noted data saturation and the process was stopped.

3.8 ETHICAL CONSIDERATIONS

Ethical considerations in research refers to the protection of the study participants' rights, obtaining informed consent from the study participants and undergoing the institutional review process (Klopper, 2008). It is the responsibility of the researcher to design a project that will not infringe on the rights and safety of the study subjects for the purpose of advocating, promoting and protecting these rights (Akaranga & Makau, 2016).

3.8.1 Approval to carry out the study

Authorization to carry out the study was sought from the Kenyatta National Hospital/University of Nairobi Ethical and Research Committee (see appendix VII), from the KNH administration and from the KNH ICU nurse manager (see Appendix VIII).

3.8.2 Protection of the participants' rights

According to Klopper (2008), the participants' rights entail right receive explanation regarding the study, right to self-determination, right to autonomy and confidentiality, right to fair treatment and the right to protection from discomfort or harm. In this study the researcher clarified to the participants that participation was voluntary. No coercion or enticement was used to influence the individuals to agree to be part of the study. Participants were also informed that they could pull out from the study at any time without fear of repercussion.

To assure their privacy and confidentiality, all coded data were de-identified, sealed in envelopes and kept secure in locked file cabinets by the researcher. The consent forms were kept separate from digital recordings and notes during the interviews, transcription and analysis. The data was only accessed by the researcher. After transcription, coding and analysis, the researcher will store the recordings for an additional five years after which they will be destroyed.

Participation was voluntary and there was no compensation to the participants. This was well explained to the participants.

3.8.3 Informed consent

This is the process whereby the study participants are given an opportunity to understand relevant information about the study and to make voluntary choice. Informed consent respects a person's right to decide whether participating in the study are in line with their interests (Grady et al., 2017). A written consent form (see appendix I) was used to obtain

informed consent from the study participants. The purpose and benefits of the study was explained to the participants before they signed the consent so that they could make an informed decision to sign the consent form (see appendix I). Consent to record the interviews was also sought from the participants.

3.8.4 Institutional review process

The study protocol was submitted to KNH/UON ethical review board for review and approval so that consent and permission to access the study site could be obtained. This is the board that regulates the conduction of studies in Kenyatta National Hospital and University of Nairobi and protects the rights and safety of clinical research.

3.9 DATA COLLECTION TOOLS

In this study data was collected using interview guides and observation checklists.

3.9.1 Interview guide

The interview guide (see appendix III) was developed by the principal investigator. The questions were aligned to the research questions. The interview guide contained six main questions with thirteen prompts. The main questions required the nurses to describe what futile care was in their own words, the situations when they felt that they were providing futile care, the kind of interventions or treatment that they considered futile in such situations, any effect of providing futile care and the reasons why they think they provided futile care.

3.9.2 Observation Checklist

The observation checklist (see appendix IV) was also developed by the researcher and it entailed the observation of the situations where the nurses provided futile care to patients. It was observed that nurses continued to give aggressive interventions to patients who had brain death and whose prognosis was bleak. It included the patients diagnosis, length of stay, whether the patient was receiving the interventions considered futile like inotropic support,

dialysis, full support mechanical ventilation, radiological investigations, routine laboratory investigations or antibiotics.

3.9.3 Pretesting of data collection tool

Reliability of the interview guide was done by pretesting the interview guide on nurses in the medical ICU. The medical ICU was appropriate because it admits mainly patients with medical life threatening conditions while in the main ICU patients with all conditions, both surgical and medical, are admitted. Three nurses who consented to participate were interviewed in the medical ICU. A need to change the guide did not arise, therefore the researcher proceeded to the main ICU to collect data.

3.10 VALIDITY AND RELIABILITY

Validity in research is concerned with the accuracy and truthfulness of the research findings. A valid study demonstrates the actual existence of a phenomena while a valid instrument measures what it is supposed to measure (Paper, 1993). Reliability refers to the consistency and reproducibility of the informants' accounts and the investigators ability to collect reproduce this data. Paper (1993) defined reliability as the ability of the research methods to produce the same results consistently over time.

In the context of qualitative research several terms have been developed to establish reliability and validity such as credibility, transferability, dependability, authenticity, integrity, explicitness, vividness, creativity, thoroughness. Pandey (2014) suggests that the concepts of validity and reliability in qualitative research can be addressed by referring to credibility.

In conducting member checks, data and interpretations are continuously tested as they are derived from members of various audiences and groups from which the data was collected (Anney, 2014). This strategy involves testing all the data to ensure there is no internal

conflict or inconsistencies. It also entails testing the analysis and interpretation against the documents that were used during data collection (Anney, 2014).

Data triangulation refers to the use of two or more data sources, investigators, theoretical perspectives in the study of a single phenomenon then validating the congruence among them (Paper 1993). The validity of this study was ensured by applying the techniques of data triangulation, audit trails, member checking and peer debriefing. Member checking strategy was used to enhance the credibility of the data whereby the analyzed and interpreted data was sent back to the participants for them to evaluate the interpretation made by the researcher. This enabled them to evaluate the interpretation made.

In this study both interview guides and an observation checklists were used by the researcher to collect data. Peer referencing and audit trials were also done by sharing and discussing the recorded interviews and the verbatim transcription with the academic research supervisors throughout the research process.

3.11 DATA COLLECTION PROCESS

Interviews were conducted by the principal investigator during the time that was convenient to **the** participants. Data collection lasted for a period of one month between 2nd august 2018 to 29th august 2018. The interviews were conducted in a room within the ICU. The interviews were conducted face to face. Interviews are effective in eliciting narrative data that enables the researcher to investigate people's views in greater depth and is considered a valuable method for exploring the construction of meanings in natural settings (Alshenqeeti, 2014). Interviewing allows the study participants to speak in their own voices and express their feelings as well as thoughts (Alshenqeeti, 2014). After consenting, the participants were interviewed for approximately 30-40 minutes and this provided them with an opportunity to build rapport and tell their stories. Follow up questions were used to probe the participants

further. To guarantee correctness of the information, the interview were audio recorded. Each participant was interviewed once.

After building rapport, obtaining consent, the participants were invited to share their experiences regarding the phenomenon under study. The interviews were carried out in a location that was convenient to the participants. The main factor in this selection was access, convenience, value system, privacy and freedom from distraction. The interview duration varied according to individuals, but each interview lasted between 30-40 minutes. Each participant was assigned an identity to avoid identification of the participants. Each interview was recorded and transcribed verbatim to ensure accuracy in data collection. Any personal identifying information on the recording was de-identified during transcription to ensure participant confidentiality. In addition, the researcher wrote expanded notes as soon as the interview is done and transcription was done as soon as possible after each interview.

Participant observation was carried out whereby the researcher observed the nurses administering futile interventions to patients who had suffered brain death. The researcher took part in the care of ICU patients and observed the type of interventions given to patients who had suffered brain death.

3.12 DATA MANAGEMENT AND ANALYSIS

Recording of the interviews was done with two different digital recorders to prevent inadvertent data loss due to malfunctioning equipment. The transcribed data was kept in a safe place only accessible to the researcher. As an analytic strategy content analysis of data was done inductively through line by line manual coding process (see Appendix VI). Content analysis is a method used to classify written or oral data into identified themes with similar meanings. It is frequently employed to answer questions like why, when and how and the common patterns within the data are searched for by applying the use of a consistent set of

codes so as to arrange the text with similar content (Cho and Lee, 2014). The researcher read through the transcripts thoroughly then underlined words that appeared commonly under each research question. These words were then coded. The codes were grouped into themes and sub themes for the final write up.

3.13 DISSEMINATION PLAN

The results of the study will be presented to the critical care nurses through workshops that will be conducted in the unit. Copies of the study findings will also be given to the Ethics and Research department as well as Kenyatta National Hospital. The study will be published in a journal and will also be presented in conferences.

3.12 STUDY LIMITATIONS

Purposive sampling technique is a non-probability sampling method based on the researcher's judgement and therefore is vulnerable to judgmental errors. The researcher therefore sought the assistance of the unit manager to assist in identifying nurses who had worked in the unit for longer periods, with different qualifications and those who could give adequate information regarding the phenomenon under study.

CHAPTER FOUR: STUDY FINDINGS

4.1 INTRODUCTION

The study sought to evaluate the experiences and perceptions of providing futile care to patients at Kenyatta National Hospital intensive care unit. The objectives of the study was to determine the critical care nurses understanding of futile care, to identify the type of interventions that nurses consider as futile and to determine whether providing futile care affects the nurses in any way. In this chapter, the researcher therefore presents the findings of the study based on the objectives. Characteristics of the study participants are also included. The research findings from the interviews and observation checklists are represented by three themes and six subthemes.

4.2 CHARACTERISTICS OF PARTICIPANTS

A total of 10 critical care nurses working in the main ICU were interviewed individually. A demographic profile of the nurses was gathered regarding their age, gender, years of experience and CCN training as illustrated in table 4.1. There were 4 male participants and 6 females. Their ages at the time of the interview ranged from 34-44 years with a mean age of 38.9. Majority were in their thirties. All the participants had worked in the ICU for a minimum of 3 years, while majority had worked in the unit for more than 6 years. Majority had critical care training, only one was not a critical care trained nurse as indicated on the table.

Table 4.1: characteristics of the nurses

Participant No.	Gender	Age	Years of experience	CCN training
P1.	Male	38	3-5	Yes
P2.	Female	39	6-10	Yes
P3.	Female	41	6-10	Yes
P4.	Female	44	6-10	No
P5.	Male	40	6-10	Yes
P6.	Female	38	>10	Yes
P7.	Female	34	6-10	Yes
P8.	Female	38	6-10	Yes
P9.	Male	40	>10	Yes
P10.	Male	37	3-5	Yes

4.3 OVERVIEW OF THEMES AND SUBTHEMES

The data was analyzed using content analysis method and from the analysis nurses perceptions and experiences were categorized into three themes and six subthemes as illustrated in figure

4.1. The three themes are related to each other.

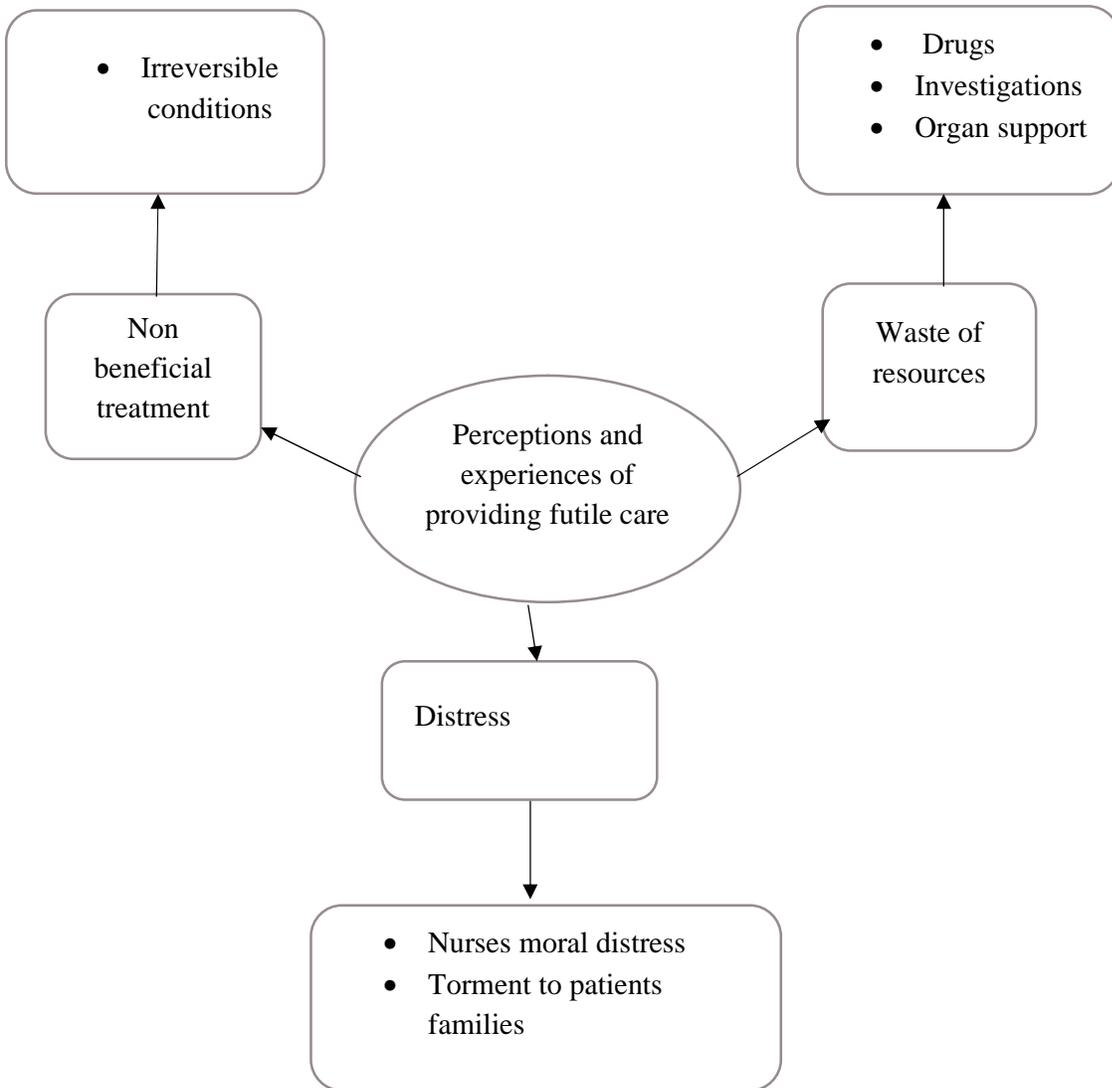


Figure 4.1 summary of themes and subthemes of the research findings

4.4 THEME 1: NON BENEFICIAL TREATMENT

This section describes the first overarching theme of ‘*non-beneficial treatment*’. During the interviews it emerged that the nurses perceived that the treatment some patients received was not useful to them. One subtheme emerged from the data, ‘*irreversible conditions*’, as a cause of this perception.

The nurses felt that care they provided had no benefit because it did not help to improve the patient's outcome. Some referred to it as interventions that are not significant or fruitful to the patient. Still others termed it as care that does not yield anything. Another nurse referred to it as medical treatment that is not beneficial to the patient in relation to the patient's condition.

P6: "futility of care is that care which you are not, which you are not supposed to give to the patient because there is documented data that if you give that care to the patient, the patient is not going to benefit from that care so there will be no further improvement on the patient's condition."

4.4.1 Irreversible conditions

The nurses considered certain interventions as not beneficial when the patient's condition had deteriorated so much so that these aggressive therapies were no longer useful to the patient. The conditions that the nurses regarded as irreversible included brain stem death, terminal multisystem organ failure and advanced malignancies. They said that sometimes patients who have gone into brain death continued with aggressive treatment because of varied reasons. They also said that occasionally patients who do not deserve ICU admission get admitted into the unit. According to the nurses such patients deserved only comfort care since the aggression in treatment would not yield any fruits and amounted to wastage of resources.

P8: "like patients who have already had brain death they still come here. They still come or at times, the patient comes with severe head injury and deteriorates to brain death."

The nurses said that in some cases patients with stage 4 cancer are admitted for reasons best known to the patient's doctor or because of outside influence. They said that sometimes they receive patients with advanced cancers who actually do not qualify for ICU admission yet they have to admit and provide the aggressive therapy usually offered in the ICU.

P2: *“there was a patient who was admitted here with cancer, eventually we knew this patient was not going to make...later on it was like we are in metastatic stage, stage four, so we were more of palliative”*

P2 indicated that it was only later that they were informed that the patient had stage four cancer. It was not clear why the cancer was not staged at the time of ICU admission. However P5 indicated that some patients with known advanced cancers were also admitted for other reasons.

P5: *“let’s say like someone with cancer of the colon stage four, they come here may be because of influence. They come here for ventilation for as long as they will be there...sometimes it is the doctor who wants to please the relatives. So the doctor takes the patient to theatre knowing very well the cancer is inoperable, the patient from theatre comes to the ICU for palliative care till he dies.”*

These indicated that having cancer of whatever stage was still an indicator for ICU admission.

4.5 THEME 2: WASTE OF RESOURCES

This section describes the second overarching theme namely ‘*wastage of resources*’, from the perspective of the nurses. During the interviews it emerged that provision of futile care to particular patients lead to wastage of resources. The resources which were considered as wasted did not only include staff, time and family resources but also wastage of drugs, investigations and resources utilized for organ support. They stated that sometimes when they provide the treatment that they feel will not benefit the patient in relation to the patient’s condition, they felt their energy was being wasted, that the patient’s family was incurring unnecessary cost and that the ICU resources could have been used on a more viable patient.

P6: *“yes sometimes it is late and they have incurred a lot of expenses and we have wasted that bed for a patient who would have benefitted”*

P7: *“but we also feel like there is nothing much we are doing, much as you are intervening you are not going anywhere. You are just giving the services but it is not adding value to the patient.”*

Under this theme emerged three sub themes namely ‘*drugs, investigation and organ support*’

The ICU resources that were considered as futile when used on patients with irreversible conditions were drugs, investigations and organ support mechanisms. The nurses said that offering these interventions resulted in wastage of resources because the interventions were not beneficial to the patient and bore no fruit.

4.5.1 Waste of drugs

Some nurses felt that sometimes they administered some medicines that they thought would not benefit the patient. Some said that sometimes they administered expensive antibiotics to patients with brain death and this was not going to add value to the patient.

P7: *“the antibiotic will not add value yes but since it is prescribed we don’t stop”*

P8: *“the patient was not responding at all but was still on fully supported mechanical ventilation, with antibiotics, inotropes you see... yes giving antibiotics must continue despite the fact that our braindead patient will not benefit. As a nurse, maybe I don’t know but I think things like that are not beneficial to the patient but we have to do them.”*

4.5.2 Wasted investigations

The nurses said that sometimes unnecessary investigations are carried out on patients with brain stem death or multiple organ failure with poor prognosis. Others said that in some

instances routine blood investigations are carried out on such patients probably because there is no documented order to stop.

P6: “something like a CT scan, the patient does not need because one thing it is very expensive.”

4.5.3 Wasted organ support

The nurse explained that in some cases they take patients for dialysis when ideally the patient does not need such kind of aggressive organ support because the patient will not benefit from such. Another one said that in cases of brain death hemodynamic support did not achieve anything.

P4: “sometimes we have patients with multisystem organ failure and they are terminally ill yet we take them for dialysis”

P6: “you keep mechanically ventilating the patient for even one year and you know very well there is no outcome on this patient, so the patient is just on machine incurring expenses, we are using even expensive drugs.”

P6 explained that in addition, the patients incurred more expenses due to the drugs they continually received over prolonged periods, even as long as one year.

It was evident from the data that some nurses felt that whatever form of treatment or intervention they offered to the patient while in their care was hopeless as it would bring no improvement in the patient’s condition, they also felt that this was not the best use of resources which would probably benefit another patient.

4.6 THEME 3: DISTRESS

The last overarching theme that emerged from the data was ‘*distress*’. When the nurses were asked they expressed that they felt some distress while providing what they regarded as futile

care. Some nurses also felt that patients' families also experienced some distress. These type of distresses identified were termed as '*nurses moral distress*' and '*torment to patients*' families which became subthemes. These were attributed to delayed documentation and treatment decision conflicts as discussed in the next two sections.

4.6.1 Nurses moral distress

The nurses made statements that showed that they were experiencing some degree of moral distress while offering treatment that they considered futile. Some nurses said at times they felt stressed, demoralized and frustrated when they were required to offer treatment and interventions that they felt were not beneficial to the patients. Some indicated that they had to give these kind of futile care because relatives wanted so. Or sometimes the doctor has not documented the minimal support order or still there was pressure from outside influence that required them to continue the aggressive therapy despite the patient's irreversible condition.

P2: "*sometimes it is depressing because eventually you know the outcome, yah, it is depressing... it is kind of also additional work to us and at the end of the day, it is like we are not providing the care that ideally should be provided in the ICU set up.*"

P4: "*like.....when...it is so stressful, as in you just feel for them, both the patient and the relatives*"

It was therefore evident that the nurses were experiencing some degree of moral distress because they felt that patients with irreversible conditions, as explained under *theme 1* would not benefit from futile interventions yet they (the nurses) were required to administer them. Circumstances that contributed to nurses' moral distress were delayed documentation and treatment decision conflict.

The expressed said that delay in the documentation of the orders to minimize support lead to the continued aggressive therapy and organ support when it was clear that the patient had suffered brain stem death. One said that the doctor may say verbally that the support should be put at minimum but he will not go ahead to document so it was not possible for the nurses to act on verbal orders for fear of litigation. The nurses then had to continue till the orders are documented.

R2: “they may indicate minimal support but they have not gone through the process and procedures, like counselling of the relatives and even making sure that it is well documented....they don’t follow that so they may talk of minimal support but in real sense they have not documented, you can’t implement.... So as the nurse you just continue until it is documented”

The nurses stated that in most cases there was no agreement between the patients’ relatives, family or surrogates and the ICU health care providers on the treatment modalities when treatment was considered futile by the latter. They stated that it was very rare to find the family agreeing to the medics’ suggestion that medical support be minimized in cases considered irreversible. This lead to the nurses having to continue offering interventions that they felt was not beneficial to the patient considering the patient’s condition.

R1: “Where we have talked to the relatives and they have agreed, which is almost one percent. Once the relatives are not comfortable we just continue.”

R4: “If the relatives want like that what is the reason as to why you don’t give the care.”

R6: *“the only thing we do is to try counsel the relatives, if they consent fine, if they don’t we go on full support and full management of the patient. Quite often they decline and we continue.*

The study established that in most cases provision of futile care depended on the patients’ relatives who in most cases did not readily accept minimization of support once their patient’s condition was declared irreversible. This resulted in moral distress among the nurses.

4.6.2 Torment to the patients families

Some nurses expressed that sometimes when they provided care that they felt that the care prolonged the patients suffering as well that of the patients’ families. They felt that the prolonged patient suffering caused pain and suffering to the family as well.

P4: *“yes at some points some of the events and some of the issues we prolong the life of this patient, yah, and the relatives...the relatives are also suffering coz they have to come to the hospital....so much exhausted and in pain... so long as I have seen we will just prolong life and the outcome is poor...so someone with brain hypoxia, brain death, why should I continue suffering. As in I come to the hospital daily, there is a bill that awaits me at the end of the day, this patient despite being in ICU he will not leave so why should the patient suffer.”*

This shows that the nurses acknowledged that the health care team in the ICU needed to make prompt decision to shorten patient and relatives’ pain and suffering once the patient’s condition was confirmed to be irreversible.

4.7 ANALYSIS OF THE OBSERVATION CHECKLISTS

The researcher also observed the diagnosis, treatment and care of patients who were considered to be receiving futile care for a period of one month. A total of seven patients were observed. Five of them had suffered severe traumatic brain injuries and had ended up in brain stem death. Of these only one had withdrawal of treatment implemented after confirmation of the brain stem death, that is, the ventilator settings had been set at minimum levels and the inotropic support withdrawn. The remaining four were on full organ support which included maximum ventilator support and inotropic drugs. They were also receiving antibiotics. This was because their relatives and significant others had not agreed with the health care team on minimizing organ support despite having undergone counselling. The ones on full organ support were still receiving inotropic support, routine radiological exams and routine blood tests. In addition there were no DNR orders placed for any of these patients with brain stem death.

Out of the seven patients, the remaining two had suffered eclampsia resulting in brain stem death. They were still on inotropic support, mechanical ventilation and antibiotics since the relatives had declined withdrawal of treatment even after counselling.

4.8 SUMMARY

In summary the nurses described futile care as non-beneficial treatment given to patients. They also confirmed provision of futile care in the ICU. This they related to the clinical situation of the patient. It was also a finding that provision of futile care was a cause moral distress among the nurses. They felt that certain interventions were aggressive for some conditions like brain stem death yet they still had to give them either because there were no proper guidelines or that the patients' relatives had not agreed with the health care team on

withdrawal of treatment. Some nurses felt that provision of futile care amounted to wastage of resources but others felt otherwise, that human life is very important.

Cases of brain stem death are frequent in the ICU and the protocols of withdrawal of treatment can only be implemented when the health care team have held conferences with the patients' relatives and the two parties are in agreement. If they fail to agree then the health care team has to continue providing the interventions even if they feel that they are doing it in futility.

CHAPTER FIVE: DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.1 INTRODUCTION

This chapter discusses the findings of the study. The study sought to determine the critical care nurses understanding of futile care, to establish the kind of interventions considered as futile by the critical care nurses and finally to determine if providing futile care affects these nurses in any way.

5.2 UNDERSTANDING OF FUTILE CARE

From the findings of the study it was established that some critical care nurses who participated in the study considered futile care as useless and non-beneficial to the patients in relation to their clinical situations. The nurses considered certain interventions and treatment as serving no purpose since the patients' conditions were physiologically irreversible. Armstrong et al described futile care as the unfortunate situation in which continued therapy will not benefit the patient. In this study the nurses view futility of care existed where the provision of certain interventions were considered as having no benefit to the patient.

Pope in 2016 in his article titled, "Nearly a model dispute resolution mechanism for intractable medical futility conflicts", stated that medical writers, clinicians and ethicists have realized that the definitions of medical futility can be confusing, inconsistent and controversial and is often stated to reflect the definer's point of view. Each and every nurse's definition of futile care in this study was his or her point of view and the use of individual interviews enabled the researcher to give each participant an opportunity to describe the concept of futile care as he understands. The nurses in this study perceived futile care as non-beneficial interventions in relation to the patient's condition.

In this study situations of futility according to the nurses were mostly related to the cases where there was brain stem death. This is comparable to Lilia et al in 2004 who found out that determination of medical futility can only be made within the context of the individual clinical situation. The study established that brain stem death was frequently mentioned by the critical care nurses as one clinical situation that led to the nurses feeling that aggressive therapy was not beneficial to the patient.

The nurses also felt that provision of futile care amounted to wastage of resources in terms of human resources, money as well as time. Rotsami et al in (2016) did a study in Iran and found that nurses perceived futile care as useless and ineffective care associated with waste of resources and torment of patients as well as the nurses themselves. Other nurses believed that futile care was aimless and least effective in improving the health of the patient.

Pope in (2010) realized that the concept of medical futility was an empty, indefinable and a useless concept. On the contrary critical care nurses interviewed in this study were able to define futile care as not beneficial treatment that did not help to improve the condition of the patient.

5.3 INTERVENTIONS CONSIDERED FUTILE BY THE CRITICAL CARE NURSES

In this study it was established that when brain death occurred the critical care nurses felt that some aggressive interventions were no longer beneficial to the patient. These interventions include dialysis, use of antibiotics, routine blood works, radiological investigations and hemodynamic support with inotropic drugs. This compares well with a study done by Kim (2016) in Canada where the interventions considered futile included resuscitation attempts, dialysis, radiotherapy as well as use of cardiovascular drugs at the end of life. Yekefella et al (2016) also did a study on futility of care in the ICU and categorized futile interventions as

futile admission, futile diagnostic procedures, futile medical orders, futile nursing interventions as well as irrelevant duties for nurses.

In this study continued provision of these futile interventions was considered a waste of resources as was stated by the critical care nurses. The nurses said that sometimes they felt that their energy was going to waste and the patient's family was also wasting money insisting on continued provision of futile care. The nurses felt that the patients only needed comfort care which brings in the concept of palliative care in the ICU.

5.4 EFFECTS OF PROVIDING FUTILE CARE ON NURSES AND PATIENTS FAMILIES

The study established that critical care nurses experienced moral distress together with the patients' families as a consequence of providing futile care to ICU patients. The fact that the critical care nurses felt that the clinical situation of patients with a diagnosis of brain death did not warrant aggressive therapy and interventions yet they had to administer such was an indication that the nurses experienced moral distress. This was due to the fact that in most cases there was no agreement between the health care providers and the patients' families on when and how to withdraw treatment in a dying patient. This was also due to the fact that there is no protocol on treatment withdrawal in the unit.

Meltzer et al (2014) carried out a study in Iran and established that the major occupational sources of stress affecting critical care nurses that could lead to burnout included conflict with colleagues and management, emotional demands of patients and patients' families, dealing with the ethical aspects of life-sustaining technology and exposure to death and dying. Meltzer went on to conclude that the ICU is such an emotionally charged environment where life and death issues are encountered on a daily basis and this could be extremely stressful and could contribute to the experience of moral distress. Some of these findings

corroborated with the findings of this study which established that provision of futile care to ICU patients resulted in moral distress.

The study also established that the nurses felt that continued provision of non-beneficial treatment meant prolonged suffering not only for the patient but also for the patient's family as well. No other study has been done to qualify or quantify the family's suffering when their patient is receiving treatment that the ICU health care providers consider futile while they (family) feel that treatment should be provided at all cost.

The study also established that there were cases of treatment decision conflicts between the patients' families and the ICU health care providers. This meant that the nurses had to continue providing futile care until the time that the family accepted withdrawal of treatment. This also contributed to the nurses' moral distress since they had to act against their ethical morals. Bosslets et al (2016) stated that when responding to requests for futile interventions, clinicians should seek to understand the reason for such requests, empathically correct misperceptions, provide emotional support and explain why the requested intervention may not be provided. They further said that if disagreements persist, clinicians should obtain expert consultation to assist with conflict resolution.

This study also established that ICU admission protocols are never followed to the letter and sometimes patients who would not benefit from the ICU are brought into the unit for various reasons in spite of the limited and expensive ICU resources.

5.5 CONCLUSION

The participants had an understanding of the concept of futile care in various ways just as other studies found. This is because the concept is complex and difficult to define, and is best understood from the definer's point of view. Interventions considered futile by the critical care nurses were similar to those mentioned in other studies done on futile care in the ICU.

However the only thing that the nurses in other studies avoided mentioning was the use of mechanical ventilation. Moral distress among the nurses was a common finding as a consequence of providing futile care. Studies done elsewhere have shown that futility of care was one of the factors that frequently lead to critical care nurses experiences of moral distress. When the nurses continued to administer futile interventions, they felt that they were prolonging patient and family pain and suffering and this also contributed to moral distress.

5.6 RECOMMENDATIONS

5.6.1 Recommendations for policy and practice and training

The study set out to gain an insight into the experiences and perceptions of critical care nurses regarding provision of futile care to patients in the ICU. The findings from the study provided some leads which if further explored and acted on, should improve the experience of ICU nurses taking care of patients with irreversible conditions. Some of the areas identified from the study with implications for policy, training and practice include:

There is need for KNH management to develop and implement hospital policies to prevent situations of medical futility such as DNR orders, advance directives so as to protect the practitioners from litigation. These policies should be made accessible to the health care providers in the ICU.

ICU admission protocols should be adhered to by the admitting doctors and the nurse managers so that patients with poor prognosis are not admitted

The critical care nurses need support from the management in terms of training on end of life issues, resilience to help them manage the moral distress that they are currently experiencing.

Effective communication should also be ensured between ICU healthcare providers and patients families when treatment seem futile and death is imminent to prevent treatment decision conflicts. End of life conflicts usually arise form inadequate communication between

stakeholders. To avoid treatment decision conflicts, proactive, open, honest and sensitive communication concerning the values of the patients and their families, prognosis of the patient and the interaction is important.

An instrument on mortality prediction should also be developed and instituted in KNH ICU so as to be able to identify situations where end of life discussions can begin. This is necessary so that there will be adequate time to hold several family conferences and provide an opportunity for the family to understand and accept the situation so that care can be minimised in good time to avoid prolonged duration of providing futile care.

There is also the need to make the public aware of the limitations of ICU interventions so that they understand that ICU interventions have limits and it reaches a point when even the most aggressive care cannot reverse a patient's condition. Also the public should be made aware that ICU resources are limited yet the demand is very high.

5.6 2 recommendations for further studies

The following topics are suggested for further studies:

- I. Challenges in the management of end of life issues in the ICU
- II. Prevalence and causes of moral distress among critical care nurses
- III. A similar study should be carried out in the major private hospitals in Kenya so as to compare with these study findings that have been done in a public hospital.
- IV. Effectiveness of family conferences in discussing end of life issues in the ICU.

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APPENDICES

APPENDIX I: CONSENT FORM

TITLE: CRITICAL CARE NURSES EXPERIENCES AND PERCEPTIONS OF PROVIDING FUTILE CARE TO PATIENTS AT KENYATTA NATIONAL HOSPITALS INTENSIVE CARE UNIT

PRINCIPAL INVESTIGATOR: OWITI TERESA

INTRODUCTION

I am Teresa Owiti, a master of science in nursing student at the University of Nairobi. I am carrying out a study to explore the experiences of futile care among nurses working in the critical care unit at Kenyatta national hospital. This interview will be tape recorded for purposes of reference and also so that I can pay full attention to you during the interview. Your identity will not be revealed in any way and the information given will be handled with utmost confidentiality. The purpose of this consent is to give you the information you will need to help you decide whether or not to participate in the study.

PARTICIPANT INFORMATION

You are invited to participate in this study because you are a qualified nurse currently working in the critical care unit. The main objective of this study is to explore the experiences and perceptions of futile care among nurses working in the critical care unit in Kenyatta national hospital. The specific objectives are to evaluate the understanding of futility of care, perception of futile care, determine types of care considered futile and to evaluate the experiences of futility of care in the ICU.

Study Procedure

If you agree to participate in this study you will be interviewed by the principal investigator in a private area where you will feel free and comfortable. The interview will last between 30-40 minutes and will be voice recorded for purposes of reference and also to enable the interviewer pay full attention to the process.

Risks

There will be no risks for participating in this study since your personal identification will not be recorded.

Benefits

There will be no benefits at an individual level or even compensation. However, the results of this study will be used by the hospital management so that interventions can be designed to help reduce futility of care in the ICU.

Voluntary participation and withdrawal

Your participation is entirely voluntary and should you change your mind you are free to opt out of the study anytime. There will be no penalties for withdrawing from the study

Confidentiality

You will not be identified and no information you give will make it possible for anyone to identify you. All information will be kept under lock and key and electronic information will be under a pass word.

Contact persons

I will give you my contacts: Teresa owiti 0722 210142

And also contacts of the ethics and research secretariat, telephone: 726300-9

Email: uonknh-erc@uonbi.ac.ke

If you have any questions or concerns about this study feel free to contact us directly.

Confirmation of consent. Are you willing to participate in this study?

Yes.....No.....If yes please sign.....

Principal investigator.....Time.....Date.....

APPENDIX II: INTERVIEW GUIDE

QUESTION	PROMPTS
<p>a) What do you understand by the term futile care or futility of care as pertains your practice in the critical care unit?</p> <p>b) In your practice are there instances when you have felt that the procedures or interventions you were giving to a patient were futile?</p>	<ul style="list-style-type: none"> • How would you define futile care in your own words? • Do you think provision of futile care occurs in this unit? • What do you feel about futile care provision? • Which particular procedure were you carrying out? • What made you feel that it was an action in futility? • Why did you feel that whatever you were doing was not beneficial to the patient?
<p>c) Please tell me some of the treatment or interventions you give to patients that you think are futile.</p>	
<p>d) Please tell me your experiences of futile care during your practice as a critical care nurse.</p>	<ul style="list-style-type: none"> • Can you remember the diagnoses of those patients whom you felt were receiving futile care? • Did you ever raise any concerns with your fellow health care practitioners?
<p>e) Does providing futile care to ICU patients have any impact on you as a critical care nurse?</p>	<ul style="list-style-type: none"> • How does it make you feel to provide care that you consider as futile? • What strategies do you use to motivate yourself when providing futile care?
<p>f) In your opinion why do you provide care that you think is not beneficial to the patient?</p>	<ul style="list-style-type: none"> • Do you think you should continue to carry out these futile procedures? • What do you think can be done so that case of futility can be managed in the best way possible?

Thank you very much for consenting to be part of this study and for your time.

APPENDIX III: OBSERVATION CHECKLIST

OBSERVATION	REMARKS
Patients diagnosis	
GCS score:	
Length of stay in ICU	
On inotropic support	
On mechanical ventilation	
DNR orders placed	
On hemodialysis	
CPR done at cardiac arrest	
Routine radiological studies	
Routine blood tests	
Any surgical intervention planned for the patient	
Any other comments	

APPENDIX IV: STUDY BUDGET AND BUDGET JUSTIFICATION

COMPONENTS	UNIT OF MEASURE	DURATION/NUMBER	COST(KSHS)	TOTAL(KSHS)
Personnel				
transcribing fee				20000
Printing				
consent form	1	2	10	20
interview guide	1	2	10	20
final report	1	85	10	850
Photocopying				
consent form	20	2	3	120
interview guide	20	2	3	120
final report	9	85	3	2295
final report binding	10	1	500	1500
Other costs				
ERC fees				5000
records access fees				500
tape recorder				5000
publication fees				60000
TOTAL				95425

APPENDIX V: WORKPLAN 2018

ACTIVITY	JAN	FEB	MAR	APR	MAY	JUNE	JUL	AUG	SEP	OCT	NOV
Proposal writing	■	■	■	■							
Presentation to ethics and review				■	■						
Data collection						■	■				
Data analysis								■	■		
Report writing								■	■		
Defense of dissertation										■	■
Corrections of dissertation										■	■
Submission of dissertation										■	■

APPENDIX VI: CODING PROCESS

RESEARCH QUESTIONS	RESPONDENT	CODE
1. What do critical care nurses understand about futile care?	001	There is no benefit
	002	They do not benefit the patient
	003	Does not give good end results
	004	Will not help the patient in the outcome
	005	Terminal care given to patient with poor prognosis
	006	Patient is not going to benefit from the care
	007	Not significant or fruitful to the patient
	009	When you are not expecting a good outcome
	010	Treatment that is not beneficial to the patient
	2. Which interventions do critical care nurses consider as futile?	001
002		Mechanical ventilation
003		Blood gas analysis, mechanical ventilation
004		Dialysis, medication
005		You have to go for dialysis
006		Drugs, lab investigations, dialysis, CT scans, ABGs
007		Inotropes, mechanical ventilation
008		Dialysis, antibiotics
009		Medication, feeding, inotropes

	010	CT scans, antibiotics
RESEARCH QUESTIONS	RESPONDENTS	CODES
3. Which situations lead to critical care nurses feeling that the care being provided is futile?	001	Head injury that needs surgery
	002	Cancer metastasis stage 4
	003	Resuscitation for like one hour
	004	Multisystem organ failure and are terminally ill
	005	May be GCS is very bad
	006	Hypoxic brain injury, brain stem injury
	007	Patients who are brain dead
	008	Patients who have already had brain death
	009	Patients who are brain dead
	010	When we get a brain death
4. Does providing futile care affect the critical care nurses in any way?	001	Am comfortable
	002	Depressing
	003	You will not blame your self
	004	It is so stressful
	005	Just buying time, it is so painful
	006	Occasionally you feel wasted
	0007	There is nothing much we are doing
	008	You feel demoralized, energy being wasted
	009	You feel demoralized, you feel useless
	010	Demoralizes you, discouraging, no motivation.

APPENDIX VII: LETTER OF APPROVAL FROM ERC



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



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



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

Ref: KNH-ERC/A/291

July 25, 2018

Teresa Owati
Reg. No.H56/89445/2016
School of Nursing Sciences
College of Health Sciences
University of Nairobi

Dear Teresa

RESEARCH PROPOSAL – CRITICAL CARE NURSES EXPERIENCES AND PERCEPTION OF PROVIDING FUTILE CARE TO PATIENTS AT KENYATTA NATIONAL HOSPITAL INTENSIVE CARE UNIT (P254/04/2018)

This is to inform you that the KNH- UoN Ethics & Research Committee (KNH- UoN ERC) has reviewed and **approved** your above research proposal. The approval period is from 25th July 2018 – 24th July 2019.

This approval is subject to compliance with the following requirements:

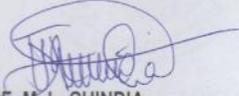
- a) Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
- b) All changes (amendments, deviations, violations etc) are submitted for review and approval by KNH-UoN ERC before implementation.
- c) Death and life threatening problems and serious adverse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

Protect to discover

UNIVERSITY OF NAIROBI

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

Yours sincerely,



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

- c.c. The Principal, College of Health Sciences, UoN
- The Director, CS, KNH
- The Chairperson, KNH-UoN ERC
- The Assistant Director, Health Information, KNH
- The Director, School of Nursing Sciences, UoN
- Supervisors: Dr. Eunice Omondi, Dr. Emmah Matheka



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APPENDIX VIII: LETTER FORM KNH ADMINISTRATION

KNH/R&P/FORM/01



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

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

Study Registration Certificate

1. Name of the Principal Investigator/Researcher
OVIITI TERESA

2. Email address: ovitiidteresa@gmail.com Tel No. 0733 210142

3. Contact person (If different from PI)..... N/A

4. Email address: N/A Tel No. N/A

5. Study Title
EXPERIENCES AND PERCEPTION OF PROVISION OF FUTURE CARE TO PATIENTS AT KENYATTA NATIONAL HOSPITALS ~~WARD~~ INTENSIVE CARE UNIT

6. Department where the study will be conducted CRITICAL CARE UNIT
(Please attach copy of Abstract)

7. Endorsed by Research Coordinator of the Department where the study will be conducted.
Name: Dr. A. Ngeza Signature: [Signature] Date 31/7/18

8. Endorsed by KNH Head of Department where study will be conducted.
Name: Dr. H.O. Okeni Signature: [Signature] Date 31-7-18

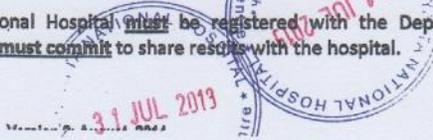
9. KNH UoN Ethics Research Committee approved study number _____
(Please attach copy of ERC approval)

10. I TERESA OVIITI commit to submit a report of my study findings to the Department where the study will be conducted and to the Department of Research and Programs.
Signature: [Signature] Date 30/7/2018

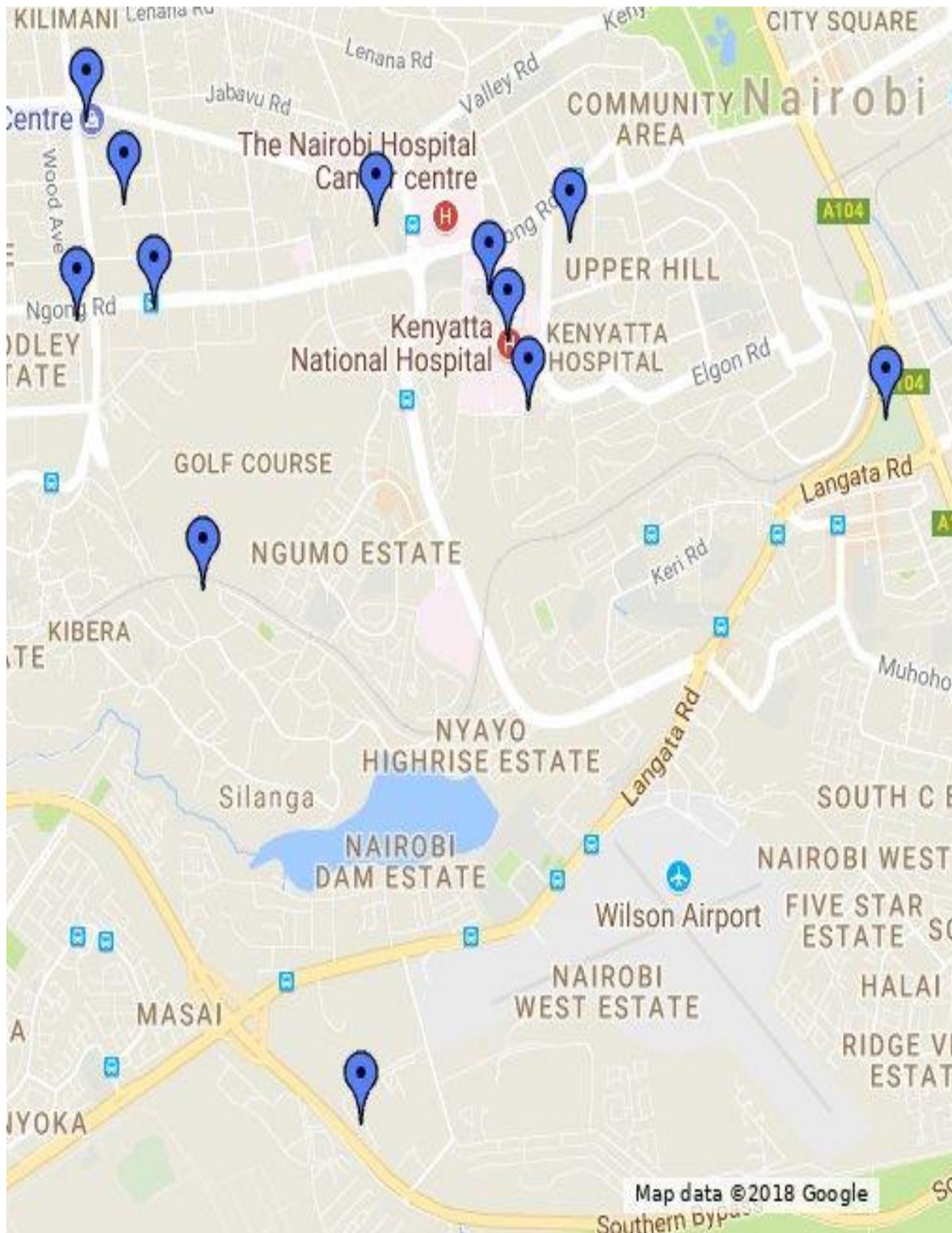
11. Study Registration number (Dept/Number/Year) CCU / 90 / 2018
(To be completed by Research and Programs Department)

12. Research and Program Stamp _____

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



APPENDIX IX: MAP OF KNH



APPENDIX X: PICTURE OF KENYATTA NATIONAL HOSPITAL



