WITHHOLDING AND WITHDRAWING LIFE SUPPORT MEASURES FROM TERMINALLY ILL PATIENTS: PERSPECTIVES OF HEALTHCARE WORKERS AT BUGANDO MEDICAL CENTRE, MWANZA REGION-TANZANIA.

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A Dissertation Submitted in Partial Fulfillment of the Requirements for the Degree of Master of Bioethics of the Muhimbili University of Health and Allied Sciences

October, 2019

CERTIFICATION

The undersigned certifies that he has read and hereby recommend for acceptance of dissertation entitled "**Withholding and withdrawing life support measures from terminally ill patients: perspectives of healthcare workers at Bugando Medical Centre, Mwanza Region- Tanzania."** in fulfillment of the requirement for the degree of Master of Science in Bioethics of Muhimbili University of Health and Allied Sciences.

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Date: _____

DECLARATION AND COPYRIGHT

I, **Ndakibae Gabriel Mabega**, I declare that this **dissertation** is my own original work, and that it has not been presented and will not be presented to any other University for a similar or any other degree award.

Signature:_____ **Date:**_____

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DEDICATION

This research report is dedicated to my late mother, Beatrice Gwajekale Mabega who died in 1997. She is the one who led me to be here, but for the willing of God he has taken away, but her soul is still living with me. I dedicate this work also to my family, my lovely wife Eligiva Abela Batungi, my sons Alfred and Norbert, and my lovely daughter Noreen. May God bless them and give them a long life.

ABSTRACT.

Background: Withholding and withdrawing life support measures from terminally ill patients are challenges in clinical practice, particularly in the ICU; it brought different opinions among healthcare workers and still there is no consensus on this practice. However, in some countries there are guidelines that help and support clinicians in making ethical decisions of withholding and withdrawing life support measures from terminally ill patients. In Tanzania, there is neither guideline nor legal frameworks governing the practices; these subjected healthcare workers in serious ethical dilemmas in end of life ethical decisions making.

Objectives: To explore the perspectives of healthcare workers on withholding and withdrawing life supportive measures from terminally ill patients at Bugando Medical Centre, Mwanza region-Tanzania.

Methods: A qualitative descriptive (QD) study was used to explore perspectives of healthcare workers regarding withdrawing and withholding life support from terminally ill patients in the ICU. In depth interviews were used to collect information from thirteen participants using a semi structured interview guide. An appointment was made with nurses and physicians depending on their availability. Data were analyzed using qualitative content analysis.

Results: A healthcare workers perspectives varies in ethical decisions of withholding and withdrawing life supportive measures from terminally ill patients. However, healthcare workers face many challenges in making ethical decisions when caring terminally ill patients ICU.

Conclusions: The ethical decisions of withholding and withdrawing life support measures from terminally ill patients in AICU of Bugando Medical Centre face many challenges. However, there is significant factors which believed by health care workers to consider when withhold or withdrawing life support measures from terminally ill patients. Due to lack of legal and ethical framework to guide the practices, physicians and nurses fear to make professional decisions regarding terminally patients.

ABBREVIATIONS

AICU	Adult Intensive Care Unit
AMA	American Medical Association
ANA	American Nurses Association
BMC	Bugando Medical Centre
CPR	Cardiopulmonary resuscitation
CUHAS	Catholic University of Health and Allied Sciences
EOL	End-of-life
ICU	Intensive Care Unit
IR	Interviewer respondent
MUHAS	Muhimbili University of Health and Allied Sciences
NASW	National Association of Social Workers
NICU	Neonatal Intensive Care Unit
PI	Principal Investigator
QD	Qualitative descriptive study
UDOM	University of Dodoma

DEFINITION OF KEY TERMS

Withholding/Withdrawing : The process whereby medical intervention or therapies are restricted from the patient.

Life supportive measures: Interventions that may prolong or support life, such as mechanical ventilators, nutrition and hydration, cardiopulmonary resuscitation.

Terminally ill: The patient who suffers from advanced, progressive, and irreversible diseases and who fails to respond to curative therapy, having a short life expectancy in terms of days or a few months.

Vegetative state: Refers to patients who have suffered damage to parts of the brain responsible for consciousness. These patients retain brain stem activity to maintain some autonomic physiological functions, including spontaneous circulation breathing and stable circulation.

Member checks: The technique used to explore credibility of results whereby data or results are returned to participants to check for accuracy.

Audit trail: This is a transparent description of the research steps from the start of a research project to the development and reporting of findings.

Mentoring team: A team of researchers who follow up the research process to ensure credibility of the study.

ICU: is a special department of a hospital or health care facility that provides intensive treatment medicine.

CHAPTER ONE

1.0. INTRODUCTION.

1.1. Background

Withholding and withdrawing life supportive measures from terminally ill patients occurs when interventions (e.g. mechanical ventilation, antibiotics, nutrition and hydration) are no longer beneficial to the patient's quality of life (1). The majority of deaths occur in the intensive care unit (ICU) after withdrawal and withholding life supportive measures (1–3). Withholding and withdrawal of life supportive measures from terminally ill patients are a stressful situation for all participants involved, including healthcare workers (3,4).

In many western hospitals, withholding and withdrawing life support from terminally ill patients in the ICU is a practice that occurs when no other treatments are deemed beneficial for a dying patient (5). Every day, a patient might die in the ICU and many ICUs have specific policies and guidelines that health care professionals can follow regarding withholding and withdrawing of life supportive measures (6–8). However, due to different cultural, religious, and other beliefs among healthcare workers, perceptions on withholding and withdrawal of life support measures from terminally ill patients may vary (2). The ultimate goal of health care professionals is to alleviate pain, suffering and to improve the quality of life of their patients; withdrawing and withholding of life supportive measures may be perceived as contrary to providers' professional and moral obligations.

Studies have shown a high prevalence of ICU mortality in Tanzania. Indeed, it accounts for 50% of admitted patients in the ICU (9). The high mortality rate in the ICU shows the need for healthcare workers to have knowledge and experience with end-of-life (EOL) issues, which is not clearly known in our context. There are no studies that explore the perceptions of healthcare workers in EOL decisions in Tanzanian ICUs. In Tanzania, however, withholding and withdrawal of life support measures is not legally authorized but traditionally are quietly practiced by healthcare workers. Sometimes patients are discharged from the health facilities in which they were being treated, especially when the health care team finds that staying in the hospital would not be beneficial to the patient. This practice is actually analogous to limitation of life sustaining measures and lets the patient die at their home or elsewhere, which is actually withdrawing or withholding of interventional treatment.

Therefore this study is going to explore the perceptions of health care professionals who are working in the adult intensive care unit (AICU) toward withholding and withdrawing of life support measures in terminally ill patients. By understanding perceptions of health care professionals, we can begin to develop guidelines that can be used in clinical practice. Thus, this study will help nurses and physicians, hospital managers, hospital administrators, policy makers and other stakeholders to have a clearer understanding of this important issue and the best way of managing EOL decisions.

1.2. STATEMENT OF THE PROBLEM

Advancement of science and technology in medical practice has led to the prolongation of life of terminally ill patients (10). Furthermore, the availability of life sustaining measures, such as mechanical ventilators has increased the duration of life of terminally ill patients in ICUs. This raises ethical concerns among healthcare workers on understanding the exact definition of death when a patient is on prolonged ventilator support. Withholding and withdrawal of life supportive measures from terminally ill patients is still a prominent debate in the world. Literature has shown that, between seventy (70%) and ninety percent (90%) of deaths in ICUs occurred after the withdrawal and withholding of life support measures(11). However, another study reported 16-90% of all deaths occur after some kind of limitation of life sustaining therapy (2). Countries such as the Netherlands, Belgium, Luxembourg, India and the United States, have legally authorized and accepted the practice of withholding and withdrawing life supportive medicine based on specific guidelines and procedures for health care providers to consider in the process of EOL decisions for terminally ill patients in ICUs.

In Tanzania, there is no law allowing withholding and withdrawing life support measures from terminally ill patients. Instead, the Tanzania constitution emphasizes in protecting the life. Part three of Tanzania constitution Article 14, the right to life states "*Every person have the right to live and protection of his life by the society in accordance with law"* Therefore to withhold or withdraw life support measures from terminally ill patients is unlawful. This makes it difficult for healthcare workers to make decisions in EOL issues in ICUs. Ethical dilemmas arise because there are no clear guidelines on withholding and withdrawing life support measures from terminally ill patients. This is due to the silence of healthcare workers perspectives on end-of-life issues. ICU nurses and

physicians are at the bedside of those who are terminally ill, trying to help patients and families make decisions related to their EOL preferences and goals. Yet, little is known about their perspectives on this sensitive ethical issue. However withholding and withdrawing life support measures are quietly practiced in ICU's.

Understanding of healthcare workers' perspectives is critical to advance EOL care in Tanzania and to develop policies and guidelines that support beneficent patient and family care. Because there is no data on the views of healthcare workers on ethical decisions in withholding and withdrawing life support measures from terminally ill patients. No policies or guidelines to help healthcare workers in making ethical decisions regarding end of life in ICU particularly terminally ill patients.

Therefore this study is going to explore perspectives of healthcare workers toward withholding and withdrawing of life support measures from terminally ill patients in AICU of BMC.

1.3. CONCEPTUAL FRAMEWORK.

Withholding and withdrawal of life support measures from terminally ill patients in ICUs pose ethical issues among healthcare workers including both physicians and nurses. These ethical issues might include conflict based on religious beliefs of the patient and families, legal implications, and cultural beliefs on death. The conceptual framework from this study developed from the literature by looking associated factors which affect withdrawing and withholding life support measures from terminally ill patients. Healthcare and patient-related factors that influence the decision to withdraw or withhold life support measures from the terminally ill patients were the major themes. However in both factors, the perspectives and attitudes may vary.

In addition, the life of terminally ill patients depends on life support measures or interventions provided by healthcare workers in ICU such ventilator supports, inotropic medications, resuscitations, nutrition and hydrations. The decisions of limiting these interventions from terminally ill patients will results to end of life of an individual. These decisions depend on patient and healthcare workers related factors**.**

1.3.1. Factors affecting decisions in terminally ill patients:

Several factors may affect the decisions of ICU healthcare workers in their approach to the terminally ill. These include the following: Health care Provider and Patient-related factors.

1.3.2. Health care related factors.

1.3.2.1. Demographic information.

Demographic characteristics such as individual religion and cultural beliefs, age, gender, experience in practice may influence decision making in EOL practice. Physician's gender, age, cultural and religious beliefs and experience is associated with decision making(12).

1.3.2.1.1. Individual religion and cultural beliefs.

Most religious faiths believe that human life is sacred and is given by God. Thus, God is the only one who can take the life of the human being. Human life should be preserved at any cost. EOL decision-making is influenced by one's culture, coping styles, health and illness, death and dying perceptions. Some cultural norms support life and disagree on taking one's life. Truth-telling is an important ethical issue in some cultures and how to

communicate EOL concerns to patients and their families can create a conflict. This might arise when families insist on 'doing everything' for the patient and don't want the patient to know that they are dying. Some cultures believe that telling the truth may fuel the patient's death and may choose to forgo discussing EOL issues (13).

1.3.2.1.2. Age.

Age is the number of years in which the person lived. It is associated with experience and wisdom of persons. In our culture it is believed that persons with advanced age has met with many challenges; an aged person can be said to have a lot of experience. In clinical settings, the age of the physicians and nurses differ. Hence, even decision making may vary according to age. Therefore, the decision to withhold and withdraw life support may be influenced by physicians and nurses of differing ages. (14).

1.3.2.1.3. Years in practice.

Number of years working in clinical practice is one of the factors that influence decision making. Persons with many years of experience in clinical settings may have more experience in making decisions. Number of years working in the ICU varies from physicians and nurses. Senior physicians have more experience in making decisions of whether to withhold or withdraw life supportive measures than junior physicians. However this has been evidenced by the study done in Egypt (14).

1.3.2.1.4. Gender.

Gender has been demonstrated to be a factor that influences decision making. The decision to withhold and withdrawing life sustaining measures is less practiced by female physicians as compared to men(12). The study had shown considerable variations in the practice of withholding and withdrawing of life support measures among male and female physicians.

1.3.2.2. Legal implications.

Withholding and withdrawal life support measures may bring forth legal issues, as in the seminal case of Karen Ann Quinlan where a legal conflict occurred between physicians and family members on EOL decisions (15). For those patients who lack decisional capacity, surrogate decisions are legally protected but can still create conflict when differences arise for loved ones at EOL. Physician and nurses might fear legal ramifications if they make decisions on EOL without specific guidelines or policies.

1.3.2.3. Ethical and professional obligations.

Physicians and nurses are trained to reduce pain and suffering and promote the quality of life of their patients. The Tanzanian Nursing Code of Ethics states: "Nurses should have the ability to make decisions on patient care approaches and values within the complex health care delivery within attainable acceptable standard (16)." A nurse or midwife is professionally and legally accountable for their professional practice. In a similar way, the Hippocratic Oath, and the Tanzanian Medical Code of Ethics bind the medical and dental professionals in five cardinal ethical principles: Beneficence, Non-maleficence, Autonomy, Justice and Veracity(17).

There is an obligation to prolong the life of the patient and to promote their welfare; any practice of ending the patient's life is against healthcare professionals' responsibilities and ethical practice(18). Therefore, withholding and withdrawal life support may create ethical concerns for healthcare professionals and what exactly their role is in this process.

1.3.2.4. Justice.

The ethical principle of justice is related to the fair distribution of health resources and services among patients. The issue of rationing of resources in clinical settings is a common ethical concern in Tanzania due to finite resources in healthcare settings(19). With limited resources, decisions need to be made in ICUs on how to allocate these resources in a fair and just way. There are times when other ICU patients may benefit more from the limited resources that are available than a patient who is at EOL and no other treatments would sustain life. These decisions are very difficult for everyone.

1.3.2.5. Beneficence and Non Maleficence.

Healthcare workers have a role to promote the good of the patient including prevention of harm. In medical and nursing practice, the goal is to reduce pain and suffering and promote the overall well-being of the patient. However, in some circumstances, family members may believe that the good for their loved one who is terminally ill is to continue life support; this might be contrary to healthcare workers' perceptions that the treatment is not benefitting the patient. Likewise, healthcare workers have a professional obligation to do no harm to their patients. But, sometimes prolonging the death of a terminally ill patient may be regarded as causing more suffering and harm to the patient.

1.3.3. Patient-related factors.

1.3.3.1 Demographic characteristics.

Patient demographic characteristics are also one of the factors that may influence decision making in EOL. Age of the patients, religion and cultural beliefs and gender may influence decision making.

1.3.3.1.1 Age

Age of the patient may reflect the ability of the patient to make decisions, and it is associated with self-determination and understanding of informations given. Therefore, age of the patient is also associated with understanding of informed consent and able to make one's own decisions. Patient with more than 18 years of age is regarded as an adult and autonomous to agree or disagree to any treatment given. In clinical settings, the age of the patient varies. Some are adult, and others are children; and, some adults who do not have capacity must have a designated surrogate.

1.3.3.2. Individual cultural beliefs.

Apart from health care related factors in withholding and withdrawing of life supportive measures to terminally ill patients, there are some factors related to the patient him or herself that may also affect end-of-life decisions. Such factors are patient autonomy, advance directives and clinical factors.

1.3.3.3. Patient autonomy.

The individual competent patient has the right to choose their own management plan, including end-of-life based on their beliefs, preferences and values. Patients have the right to refuse life sustaining treatment and therefore patients have the right to die. Ethical questions surrounding competency include when exactly an individual is regarded as a competent person to make those decisions. Surrogate decision making occurs when the patient is no longer able to make decisions on his or her behalf.

1.3.3.4. Medical diagnosis.

The decision of withholding and withdrawing life sustaining measures is accompanied by a patient assessment and the patient's condition is often deemed medically futile. However it is still difficult to make decisions to withhold or withdrawal interventions based on futility among physicians(20). The Hippocratic corpus defines medical futility as a limit of

medicine and encourages physicians not to provide treatment when it is futile, because at this point medicine will not improve the patient's condition (21).

1.3.3.5. Advance directives.

This is a document that is used as a tool for making decisions in clinical care; the document defines the limit of care and also the name of a surrogate decision maker in case of an incompetent person. For our clinical setting, advance directives are not applied. It may be due to lack of awareness in end of life issues or perceptions and beliefs. But this document is slightly analogous to which is encouraged by the government through RITA to be written by people before they die to show their distribution of wealth within the families. This is a legal document that defines the distribution of wealth among families, therefore, in our context, the legal framework concerning end of life issues in the social context is available from a financial perspective.

1.3.3.6. Relative influences.

Patient families could be one of the factors in the decisions of withholding or withdrawing of life supportive measures from terminally ill patients. Prolonged illness and cost of the health services in the intensive care units occasionally may cause families to demand the withholding or withdrawal of life supportive measures from terminally ill patients. This can also bring conflict between physicians and families in clinical settings. The best way of dealing with these conflicts is good communication and informing the patient, families and the surrogate (if designated) about the patient's prognosis.

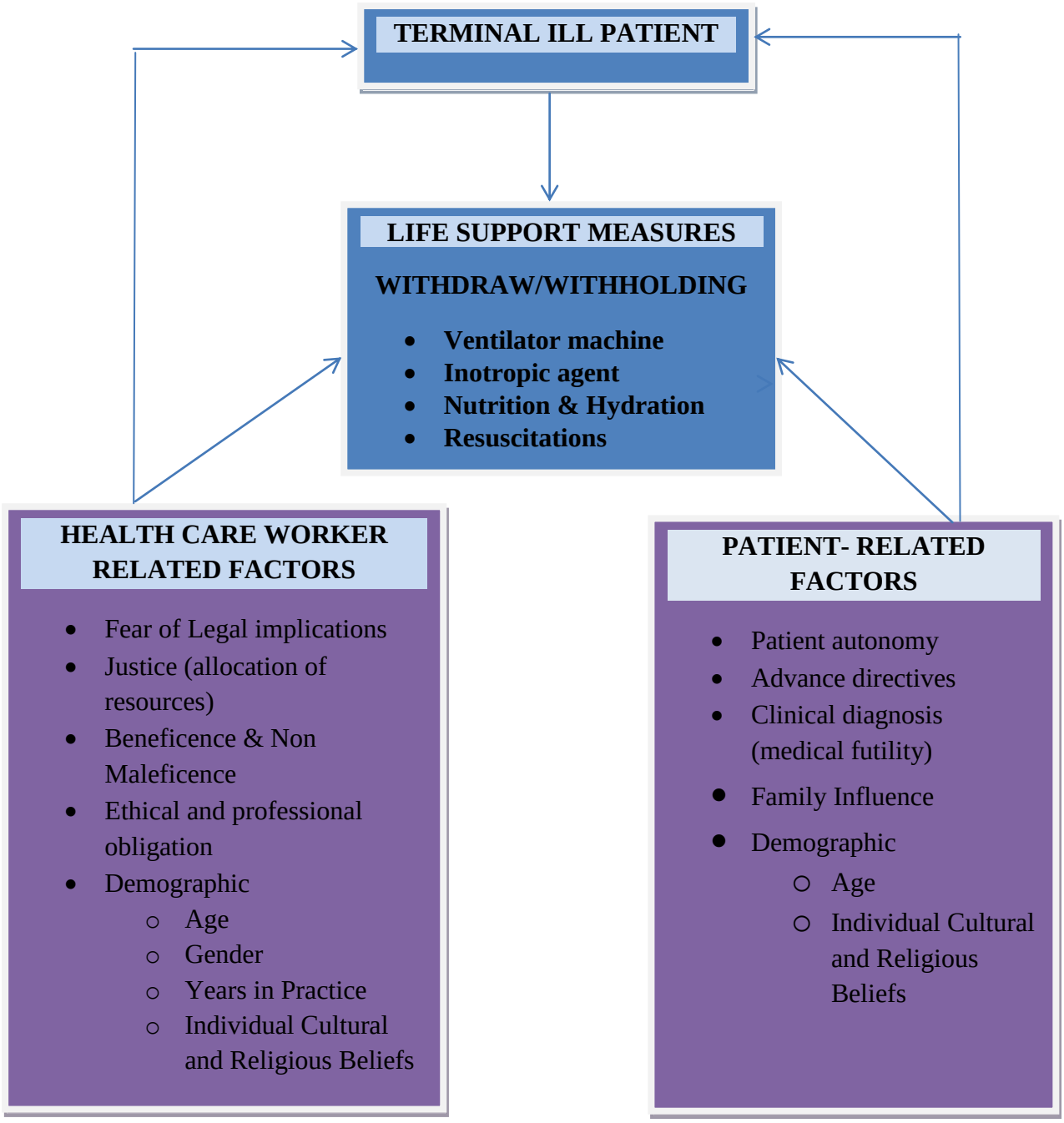


Figure I: CONCEPTUAL FRAMEWORK: Showing factors which influence the decision-making in withholding and withdrawing life support measures from terminally ill patients in Intensive Care Units.

1.4. RATIONALE.

EOL decision making is a new phenomenon in the Tanzanian context, and its practice raises many ethical issues among healthcare workers, especially those who are working in ICUs where many deaths occur. These ethical issues and concerns may include the role of healthcare workers in discussing end-of-life issues with patients and their families, the burden of aggressive interventions to those who are dying, moral distress of nurses and physicians when they are providing care that appears to be non-beneficial or curative, and religious or spiritual conflicts among healthcare workers. All these ethical challenges affect healthcare workers in making decisions in end of life issues. These all can lead to different opinions and a lack of uniformity in clinical practices regarding to withholding and withdrawing life support from terminally ill patients. Understanding of healthcare workers perceptions on withholding and withdrawing life support measures from terminally ill patients can raise the discussions among physicians and nurses in Tanzania ICUs regarding end of life. These discussions can be the foundation of developing an ethical, legal and professional framework that explains clearly how to involve patients, family members, nurses and physicians in the process of withholding and withdrawing life support measures from terminally ill patients. The findings of this study will help nurses, physicians, hospital managers, hospital administrators, policy makers and other stakeholders to have a clear understanding on this important ethical issue in clinical practice and the best way for managing end-of-life decisions with patients and their families in Tanzanian ICUs.

1.5. RESEARCH QUESTIONS.

1) What perceptions do healthcare workers have regarding ethical decisions making and factors considered when making decisions of withholding and withdrawing life support measures from terminally ill patients in ICU at Bugando Medical Centre?
2) What are the experiences of healthcare workers regarding ethical decisions making in withholding and withdrawing life support measures from terminally ill patients in ICU at Bugando Medical Centre?

1.6. BROAD OBJECTIVE.

The general objective of the study was to explore the perspectives of healthcare workers in the decisions of withholding and withdrawing life supportive measures from terminally ill patients at Bugando Medical Centre, Mwanza region-Tanzania.

1.6.1. SPECIFIC OBJECTIVES.

1) To explore healthcare workers perceptions regarding ethical challenges and factors considered when making ethical decisions about withholding and withdrawing life support measures from terminally ill patients in ICU at Bugando Medical Centre.

2) To investigate healthcare workers experiences regarding ethical decisions making about withholding and withdrawing life support measures from terminally ill patients in ICU at Bugando Medical Centre.

CHAPTER TWO.

2.0. LITERATURE REVIEW.

2.1. Explore healthcare workers perceptions regarding ethical challenges and factors considered when making ethical decisions about withholding and withdrawing life support measures from terminally ill patients in ICU at Bugando Medical Centre.

The decision on end of life in ICU is complex and it is difficult among all stakeholders involved physicians, nurses and family members.

Poor experience within the health care system and disrespect of patient beliefs and values has precipitated conflict among healthcare workers and family members in decision making concerning end of life(23). Withholding and withdrawing of life support measures are perceived in both negative and positive way among healthcare workers and family members. The mutual involvement of family members and healthcare workers in decision making in ICU concerning EOL are crucial importance.

Furthermore, the United States (US) and Europe is more experienced in withholding and withdrawing of life support to terminally ill patients in ICUs as compared to other parts of the world where more than 90% of death is due to withholding and withheld life support(24).

Nevertheless, withholding and withdrawing life support in Netherland is a common practice and has been legally and ethically justified by the law and documented in medical treatment act which provides power for the physicians to withhold and withdraw life sustaining measures. The act has stipulated the key points in guiding medical team in end of life care(3). The legally acceptance of withholding and withdrawing of life support would made the healthcare workers more experienced in this practices. In contrary to our context, the practice itself is illegal and even the healthcare workers opinion regarding the practice is not known.

In addition to the survey study of physicians' decisions to withhold and withdrawal of life sustaining measures among 1000 physicians revealed that 51% of physicians were willing to withhold and withdraw life sustaining measures despite of their moral and legal rights of the patient have on refusing the treatments(25). This means the health care provider was

against the patient autonomy, they were looking if the autonomy would precede the worthiness of the human being, if autonomy is superior to life(26).

Another study had revealed high prevalence of mortalities in ICU after withheld and withdrawal of life support measures. The study shows 35-85% of ICU deaths are due to decisions made by healthcare workers(27). However the argument of incapacitated decisions making process for some of the patients was among the issues, therefore the use of advance directives and its validity in ICU was debated.

Despite of a massive death in ICU after limiting a life sustaining measures from the patients, a little attention has made on how to withdraw the life sustaining measures, many ethical and legal aspect remain in dilemma among healthcare workers and confusing clinicians(28). This is evidenced by the lack of data on directing physician in the optimal management of dying patients.

Decision in withholding and withdrawing of life support is still a controversial practice in ICU. In US the clear guideline and legal mechanism of making decision has been stipulate for both competent and incompetent persons. The case is difference in Italy ICUs there is no widely consensus to accept the practices(29). The opinions and practices regarding the experience of physicians and nurses in ICU had revealed 93.9% and 83.9% respectively had experiences in practice of end-of-life decision making in their carrier, experience influenced their altitudes (30).

2.1.1. Religious beliefs:

The decisions related to withholding and withdrawing of life support is also influenced by religious beliefs among healthcare workers, family members and patients themselves(31). Catholic perspectives on withholding and withdrawing of life support is seen as the intention of ending of person's life and the role of health care in dying patients is to provide palliative care. However Anglican opinions about withholding and withdrawing differ; some may agree and others want life extended. Furthermore, an Orthodox perspective believes that life is from God and only God can take it away. In the Jewish faith, it is prohibited for the physician to withhold food, fluids, or oxygen to terminally ill patients; their responsibility is to treat a patient even if it means prolonging life(31). However some Jewish faith would allow withdrawing treatments. In the Islamic faith, the

lives are a gift from God and no one has the power to take it away. On the other hand in the Hindu perspective, withholding and withdrawing of life support from terminally ill patients is accepted only if the proper criteria have been followed.

In contrast to Asian and Western Buddhist faith, they have no clear consensus and opinions with regard to withholding and withdrawing life support measures from terminally ill patients. Therefore, different religions have their own perspectives regarding the practice of limiting or withdrawing of life sustaining therapies to terminally ill patients. This personal belief of health care providers may affect the decision making process in clinical settings.

Additionally, different in religions, cultures and different beliefs among healthcare workers pose the variation in decision making in end of life for ICU patients(2).

In article of Intensive Care Medicines, The World's major Religions point of view in end of life decisions in the intensive care unit analyses diverse perspectives in end of life, the Catholic Church accept withholding and withdrawing therapies which has no benefit to the patients. For the protestant is flexible to continue with life sustaining therapies if there is hope of recovery, Greek Orthodox has no position regarding end of life. For the Muslim the work must be done to prevent death, however for the Muslim patients life sustaining measures can be withheld and withdrawn from terminally ill patients when the life is inevitable(2). In contrast with Buddhist saving of life at any cost would regarded as a denial of mortality.

In others way Muslim accept withholding and withdrawing life support measures in case of considerable life is futile to a patients as in brain death or vegetative state to avoid prolonged pain of a dying patients(32).

2.1.2. Legal implications.

Withholding and withdrawing life support to terminally ill is surrounded by legal issues. The case of Karen Quinlan, Nancy Cruzan and Terri Schiavo has raised the legal lens on withholding and withdrawing of life sustains measures to terminally ill patients (33).

The issues of competent, incompetent and surrogate decisions have raised concerns to patient best interest. These affect the decisions making in end of life among healthcare workers including physician and nurses.

The legality of withholding and withdrawn life sustaining therapy brought by two concepts, an adult competent right to decide on his or her body and the right to self-determination to incompetent through surrogate decision maker(11). The court has found that, the principle of self-determination has written in many constitutions give the power of an individual to free choice after informed consent.

In the article written by Maureen Kwiecinski in US Many disagreement among healthcare workers and patient family concerning withholding and withdrawing of life sustaining measures went to court houses for solving the disputes(11). The argument of limited knowledge of patient preference, therefore their decisions might be improperly exercised and subjected to bias or institutional pressure.

Due to complexities of withholding and withdrawing life sustaining therapy practices, The Manitoba Law Reform Commission in Canada was released a discussion paper entitled *"Withholding or withholding life sustaining treatment"* explains a variety of issues concerning end of life. The paper explains the current law in Canada and went further to some other countries. In Canada the law does not clearly addressed end of life decision making (34). In England healthcare workers have given a power by law to make decision to limit life sustaining treatments form terminally ill or permanent vegetative state patients, and not be liable if they do it for best interest of the patients. However the law had reported to lack some clarity.

Legal considerations in EOL decisions addressed in Louisiana law by establishing a valid legal consent for competent adult involving medical treatment. The law does not coerce but it provides a guideline when the patient is incompetent to making decisions(35).

Nurses as part of medical team in ICUs, should have a basic knowledge of legal implications of EOL decision making. Many cases surrounding EOL has established a legal principle on how to be handled. However right to refuse or discontinue medical treatment with line of adult competent and incompetent patient has been considered(36).

Withholding and withdrawing life support is a very challenging practice. Furthermore the resistance of law recognition to govern medical practices has been shown by doctors(37).

2.1.3. Sociocultural issues.

Cultural background influences decisions making in clinical practices. Every culture has its own explanatory model of disease and the way they perceive and communicate about health problems, end of life altitudes and perceptions.

The cultural diversity in health and illness has affected decisions making in EOL in three areas. These are communications of bad news, decisions making and attitude toward advanced directives (38). Searight documented the four primary reasons for non-disclosure to terminally ill patients such as "certain cultures specifically view discussion of serious illness and death as disrespectful or impolite", "some cultures believe open discussion of serious illness may provoke unnecessary depressions or anxiety in the patients", "some cultures believed that, direct disclosure may eliminate hope" and some cultures believe speaking loud about condition makes death or terminally illness real because of the power of spoken word" These cultural perspectives regarding health and illness affect healthcare workers, family members and patient in making decisions in end of life(38).

The National Association of Social Workers (NASW) has recognize the priority of cultural competencies within medical practices in dealing with EOL decisions, because the cultural diversity of every particular groups may determine the sense of life and death in approaching end of life(39).

The importance of cultural consideration in EOL care is still increasing, since it has been evidenced to be an important factor in end of life decision making. The systematic review studies in seven European countries (German, Norway, Italy, Belgium, Netherlands, Spain and Portugal) had clearly distinguished the national cultures of end of life practices(40).

The difference in Western and Eastern culture have proven the profound distinctions of making decisions in end of life(13). Western health care professionals rely in individualistic as compared to Eastern who are collectivistic. In modern Western biomedicine the patient has right to be aware of seriousness of their illness, failure to do that you were be in the risk of lawsuits. In contrary to Non Western patient and relatives sometimes do not prefer such information (13,41).

2.1.4. Ethical and professional obligations.

Dealing with end of life care requires the healthcare workers knowledge of ethical issues (42).Withdrawing and withholding of life sustaining measures are governed by ethical principles of autonomy, non-maleficence, beneficence and justice, therefore understanding of its application by healthcare workers is important in making decisions of end of life.

However, withholding and withdrawing of life support from terminally ill patients has brought an ethical and moral challenges among physicians, nurses and family members,

Prolongation of life for dying patient is against the principle of non-maleficence of do no harm. The physician decisions of withholding or withdrawing life sustaining measures from the hopeless patient is ethically accepted. However, decisions might face with injunction from family members due to disagreement with healthcare workers decisions (43).

Withholding and withdrawing of life support from terminal ill patient is surrounded by various concerns. Such as religious, cultural, financial constraints and family members wish. Instead of rely on medical assessment(44), the need of ethical codes of conduct to govern healthcare workers obligations and practices concerning end of life decision making it seems to be an important ethical aspect in the critical care.

Responsibilities of respect of patient autonomy in the decision to forgo life sustaining therapy, including patient request in a humane and compassionate should be adhered to all healthcare workers in the decision of withholding and withdrawing life sustaining measures(45).

2.2. Healthcare workers experiences regarding ethical decisions making about withholding and withdrawing life support measures from terminally ill patients in ICU at Bugando Medical Centre.

Withholding and withdrawing life support from terminally ill patients is a common practice in ICUs. Its practice is more prominent in Western countries as compared to Eastern countries.

Four biomedical principles: beneficence, non-maleficence, justice, and respect the patient autonomy has governed the decisions making in end of life for terminally ill patients in medical practices (34). In Kantian ethics, for example, a human being as a rational being has the ability to make their own choices. This includes whether to refuse treatment or to agree to that treatment. In withholding and withdrawing life support, the patient has the right to refuse life sustaining treatment, provided that the patient has decisional capacity or the patient has designated a surrogate to make those decisions on his or her behalf.

2.2.1. Patient autonomy.

Respect of patient autonomy at end of life has brought a number of ethical issues in clinical settings(46). Concerns on whether to respect the precedent ethical principle of autonomy in end of life decisions or not is the ICU is sometimes questioned; and, this might contradict the patient's interest and wellbeing.

Furthermore, the advancement of technology has changed the practice of medicine from paternalistic to a patient-centered model where the decisions have shifted from physicians to patients. This affects the decisions on end of life practices in which the patient is given the power to decide concerning their treatment options (42). However, full autonomy in the case of serious illness may be questionable due to their capacity in deciding their individual goals of care.

With respect to patient autonomy, a competent patient or their appropriate surrogate decision maker may refuse life sustaining therapy based on written advanced directives. However, in some circumstances physicians may be able to limit life sustaining measures regardless of the presence of a surrogate decision marker or advanced directives (28). In Tanzanian case decisions to forgo life sustaining therapy it is still an ethical dilemma, because there is no clear framework that governs clinicians in making decisions on end of life issues.

The Australian and New Zealand Intensive Care Society (ANZICS) statement on care and decision making at the end of life for critically ill patients (2014) has stipulated guidelines and need of respecting the patient's autonomy at end of life. The statement also noted: "there are no legal and ethical obligations to provide care if the treatment is of no benefit to the patients(47)".

Autonomy has been identified as a biomedical and bioethical principle that emphasizes the rights of self-determinations and personal freedom and it plays an important role in end of life decision making, including limitation in life sustaining therapy(49).

2.2.2. Justice.

The fair distribution of resources among admitted patients in the ICU imposes ethical issues due to limited resources in the ICU. Continuing to use resources for patients that will not benefit is viewed as improper rationing and a misuse of finite resources(50).

Evidence has shown that, most of the patients died in ICUs with great expenses despite the intervention given to improve end of life treatments(51). Therefore, some of the decisions on limiting life sustaining therapy to terminally ill patients create concerns on resource allocation in ICUs.

In addition, the cost of ICU has changed the way in which medicine is practiced. Traditionally the patient who was in a coma or vegetative state was kept on machines and other life sustaining therapy until the patient died or passed away. Today, the practice is different; to continue with this kind of patient situation is perceived to be ethically troubling and unjust, because the used resources can be used by other patients who are more likely to benefit(52).

It has been shown that, the prolongation of life in the clinical setting (when it has been indicated that life is unsustainable) is ethically unaccepted; Therefore, withholding and withdrawing life sustaining therapy is indicated for the sake of inappropriate use of resources and when the patient is terminally ill(53).

Based on the concept of distributive justice, health care resources are very fixed and the fair allocation and prioritizations of resources are mandatory. The brain dead patient who occupies an ICU bed calls into question the dialogue that does or does not take place on withdrawing life sustaining measures (54).

2.2.3. Beneficence and Non Maleficence.

Decisions to withhold and withdraw life support is made when ICU physicians have made the risk and benefits of an interventions known to the patient or his or her family (33). Poor prognosis, futility, and brain death were among the mentioned reasons to withhold and withdraw life sustaining measures.

Furthermore, section three of the Position Paper of the American Thoracic Society (ATS), based on the ethical principles of beneficence and non-maleficence has defined the goal and purpose of life sustaining therapy. It has addressed that life sustaining therapy can be withheld or withdrawn if the treatment lacks benefit to the patient(45).

Moreover, the advancement of technology in medicine (which has been used to preserve and prolong the life of terminally ill patients) has brought forth the movement of right to

die. Here, not all patients need aggressive treatment and they may choose to forgo such treatment. This has led the medical profession to realize in some patients, treatment has little effects and causes more harm. Thus, there is a need to balance the potential risks with the potential benefits and guidelines to support clinician decision making in these circumstances (34).

Understanding of ethical issues surrounding end of life is an important consideration in ICU care. Analysis of risks and benefits can help to measure the risk-benefit ratio of the interventions being offered and making an appropriate decisions based on all information. Treatment should not be given if the intervention would cause more harm and suffering than benefit(55).

The primary role of medical practice is to preserve and prolong life, but every day in ICUs the decisions regarding withholding and withdrawing life support is made. These decisions are always made after the benefits and risks analysis for the best interest of the patients(56).

CHAPTER THREE

3.0. MATERIAL AND METHODS.

3.1. Study design.

A qualitative descriptive (QD) study design was used to explore perspectives of healthcare workers regarding withdrawing and withholding life support from terminally ill patients in the AICU of Bugando Medical Centre. A QD research design is used when the relevant information is required directly from those experiencing the phenomena under investigation; and, where the time and resource is limited (57). It draws from a naturalistic inquiry, which focuses on studying something in its natural state (58). It also seeks to discover and understand a process or perspectives and the world view of the people involved.

The purpose of this research design was to explore the perspectives of healthcare workers about withholding and withdrawing life support measures from terminally ill patients in AICU of Bugando Medical Centre. The design was intended to understand the perspectives of physicians and nurses with experience in the AICU setting as study participants. This population was recruited because physicians and nurses are directly involved in decision making on whether to withhold or withdraw life supportive measures from terminally ill patients in the ICU. The QD approach gathered information from experienced AICU practitioners using an open ended inquiry format. The study also involved naturalistic inquiry and explored withholding and withdrawing life support in its natural state in the AICU.

3.2. Study area.

The study was conducted at Bugando Medical Centre (BMC) in Mwanza Region at Nyamagana District. BMC is a consultant and University teaching hospital for the Lake and Western zones of the United Republic of Tanzania. It has a bed capacity of 950 beds. It is situated along the shores of Lake Victoria in Mwanza City. BMC serves a population of 16 million people from eight regions of the United Republic of Tanzania. This includes Mwanza, Kigoma, Geita, Simiyu, Tabora, Kagera, Shinyanga and Mara regions. The study was conducted specifically in the adult intensive care unit (AICU). The bed capacity of Bugando AICU is thirteen beds (13).

BMC Adult Intensive Care Unit (AICU).

Bugando Medical Centre has three ICU's, Neonates ICU (NICU), Pediatric ICU (PICU) and Adult ICU (AICU). The study were specifically conducted in AICU bed capacity of AICU at Bugando medical Centre is 13 beds, most of the beds are normally occupied by patients, and one bed is always left for Isolation. However due to high demand of ICU care, sometimes no empty beds will be available. The AICU bed capacity is few as compared to patient's needs. These rise to some ethical concern when caring patients in ICU. However insufficiency of life support machines such as mechanical ventilators positioned the AICU staffs into ethical dilemmas when two competing patients need the lifesaving interventions such as mechanical ventilator. The available mechanical ventilators in AICU are eight. The observations and interviews made during data collection revealed that, once the terminally ill patient is in mechanical ventilators, there is no way can be withdrawn from the interventions, it should wait until nature takes place. However, because of ICU cost, there is a time where the patient relatives request from the ICU team to withdrawn their patients from the mechanical ventilators and let him died. Due to lack of legal and ethical document governing the healthcare workers in making decisions concerning withholding and withdrawing life support measures from terminally ill patient, the physicians and nurses fear to make such ethical decisions. These made the hopeless patient to stay in life prolonging interventions until nature takes place. These practices sometimes limit accessibility of other patients who would benefit from lifesaving interventions.

On the other hand, the ICU human resources are twenty six (26) nurse and two physicians (2). The required staffs need to meet to ICU protocol of one to one proportion is at least thirty six (36) nurses. Therefore Bugando AICU is running with a shortage of ten nurse's which equivalent to 28%. This resulted to hinder the quality of ICU care.

3.3. Study population.

The study populations were healthcare workers currently working in AICU at Bugando Medical Centre, specifically nurses and physicians. The ICU human resources were twenty six (26) nurses and two physicians (2) during the study.

3.4. Exclusion and Inclusion Criteria.

3.4.1. Inclusion Criteria.

- Physicians and nurses who were currently working in the AICU of Bugando Medical Centre.

3.4.2. Exclusion criteria.

- Physicians and nurses who were working in the AICU of Bugando Medical Centre with less than three months experience in that setting.

3.5. Sample size.

The sample sizes for this study were 13 respondents (2 physicians and 11 nurses). Among them four were female and nine males.

The study were intended to recruit 20 respondents (10 physicians and 10 nurses), among them some of the AICU staff refused to participate in the study, others were not met the inclusion criteria. They were new employed and therefore were working less than three months in ICU as well as in other clinical setting. In addition the AICU physicians were not enough to reach the targeted sample; the AICU was having only three physicians who permanently work in ICU among them one refused to participate in the study. The study involved considerable variations in the years of clinical practice, years in ICU practices, age, experience, years of graduation and religion.

3.5.1. Sampling procedure.

The study employed purposive sampling in recruiting the participants. Maximum variation sampling, a type of purposive sampling, was used. This type of sampling helps to include diverse perspectives of nurses and physicians from different lengths of time in clinical practice, age, gender, individual cultural and region beliefs. A diverse subject pool captured a wide range of perceptions about withholding and withdrawing of terminally ill patients in ICUs and allows us to "identify important common patterns that cut across variations(59)."

3.6. Data collection methods.

A semi-structured interview guide was used to explore perspectives of healthcare workers at AICU at BMC. In addition, observation and note taking was used in the data collection process during the study. Withholding and withdrawing of life support is a new

phenomenon to explore within the Tanzanian context, therefore it took some time for clarification of terms and probing to expand the issues that were being asked to participants. The length of the interview was on average of 30- 45 minutes.

The study was conducted in a private separate room in the hospital and two-way communication was encouraged to ensure free talking of participants and researcher. All conversations were audio taped; the study recruited and trained two research assistants to assist the principal investigator in collecting and transcribing the interviews. The rigor and credibility of the qualitative data were assured by various methods described below.

The role of the principal investigator was to make sure that, all rules governing data collections was adhered, management and handling the research transcripts in confidential and save in a computer with key password. Also to notes some observations during the period of data collections in AICU. The PI used naturalistic observations whereby recorded what has been seeing in the AICU.

3.7. Rigor of the data.

3.7.1. Trustworthiness.

Trustworthiness is a measure of the overall quality of the qualitative data (60). Guba's four criteria were used to ensure the trustworthiness of the study: credibility, transferability, dependability and conformability (61). The following strategies were addressed in order to maximize the trustworthiness of the study.

Credibility refers to how confident researchers can have in the study findings. The principal investigator made the raw data available to the mentoring team to examine. Five member checks were done to confirm findings. Regular meetings with research assistants were conducted to discuss experiences and thoughts related to the research process.

Transferability refers to the ability of the study to provide sufficient information so one can determine that the findings are applicable to a new situation. Here thick descriptions of the interviews were provided, and purposive sampling was used.

Dependability refers to the ability of another researcher to follow the process of the qualitative study. To meet these criteria, the principal investigator used an audit trail technique to record all activities of the study, including memos, field notes and made the

raw data available. Therefore another researcher can examine both the process and research product consistency.

Confirmability refers to the degree to which the results could be confirmed or verified by others. The objectivity of the study was assured by regular communication and meeting. The PI, study team, and qualitative experts met regularly to discuss research assumptions or biases that might exist and to follow methodological rigor of implementing the study. The PI was also discussing any limitations of the study in his final methodological reports. Triangulations of methods of data collection were used, that is structured interview, observation and field notes.

3.7.2. Tool testing.

In order to ensure trustworthiness of the research findings and the clarity of the interview guide, the interview guide was pretested with a small number of individuals (5). The interview guides were pretested with participants in the ICU of Mloganzila Hospital. Mloganzila Hospital, which is a teaching hospital of Muhimbili University of Health and Allied Sciences. Revisions were discussed with the PI's Supervisors prior to implementation of the full study.

3.8. Data analysis.

Data analysis used both inductive and deductive thematic analysis, themes were pre-determined from conceptual frame work and interview guide, some categories were emerged during data analysis. Data were analyzed by using thematic content analysis with the assistance of computer software, NVIVO. Field notes, audio, and field observations were prepared, producing a verbatim transcript of the interviews. Identifiers were removed to secure anonymity. Each transcript was labeled with a file name. The verbatim transcripts were translated into the English language and the development of codes was done from both the interviewer and interview guide to formulate a code book. Lists of all codes were given a name and concise definition to create a label segment of text (theme). All the data listed in the code book were labeled to identify all segments of the text, condensed and the codes were assigned to develop sub categories and categories and the themes was then identified from the codes, subcategories and categories.

3.9. Ethical consideration.

The proposal was submitted to Muhimbili University of health and Allied Sciences (MUHAS) ETHICAL COMMITTEE and granted an ethical certificate approval Ref. No DA.287/298/01A/. Also, the proposal was submitted to CUHAS/BMC RESERCH AND ETHICAL COMMITTEE and granted an ethical certificate approval number: No CREC/351/2019. Permission for conducting the research was also sought from the Director of Bugando Medical Centre. Written consent was obtained from all participants following ethical clearance. This study was potentially sensitive; it dealt with EOL practices in ICUs. However, the study instruments were noninvasive, and participants did not have to participate in the study if they chose not to do so. In addition, participants did not have to answer any question in which they felt uncomfortable. If for any reason participants became upset with the question, the PI asked the participant if he/she needed to take a break or discuss the interview at another time. In addition there were potentials to disclose ICU practices by study participants. The participant's privacy and confidentiality were protected throughout the research process. No names were associated with the data or interview. Special codes were assigned to each participant, and a private room was used to conduct interviews.

3.9. 1. Study limitations.

There were several limitations to this study. First, was the potential for religious bias as Bugando Medical Centre is a Catholic institution and life is sacred in the Catholic faith, so withholding and withdrawing life support were perceived in a negative fashion. Therefore, some responses reflected religious beliefs rather than the clinical situation. Participants were asked to identify how their religious beliefs influence their clinical practice for patients at EOL. Second, this study was focused on one institution in one geographical location and therefore, differences might exist in other institutions and geographical locations in Tanzania. Third, generalizations of these study findings are limited due to limited sample used; therefore future studies will be needed to make comparisons of the data. Fourth, the majority of the participants were nurses because, most staff in the BMC AICU were nurses. Therefore, there were only a few physicians who participated in this study. Therefore the study findings rely more on nurse's views.

CHAPTER FOUR

4.0. RESULTS.

4.1. Introduction.

This section summarizes the findings from the interview conducted from healthcare workers to explore their perspectives regarding withholding and withdrawing life support measures from terminally ill patients. The interview was conducted to healthcare workers, nurses and physicians working in AICU of Bugando Medical Centre.

Participant's characteristics.

The study involved 13 respondents, nine were males and four females, among them two were physicians and twelve were nurses of different cadres, four Nursing officers and seven assistant nursing officers. The mean ages of the respondents were between 36 - 43 years. ICU and clinical experience were differs with respect to respondents, however majority of respondents range between 11-20 years and 3-10 years' experience in clinical and ICU practice respectively. However, the table below describes the professionals of respondents and years of graduation. These reflect the experience of healthcare workers opinions with regard to withholding and withdrawing life support measures from terminally ill patients.

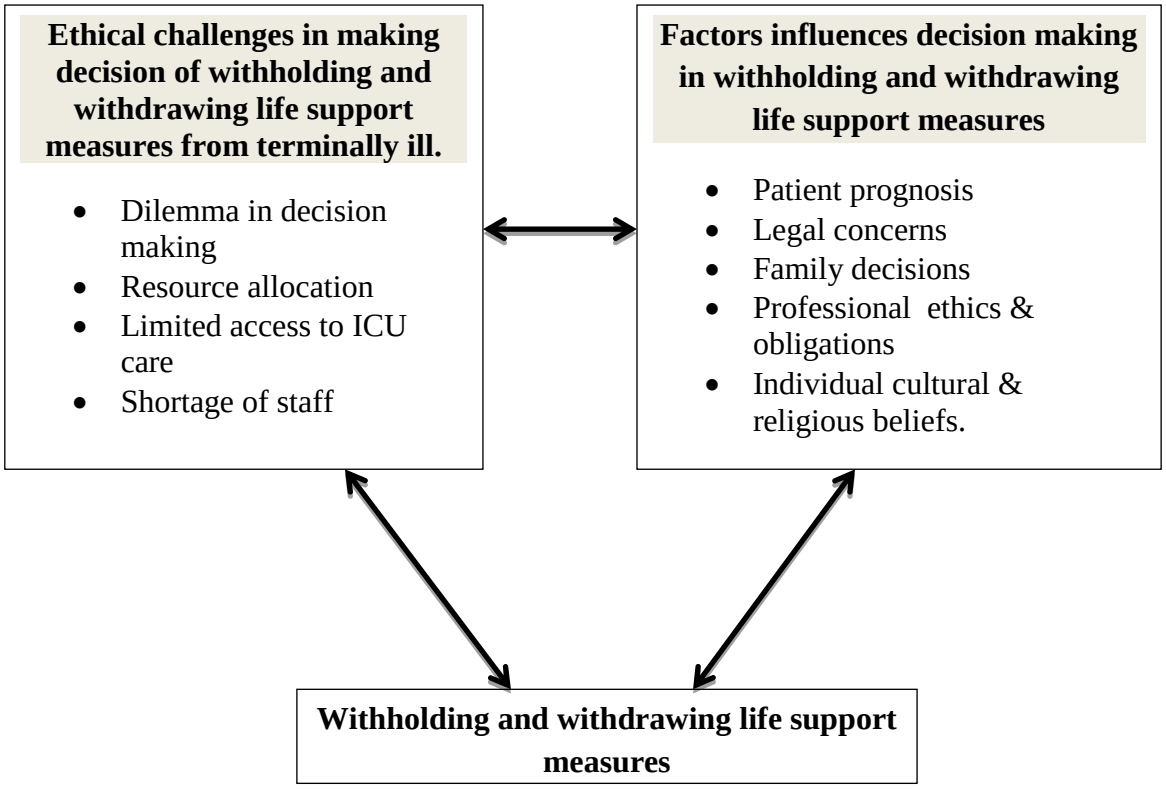


Figure 1 Summary findings illustrating how the two categories are related to one another and subcategories within each category.

From the analysis of interview documents two main themes related to healthcare workers perspectives in withholding and withdrawing life support measures from terminally ill patients were emerged. (1) Ethical challenges facing healthcare workers in making decisions of withholding and withdrawing life support from terminally ill (2) Factors influences the decision of withholding and withdrawing life support measures from terminally ill patients.

Theme 1. Ethical challenges facing healthcare workers in making decisions of withholding and withdrawing life support from terminally ill.

- **Dilemma in decision making**

Data from interviews found that, healthcare workers in the ICU face many challenges in making decisions in withholding and withdrawing life support measures from terminally ill patients. They face many ethical dilemmas, especially when it comes to the point to decide whether to continue or stop interventions for terminally ill patients. However they have a diverse views and perspectives in making decisions of withholding and withdrawing life support measures from terminally ill patients. In some cases healthcare workers might think that, patient condition can never be recovered but sometime when they continue interventions, the patient prognosis become well. Due to that, early withdrawing or withholding life support from terminally ill patients is somehow delayed ICU. As one nurse participant noted below the concern that some patients might recover:

> *"... The patients you may think that they cannot be improved, but they improved, we indicated to stop continuous medication or all management, but when we continue management the patients recover. So we found that stopping early the interventions or whatever medication is dangerous, we decide to leave the nature to take place. There are some patient you expecting is going to die soon but they are not died they recovered" (Nurse # 11).*

On the other hand, healthcare workers views to continue interventions for terminally ill patients who are ventilators dependent may be perceived as a misuse of resources and energy, because there is no chance of patient survival. Therefore, more effort is better directed to patients who have a high chance of recovery. As one of the nurse views in caring terminally ill patients in ICU.

> *"To me such patients who are seriously depend on the mechanical ventilators it is better to educate relative to remove from the machine rather than put on expenses which are painful in future" (Nurse # 3)*

Withholding and withdrawing life support from terminally ill patients was also seen in a different way to other participants. ICU services are very expensive, and the one who is responsible for payment is the patient himself or their relatives. If the patient stays on mechanical ventilator for a long time, the hospital expenditures becomes high. Therefore

keeping the hopeless patient on a mechanical ventilator for a period of time may be beneficial to the hospital and not to the patient, because they generate income despite the patient condition. This was noted by a one participant below:

> *"…but for the hospital is a benefit because themselves are just using material and this material will be paid by relatives so actually for other side it is paining because sometime relatives use money for the patient who have no hope…"(Nurse # 1).*

In addition, the duration of patient to stay on a mechanical ventilator before decision is made, on withdrawing or withholding life support measures. It has been found that, there is no specific time for the terminally ill patient to stay in mechanical ventilator. Patient has to stay in mechanical ventilator until the nature takes place. The study has found that, once the ICU is full occupied there is no chance of receiving another patient. One participant stated the following:

> *"Actually, we do not stop ventilators because other patients are coming. If you stop the ventilator you are terminating the life of the patient. We wait until the nature takes place, but may be if anybody happens to die, we can continue to use the available ventilators" (Physician # 6).*

- **Poor resource allocation.**

Moreover, the study showed inadequate of resources. Both human and non-human resources are among the ethical challenges in the ICU. The decisions of allocating resources in ICU have reported to be a challenging among healthcare workers. This concern was expressed below by two quotes from two participants.

> *"Here in Bugando, decisions are very challenging, because the ICU is not well established we have some materials but actually are not enough" (Nurse # 8).*

> *"The availability of beds is a challenge, we need to have more beds but for only present some time is not enough. It is challenging once you receive a patient who needs ICU care and that time all bed are fully covered" (Nurse # 9).*

- **Limited Access of ICU care.**

The study had revealed that, The ICU infrastructure of Bugando Medical Centre limit the access of care to other patients. The ICU room is small and occupies a limited number of beds Bugando medical Centre has only on AICU which is used to all hospital departments and all referral patients from eight regions of Lake Zones. Therefore some time demand for ICU care for patients is high but the ICU does not able to accommodate all patients at a time. These limit the access of other patient to ICU, however they also making the healthcare workers in an ethical dilemma to decide who should be given priority to ICU care. As one of the participant responded.

> *"…The ICU needs more beds but this should relate with room itself, the room we have is enough for only twelve beds. If we could have enough space also we could need more bed" (Nurse # 9).*

- **Shortage of human resources**

The study showed a shortage of human resources in ICU; the available human resource is 26 nurses and two physicians and one registrar, who are permanent employees in the department. Human resource capacity in the ICU of Bugando Medical Centre is not enough; one nurse can care more than three to four patients per shift. These sometimes affect the quality of care for patients. ICU patients always need special and close attention. The nurse patient ratio should be at least one nurse for two patients in order to provide a good quality care. However for the Bugando ICU is different. This is discussed below by several participants.

> *"… although we know that, one patient should be cared by one nurse but here is vice versa one nurse care three to four patients who in is critically ill. So this is a big challenge, may be the administrator may think about this, so that the care which are delivered to be goo and quality" (Nurse # 12).*

To improve quality of care in the ICU of Bugando Medical Centre, the hospital management should increase the number of staff including nurses, physicians and intensivist.

"...for the staff we have a shortage, in order to provide good and quality care to our critically ill patient in ICU should at least [be] one nurse [to] two patients or if there is enough staff should [be] one [patient to nurse] ratio one, one nurse one patient but nurse's care [for] two, three up to four patients."(Nurse # 10).

Theme 2. Factors considered in the decision of withholding and withdrawing life support measures from terminally ill patients.

Participants were conflicting in the views of the factors which considered in withholding and withdrawing life support measures from terminally ill patients.

- **Patient prognosis**

One of the factors which were revealed by the study to be considered by healthcare workers to withhold and withdrawal life support measures from terminally ill patient were patient prognosis. Data from interviews revealed diverse perceptions among healthcare workers in withholding and withdrawing of life support measures from terminally ill patient. Some respondents believe, patients with brain death have to be withdrawn from mechanical ventilation because of poor prognosis; however others believe that, even if the patient is diagnosed with brain death they should continue to stay on mechanical ventilation waiting for nature to take place. As one participant responded.

"Even if we are notifying this patient have brain death, we are waiting nature to take place although heart is pumping but brain died" (Nurse # 9).

Moreover, other participants believe that, as evidenced by diagnosis, once the patient condition is not promising or there is no hope of recovery, withholding and withdrawing life support measures should be considered. One nurse respondents from the interview

"To my side I think if the condition of the patient is promising as you know by diagnosis, by illness status of the patient if it is not promising in any way I think it is the right time to start withdrawal and withholding process"(Nurse # 4).

However, withholding and withdrawing life support measures from terminally ill patients in ICU have to consider all parameters before making the decisions. As quoted from one physician.

"…But before you make decisions you have to check all parameters of the patients such as vital signs, electrolyte balance, and urine output. When we see these parameters are diminished we must involve patients' family before making such decisions" (Physicians # 2).

- **Legal concerns.**

However, the study has discovered that, legal concerns is an issue in withdrawing and withholding life support measures from terminally ill patients. Withholding and withdrawing life support is generally regarded as intention killing, therefore healthcare workers afraid to make decisions because of troubled from legal prosecuted. This was reported by one of the participant.

"… I think this has to be now transformed in the legal status. These decisions should not being taken as just traditional decisions should be smart and legally accepted" (Nurse # 4).

Additionally, some respondents worried if medical personnel are scared to make decisions because of being fearful of prosecuted by the law, this could interfere medical practice. Despite concerns regarding legal issues, healthcare workers should have the power to make decisions in the best interests of their patients in order to protect medical practices from being impeded by law. As stated by one respondents.

"… My suggestions it will be not good to allow legal issue to cover everything for what we are doing in medical practice, because it will interfere [with] the care what we are giving to the patients" (Nurse # 12).

The availability of legal documents for withholding and withdrawing life support measures from terminally ill patients in ICU to help patients, families, and healthcare workers to have a clear understanding on end of life issues. This was discussed by a participant below.

"…Because we don't have a law on how to terminate life for terminally ill patients. We are just following the practices without laws [and] I think we should have clear protocol" *(Nurse # 1).*

- **ICU Cost**

The cost of ICU has also considered in withholding and withdrawing of life support measures. Data from interviews revealed that, affordability of the patients or patient's family to pay ICU cost can prolong the terminally ill patients in life support measures. Patient with high economic status have a great chance of staying on the ventilator for a longer period. As expressed by two participants in the following quotes:

> *"We can leave the patient even one-year on mechanical ventilator it depends on economics of the family if they afford paying or the government can pay for them*" *(Physician # 2).*

Sometimes healthcare workers find that it is good to withhold or withdraw life support from terminally ill patients in order to avoid unnecessary expenses to the patient who has no chance of gaining consciousness.

> *"My views for sure. In order to reduce expenses is better to withhold interventions because even if you continue with management there is no life"(Physician # 2).*

- **Family decisions**

Most of the respondents reported that, before making decisions of withholding or withdrawing life support from terminally ill patients, the patient's family or relatives should be involved. Normally family involvement helps to avoid conflict among healthcare workers and the patient's family.

> *"…decision relies on the sharing of the condition of particular patient to his or her relatives, and staff team as a whole after sharing of that information and counseling to family members. After that we direct go in to the real decision whether to withdrawal or keep the patient" (Physician # 6).*

The study showed, physicians and nurses have no direct mandate to decide whether to continue or to limit life sustain interventions to terminally ill patients, instead the decisions is made by patient family and healthcare team.

> *"However, for us sometimes we have no decisions direct, but the patient families are the ones who make decisions about their patient's conditions. We normally involve the family when we see poor prognosis" (Nurse # 8).*

- **Professional ethics and obligations.**

Study has showed that, physicians and nurses are opposing the practice of withholding and withdrawing life support from terminally ill patients. They said that, this is contrary to their professional ethics and obligations. Their concerns are to make sure that patient's life is secured at any cost. The ICU practice should rely on professional and ethical conduct of both nurses and physicians as indicated in the following physician's quotes:

> *"The patient is priority for the doctors and always save the life of the patients and my working is to save patient life. Every time I have to work on the patients' interests until the nature take place" (Physician # 2).*

> *"Me as a physician, patient is my priority, I always work on the patient interest. During my whole medical training I know I should care [for]the patient until the last minutes even if I know that this patient is going to die two or three minutes later."(Physician # 6).*

On the other hand, nurses have negative perceptions in terminating one's life, to withhold and withdrawal life support is against professional obligations and nurse's ethics. As reported by a nurse in the quote:

> *"No I did not ever withdrawing care from terminally ill patients, because we as a nurse we have saying nurse for life. The heart is still working but brain may be died. So we continue to care the patient" (Nurse # 5).*

- **Individual cultural and religious beliefs.**

However, individual cultural and religious beliefs are among the factors that are considered in withholding and withdrawing life support measures from terminally ill patients. Since withholding and withdrawing is generally regarded as a "killing", this has affected individual decisions in the ICU. Respondents reported their religious beliefs are among the reason that prohibits them from withholding and withdrawing life support from terminally ill patients. Because human beings have been created by God and only God is the one who has the mandate of taking the life of the human being. This was quoted by one of the participant below.

> *"...I' m not allowed to do anything that can cut life of any person, withholding and withdrawing life support is like a killing and according to our beliefs no one is allowed to terminate the life of anybody unless otherwise only the God who created us" (Nurse # 1)*

Therefore, if the patient is on mechanical ventilator and even if there is no hope of recovery, it is better to leave the patient until the nature takes place and God intervenes.

> *"...You can't terminate the life of a person. Only God can terminate not me. If it is possible to continue give him the oxygen, blood and life supportive measures" (Nurse #7).*

None of the respondents reported the influence of their traditional culture on their patient-related decisions at end of life. As stated by two quotes below from nurses.

> *"My individual culture does not affect my decisions, but religions affect much because we have told that do not kill or terminate the life of others. It is difficult to make such kind of decision" (Nurse #7).*

"My traditional cultures do not affecting me rather than legal and religions. Legal issues are very important as a nurse you are not allowed to support life support measures unless the doctor have made a decisions" (Nurse # 4).

CHAPTER FIVE

4.0 DISCUSSION.

This study has revealed that, there a variation in perspectives of healthcare workers towards withholding and withdrawing life support measures from terminally ill patients. However, the healthcare workers face many challenges in decision making to withhold and withdraw life support measures.

Ethical challenges facing healthcare workers in making decisions of withholding and withdrawing life support from terminally ill.

The study was aimed at exploring the perceptions of healthcare workers on withholding and withdrawing life supportive measures from terminally ill patients. This study found that, healthcare workers have diverse thoughts and perceptions in the practice of withholding and withdrawing life support from terminally ill patients. Similar to the study conducted in Asia(62), the decision on withholding and withdrawing life supportive measures varies according to economic status, cultural, religious, age, years in clinical practice, years in ICU and legal concerns. However, Hinkka et al reported considerable variation in doctor's decision to forgo specific life sustaining treatments (12).

However, the findings has revealed that, Healthcare workers still are facing many challenges in making decision of withholding and withdrawing life support from terminally ill patients. The practice brought diverse views among healthcare workers, the study is similar to article (29) written by Massimo stated, end of life is among the prominent area of controversial in contemporary bioethics. However, the absence of guidelines on when to consider withholding and withdrawing life support from terminally ill patients is one of the findings in this study. The healthcare workers have no standard operating procedure in withholding and withdrawing life support from terminally ill patients. This brings the issue of inconsistency in the practice. This situation is different from the Netherland, where they have provided the tools for healthcare workers to consider in withholding and withdrawing life support which guides all medical team(3). The tool harmonizes the practice of end of life decisions for terminally ill patients. The tool helps the medical team to make decisions in congruent with patient situations. However, it went further to describe when to involve patient families in making decisions.

In addition to unfair distribution of resources such as ICU beds, ICU infrastructure, mechanical ventilators and human resources in the ICU is among the factors that put healthcare workers in a difficult position for making decision on withholding and withdrawing life support. The study has found that, there is a limited resource in ICU and patient stay until the nature takes place. However some healthcare workers opinions were to consider withholding or withdrawing life sustaining therapies for the irreversible patients. They perceived to continue to use resources for the patient, who has no hope of recovery, is wastage of money and materials. However, the study is similar to Lanken et al. (50) stated continuing to use resources for the hopeless patient is viewing as improper rationing and misuse of resources.

The study reported a high demand of ICU care, as compared to the capacity of the ICU. There are times where patients need ICU but the beds are few which limit accessibility of other patients to ICU care. The study conducted by Luchetti (53) stated that, *"the prolongation of life for the patient who had proved the life is irreversible is ethically unacceptable."* The risks and benefits of further treatment should be analyzed in order to save finite resources. (54).

Due to finite resources in the ICU, healthcare workers have established mechanisms to ensure that resources are distributed fairly. The study revealed that, patients are ranked according to their level of seriousness. Those who are at least recovery are transferred to the normal ward. Comparable to Simon, (19) who said that, "the issue of rationing is a common ethical concern in Tanzania." Therefore rationing is inevitable in an area with scarce resources.

Factors considered in the decision of withholding and withdrawing life support measures from terminally ill patients.

Patient prognosis

Patient prognosis is an important factor in end of life decisions. Patients diagnosed with brain death have no hope of recovery and is generally deemed as futile due to poor prognosis. The study finding has shown that, withholding and withdrawing can be considered if the patient prognosis is poor. The study conducted by Aachrya et al said that, a futile medical treatments are incapable of attaining the desired goal(63) therefore there is no need of continuing treatment when it considered a futile. Also another study stated that, "to attempt futile treatment is to display an ignorance that is allied to madness(64)."Thomas Liqueur (21) define futility as the limit of medicine and physicians should not provide treatments. However, still there is no agreement (29) in the practice of withholding and withdrawing life support in some parts of the world among healthcare workers. The findings of this study show that regardless of patient diagnosis, healthcare workers perceptions differ in withholding and withdrawing life support from terminally ill patients. Therefore the concept of withholding and withdrawing life support from terminally ill patients is still controversial to healthcare workers in the ICU of Tanzania.

Moreover, Withholding and withdrawing life support from terminally ill patients is surrounded by legal aspects, fear of being prosecuted by family members and conflict. In this study, respondents perceived that the lack of legal documents to explain clearly defined procedure to withhold and withdraw life support is a moral challenge. The case of Karen Ann Quinlan, Nancy Cruzan, and Terry Schiavo has raised legal attention in the practice of withholding and withdrawing life support because of misunderstanding between patient families and medical team in limiting life prolonging interventions(33). The concern of competent and incompetent patient is serious issue in decision making. The study results show that, most of the patients come to the ICU in a critical stage; thus, their decisions are often made by relatives. We argue if these surrogate decisions is for the best interest of the patients meanwhile there is no clear mechanism of selecting surrogate decision maker, however legal consideration provide guideline when the patient is incompetent to make decisions(35). Of which in our practice we are lacking these

guideline. McGowan (2018), (36) stipulated the procedure who should be a surrogate decision maker if the patient does not have mental capacity to make a medical decision.

Moreover, the study discovered most of the respondents in ICU need to have the law which governs these practices in order for them to be safe and practiced in a lawful way. They fear to make decisions because of negative perceptions of withholding and withdrawing life support from terminally ill patients, as it perceived as intentional killing and the absence of law to support the practice. However the importance of the law in the practices has been exposed by (65), states, the law that governs whether life sustaining medical treatment at the end of life should withdraw or withheld. The availability of law guiding the practices of end life will provide clear scope of practices to healthcare workers.

Traditionally, the vegetative and comatose patient was kept in the ICU until death, but today the practice is different in some other parts of world. To continue with aggressive treatments for patients in this condition is often perceived as an injustice to other patients who will benefit from ICU care. Our findings have discovered that, the ICU cost is very high for those on ventilators. Some believes that, withholding and withdrawing life support for terminally ill patient is appropriate to decrease costs for both the hospital and the patient's relatives. This is similar to Luchetti (53), written that, "prolongation of life for irreversible patients is inappropriate use of resources." It is ethically an injustice to use resources to continue support for the vegetative and comatose patient who is not going to benefit from further treatments in the ICU (52) is unacceptable.

CHAPTER SIX

6.0. CONCLUSION AND RECOMMENDATIONS.

6.1. CONCLUSION

The practice of withholding and withdrawing life support measures from terminally ill patients in ICU of Bugando Medical Centre face many challenges. However, there is considerable factors which believed by health care workers to withhold or withdrawing life support measures from terminally ill patients. Due to lack of legal and ethical framework to guide the practices, physicians and nurses fear.

6.2. RECOMMENDATIONS.

i. The government and stakeholders should look forward the establishment of legal and ethical framework in the practice of withholding and withdrawing life support measures from terminally ill patients in ICU.

ii. The hospital administration should look forward to establishment mechanism of guidance and dealing with ethical dilemmas in the ICU as well as to other clinical settings.

iii. Further study can be done to determine underlying issues relating to end of life ethical issues and magnitude of the problem in ICU's of Tanzania.

DISSEMINATION PLAN.

The proposed publications: Two articles are expected to be published after the approval from Postgraduate studies following the research defense. The first article was be *"Healthcare workers' perceptions regarding withholding and withdrawing life support measures from terminally ill patient in Tanzanian ICUs"* and "*Factors which determine the decision of withholding and withdrawing life supportive measures from terminally ill patients in Tanzania ICUs.*

Institutional and University research seminars

Research a finding of this study will be shared at Bugando Medical Centre, Catholic University of health and Allied Sciences.

Local and International conferences

The findings will be disseminated to local scientific Conferences at MUHA, CUHAS, UDOM and any other areas provided the opportunities is available to share the findings. However, the study findings will also be shared in the Bioethics International conference.

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ANNEX 1: INTERVIEW GUIDE: ENGLISH VERSION

1. What is your age?
    a) When did you graduate from nursing or medical school?
    b) How long have you been working in the ICU?
    c) How long have you been in clinical practice?

1. Can you describe to me your experiences in making decisions concerning terminally ill patients; can you share with me an example of what that was like for you both a positive and challenging experience. What kinds of issues arose? (*probe how experience has assisted you in making decisions to terminally ill patients)*?
2. Can you describe how the ICU resources meet the demand of patient's needs? *(probe availability of beds, ventilators, human resources, medical supplies)*
3. To what extent do ICU resource allocation issues influence your decision making concerning withholding or withdrawing life support from terminally ill patients?
4. What do you understand by the term "life support measures" for terminally ill patients *(Probe ventilator machine, resuscitations, medication)?What does this mean to you?*
5. From your opinion, what is the average time that most terminally ill patients stay on life support measures such as mechanical ventilator machine in ICU? What do you think about this time frame? *(Probe for life, till death).*
6. What are your views on withholding and withdrawing life support measures from terminally ill patients in ICU? Can you share with me when this has occurred and your experience? How do you define "withholding and withdrawing life support measures" in the ICU?
7. What factors or conditions do you think are important to consider regarding withholding and withdrawing of life support measures from terminally ill patients*? (Probe poor prognosis).*
8. What could be an appropriate time to withhold or withdrawal life support measures from terminally ill patients?
9. What factors do you think could affect the decision making in withholding and withdrawing of life support measures from terminally ill patients? *(Probe legal concern, beneficence & non maleficence, religious concerns, family conflict, lack of advance directive).*

10. How do sociocultural issues affect your decisions in withholding and withdrawing life support measures from terminally ill patients *(probe religious beliefs, cultural beliefs)?*
11. What are your thoughts on the rights of the patient to refuse life prolonging interventions in ICU? Such as mechanical ventilator, medications. *(Probe right to self-determination, application in our context).* Can you share with me when this has occurred in the ICU?
12. Are there any other issues on this topic that you would like to share with me?

ANNEX-2: INTERVIEW GUIDE: SWAHILI VERSION

1. Una umri gani?
    a) Lini umemaliza masomo yako ya uuguzi/udaktari?
    b) Ni kwa muda gani umefanya kazi kwenye chumba cha wagonjwa mahututi?
2. Unaweza kunieleza uzoefu wako katika kufanya maamuzi ya kitabibu kwa wagonjwa walio katika hatua za mwisho wa maisha yao. Unaweza kunishirikisha mfano halisi wa vikwazo ulivyowahi kukutana navyo katika kutoa maamuzi. Ni tukio gani lilishawahi kutokea (Dodosa kuhusu uzoefu kama umesaidia kufanya maamuzi)
3. Unaweza kunieleza ni kwa namna gani mgawanyo wa rasimali katika chumba cha wagonjwa mahututi unavyoakisi mahitaji ya wagonjwa? (Dodosa kuhusu vitanda, machine za kusaidia kupumua, rasimali watu na vifaa tiba).
4. Ni kwa kiasi gani mgawanyo wa rasilimali katika chumba cha wagonjwa mahututi unaweza kuathiri maamuzi yako hasa katika kutoanzisha au kusitisha huduma kwa wagonjwa walio katika hatua za mwisho wa maisha yao?
5. Unaelewa nini kuhusu huduma za kumsaidia mgonjwa kuongeza maisha yake (Dodosa kuhusu mashine za kusaidia kupumua, kuamsha moyo)?
6. Kwa mawazo yako. Ni muda gani muafaka kwa wagonjwa walio hatua za mwisho wa maisha yao kukaa kwenye mashine za kumsaidia kurefusha maisha (dodosa muda wote, mpaka kifo,)?
7. Nini maoni yako kuhusu kutoanzisha au kusitisha huduma za kumsaidia kurefusha maisha kwa wagonjwa walio katika hatua za mwisho wa maisha yao. Tafadhali unaweza kuniambia ni lini suala kama hili limewahi kukutokea na uzoefu wako.
   Kwa namna gani unaweza kuelezea kuhusu kutoanziasha au kusitisha huduma za kumsaidia kurefusha maisha.
8. Ni vitu gani unafikiri ni muhimu kuzingatia katika kutoanzisha au kusitisha huduma kwa wagonjwa walio katika hatua za mwisho wa maisha yao (Dodosa meandeleo duni ya mgonjwa, matakwa ya mgojwa mwenyewe nk)?
9. Ni wakati gani muafaka kutoanzisha au kusitisha huduma kwa wagonjwa walio katika hatua za mwisho wa maisha yao?

10. Unafikiri ni sababu zipi zinaweza kuathiri kufanya maamuzi ya kutoanziasha au kusitisha huduma kwa wagojwa walio katika hatua za mwisho wa maisha yao (Dodosa mambo ya kisheria,faida na hasara kwa mgonjwa, dini, migongano ya kifamilia)?
11. Ni kwa naman gani masuala ya kijadi na kijamii yanaweza kuathiri maamuzi yako katika kutoanzisha au kusitisha huduma ya kurefusha maisha kwa wagonjwa walio katika hatua za mwisho wa maisha yao (dodosa imani za kidini, imani za kijadi)
12. Ni nini mawazo yako kuhusu haki za wagonjwa walio katika chumba cha wagonjwa mahututi kukataa matibabu ya kuongeza urefu wa maisha yao. (dodosa kuhusu haki mgonjwa kufanya maamuzi yake mwenyewe).
13. Kuna jambo lolote linalohusu mada hii ungependa kujadili kwa pamoja?

ANNEX-3: INFORMED CONSENT FORM (ENGLISH VERSION.

Introduction:

My name is_____

I'm a Postgraduate student at Muhimbili University of Health and Allied Sciences (MUHAS) pursuing a Master of Science in Bioethics: I am conducting a research entitled *"Withholding and Withdrawing life support measures from terminally ill patients: perceptions of healthcare workers at Bugando medical Centre."*

Purpose of the research:

In Tanzania, withholding and withdrawing of life support measures is not legally authorized but is traditionally practiced by healthcare workers. Healthcare workers in Tanzania ICU's face ethical dilemmas in caring for terminally ill patients, particularly in making decisions at end-of-life. Many factors may affect decision making at end-of-life including cultural, religious, and professional issues. The purpose of this research is to better understand from physicians and nurses their perceptions on end-of-life issues for terminally ill patients in ICUs and the factors that influence their decisions.

Procedures:

You are being asked to participate in this research because you are a physician or nurse who is currently working in the ICU. You will be asked to participate in an interview about end-of-life issues in the ICU that should take about 45 minutes. If you accept, you will be asked some questions concerning end-of-life and how you make decisions. Also I am asking your permission to use a tape recorder to record your voice because it is difficult for me to capture all information by writing and to make sure that I have all of your information correctly stated.

Risks and discomforts:

Because this study is discussing end-of-life issues, it may be sensitive to some. You are not under any obligation to participate and participants have every right to answer only those questions that they choose to answer without penalty. All information provided by participants will be confidential. Though, in case of any unanticipated physical and emotional discomforts the moderators, who was be the persons with background of health and counseling skills, was ask if participants would like to stop the interview and start at another time.

Benefits:

The findings of this study have no direct benefit to you, but your participation will help the entire health care system in Tanzania, policy makers, physicians, nurses and other stakeholders in health system to develop the best way of dealing with end-of-life issues which are common in Tanzanian ICUs.

Confidentiality and anonymity:

The information that collects from this research will be kept confidential. No information other than this consent form will be having your identification on it. Data will only being available to the PI and supervisors.

Right to refuse or withdraw:

Participating in this study is voluntary. You do not have to take part in this research if you do not wish to do so, and refusing to participate was not affect you in any way.

Duration:

The interview will take approximately forty five minutes to one hour.

Who to contact:

If you have any inquiry, please contact the

Principal Investigators (PI)
Ndakibae G Mabega
P.O.BOX 5108
MWANZA.
Mob : +255759271430
+255787745937
Email: mabega2k@yahoo.com
DR BRUNO SUNGUYA,
DIRECTOR RESEARCH AND PUBLICATIONS
MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES
P.O.BOX 65001
DAR ES SALAAM.
TEL: 2150302-6

Certification of Consent:

With the clarity of my mind without undue influence; I have read the information, or it has been read to me. I have been given the opportunity to ask questions about study. I consent voluntarily to be a participant in this study and understand that I have the right to withdraw from the interview at any time without any effects.

I ……. On this day……..of……..2018 have read and understood the information about the study and voluntarily agree to participate.

Signature of the Participant_____ Date: _____

Name of the Interviewer:_____ Signature of the Interviewer_____

ANNEX-4: INFORMED CONSENT FORM (SWAHILI VERSION.

Utangulizi:

Kwa majina naitwa _____

Ni mwanafunzi wa shahada ya uzamili, Chuo Kikuu cha Tiba na Sayansi Shirikishi Muhimbili.

Nafanya utafiti kuhusu mitazamo ya watumishi wa afya wanaotoa huduma katika chumba cha wagonjwa mahututi. Kutoanzisha au kusitisha huduma kwa wagonjwa walio katika hatua za mwisho za maisha yao.

Lengo la utafiti.

Kutonzishwa au kusitishwa huduma kwa wagonjwa walio katika hatua za mwisho wa maisha yao ni kitendo ambacho bado hakijapata baraka za kisheria ingawa kwa upande mwingine kinafanyika kwenye maeneo ya kazi za kitabibu.

Kutokuwepo kwa miongozo sahihi kunawafanya watoa huduma za afya katika vyumba vya wagonjwa mahututi kuwa katika wakati mgumu wa kufanya maamuzi.

Hata hivyo kuna mambo mengi yanayoathiri utoaji wa maamuzi kwa watoa huduma za afya wakati wa hatua za mwisho wa maisha kwa wagonjwa. Mambo hayo ni pamoja na kuwa na mitazamo tofauti katika nyanja za kidini, kijamii, na kiutendaji katika utoaji wa maamuzi. Hivyo kutokuwepo kwa miongozo ya kitabibu na kisheria inayotoa maelekezo ya kufanya maamuzi kwa wagonjwa waliokaribia mwisho wa maisha yao kunawaweka watoa huduma katika wakati mgumu wa kufanya maamuzi kwa wagonjwa hao.

Hata hivyo hakuna utafiti uliofanyika hapa Tanzania kwa watoa huduma za afya wa chumba cha wagonjwa mahututi kuhusu mitazamo yao juu kutoanzisha au kusitisha huduma za kusaidia kurefusha maisha kwa wagonjwa walio katika hatua za mwisho wa maisha yao.

Kwa hiyo utafiti huu unalenga kuangalia mitazamo ya watoa huduma za afya katika vyumba vya wagonjwa mahututi juu ya kutoanzisha au kusitisha huduma za kurefusha maisha kwa wagonjwa wanaokaribia mwisho wa maisha yao.

Mbinu zitazotumika.

Ili kuweza kupata majibu ya maswali haya, napenda kuchukua nafasi hii kukualika uwe mmoja wa utafiti huu. Hii ni kwa sababu una uzoefu katika kuhudumia wagonjwa ambao wapo katika hatua za mwisho maisha yao.

Nina imani ushirikiano wako utachangia mawazo muhimu katika utafiti huu. Kama utakuwa tayari kushirki nitakuuliza maswali yanayohusu mada hii. Pia nitaomba ridhaa yako kutumia kinasa sauti ili kuweza kunasa sauti yako wakati wa mahojiano. Hii ni kuwezesha kutunza kumbukumbu.

Madhara

Kutakuwepo na madhara kidogo yatakayotokana na kuweka wazi kwa vitendo vinavyofanyika katika vyumba vya wagonjwa mahututi. Lakini nakuhakikishia mambo yote tutakayojadili mimi na wewe yatabaki kuwa siri kati yangu mimi na wewe na hayatatoka kwa namna yoyote nje ya hapa.

Faida

Matokeo ya utafiti huu hayatakuwa na manufaa ya moja kwa moja kwako bali kwa ushiriki wako utasaidia mabadiliko katika mfumo wa afya wa Tanzania, watunga sera, madaktari, wauguzi na washika dau wa afya kuweza kubuni namna ya kufanya maamuzi sahihi na kuhudumia wagojwa walio katika hatua za mwisho wa maisha yao.

Usiri

Taarifa zote zitakazopatikana katika utafiti huu zitakuwa siri. Hakutakuwa na taarifa yoyote itakayoonyesha utambulisho wako zaidi ya hii fomu.

Haki ya kujitoa

Kushiriki katika utafiti huu ni hiari. Hivyo mshiriki una haki ya kujitoa wakati wowote katka utafiti.

Muda wa mahojiano.

Mahojiano haya yanakadiriwa kuchukua dakika 45 mpaka dakika 60

Mawasiliano

Kwa maswali wasiliana na wafuatao

1) MTAFITI MKUU
   NDAKIBAE G MABEGA
   P.O.BOX 5108
   MWANZA
   Mob: +255759271430
   +255787745937
   Email: mabega2k@yahoo.com

2) DR. BRUNO SUNGUYA
   DIRECTOR OF POSTGRADUATE AND PUBLICATIONS
   MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES
   P.0.BOX 65001
   DAR ES SALAAM
   TEL: Tel: 2150302-6

Uthibitisho wa ushiriki

Kwa maelezo niliyopewa, bila kulazimishwa, Nimesoma maelezo/ Nimesomewa, nimepwewa nafasi ya kuuliza maswali kwa ridhaa yangu nimekubali kushiriki utafit huu. Mimi ……. Siku ya ……..ya……..2018 nimesoma kuelewa maelezo kuhusu utafiti na kuamua kushiriki utafiti huu.

Jina la mshiriki_____Sahihi ya mshiriki_____Date: _____

Jina la mtafiti:_____ Sahihi ya mtafiti_____Date_____

ANNEX-5. MUHAS ETHICAL CLEARENCE

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES
OFFICE OF THE DIRECTOR OF POSTGRADUATE STUDIES

P.O. Box 65001
DAR ES SALAAM
TANZANIA
Web: www.muhas.ac.tz

Tel G/Line: +255-22-2150302/6 Ext. 1015
Direct Line: +255-22-2151378
Telefax: +255-22-2150465
E-mail: dpgs@muhas.ac.tz

Ref. No. DA.287/298/01A/

5th March, 2019

Mr. Ndakibae G. Mabega
Master of Science in Bioethics,
MUHAS.

RE: APPROVAL OF ETHICAL CLEARANCE FOR A STUDY TITLED: "WITHHOLDING AND WITHDRAWING LIFE SUPPORT MEASURES FROM TERMINALLY ILL PATIENTS: PERCEPTION OF HEALTHCARE WORKERS AT BUGANDO MEDICAL CENTRE, MWANZA REGION-TANZANIA

Reference is made to the above heading.

I am pleased to inform you that, the Chairman has, on behalf of the Senate, approved ethical clearance for the above-mentioned study. Hence you may proceed with the planned study.

The ethical clearance is valid for one year only, from **22nd February, 2019 to 21st February, 2020.** In case you do not complete data analysis and dissertation report writing by 21st **February, 2020,** you will have to apply for renewal of ethical clearance prior to the expiry date.

Dr. Emmanuel Balandya
ACTING: DIRECTOR OF POSTGRADUATE STUDIES

cc: Director of Research and Publications
cc: Dean, School of Public Health and Social Sciences, MUHAS

ANNEX- 6. CUHAS/BMC ETHICAL CLEARENCE

CATHOLIC UNIVERSITY OF HEALTH
AND ALLIED SCIENCES
BUGANDO

P.O. Box 1464 Phone: (255) 28-250-0881 Email: vc@bugando.ac.tz
Mwanza, Tanzania Fax: (255) 28-250-2678 Website: www.bugando.ac.tz

CUHAS/BMC RESEARCH & ETHICAL COMMITTEE (CREC)
ETHICAL CLEARANCE FORM

Date	**21st March 2019**
Research Clearance Certificate No	**CREC/351/2019**
Name of researchers/PI and Institution	▪ **Ndakibae Gabriel Mabega** ▪ **MUHAS**
Purpose of the research	**MSc. In Bioethics of the Muhimbili University of Health and Allied Sciences.**
Title of the Research	**Withholding and Withdrawing Life Support Measures from Terminally Ill Patient: Perception of Health Care Workers at Bugando Medical Centre, Mwanza Region-Tanzania.**
Budget and Sponsor (s)	▪ **Tshs 2,400,000/=** ▪ **DMRET**
Research period	**March 2019 to February 2020**

Ethical clearance is hereby granted.

A progress report shall be submitted to the relevant Directorate every 6 months.

CREC Chairperson **CREC Secretary**

Director RESEARCH AND PUBLICATION CATHOLIC UNIVERSITY OF HEALTH AND ALLIED SCIENCES P.O. BOX 1464 MWANZA, TANZANIA