

**CAREGIVERS' PERCEPTIONS TOWARDS DECISION-MAKING FOR DO
NOT RESUSCITATE ORDERS: A QUALITATIVE STUDY IN RURAL
SOUTHWESTERN KENYA**

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in Partial Fulfillment of the Requirements for the Award of the Master of Medicine
in Family Medicine**

KABARAK UNIVERSITY

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DEDICATION

I would like to dedicate this work to my family.

ABSTRACT

The need for palliative care services has increased with the rise of patients with terminal illnesses. Unfortunately, there is a need for more research in palliative care, especially on end-of-life care and in African societies. Conversations during that period presented ethical and cultural challenges in both collectivistic and individualistic societies. Do not resuscitate (DNR) orders and decision-making surrounding them are a core part of end-of-life discussions. Worldwide, the laws regulating Do Not Resuscitate orders differ from country to country. The factors influencing decision-making also vary from society to society. Studies have shown the need to involve families in this era of rising advocacy for patient-centered care. Caregivers have an essential role in decision-making at the end of life and are involved in end-of-life decisions. However, how they perceive Do Not Resuscitate orders, their expectations while discussing, and the factors involved in decision-making still need to be discovered in our settings. This study aimed to describe caregivers' perceptions of Do Not Resuscitate orders. It also sought factors involved in the Do Not Resuscitate decision-making process for caregivers. Finally, it helped to determine the expectations of the palliative care patients' families while making do-not-resuscitate orders. The study used a qualitative approach and phenomenological research design. The study involved eighteen caregivers of patients receiving palliative care and six healthcare providers. The sampling procedure was non-probability, purposive, and convenient. Data was collected using in-depth interviews and focus group discussions. Thematic analysis was used to analyze the data. The main themes that emerged were lack of awareness and misunderstanding of resuscitation methods. Besides that, there were subjective perceptions based on caregivers' beliefs and emotional responses. Life extension was an overarching factor while having DNR status conversion. Social, economic, spiritual, and cultural factors, the patient's condition, and the healthcare system influenced DNR orders. Appropriate and early communication was the expectation from the caregivers and collectivist decision-making. To have better and more successful Do Not Resuscitate conversations, there is a need to educate caregivers of patients on palliative care on Do Not Resuscitate and resuscitation methods, a need for counseling and preparation, and a need to empower Healthcare providers to hold those discussions.

Keywords: *Caregivers, Decision-Making, DNR, End-of-life, Palliative Care*

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ABBREVIATIONS AND ACRONYMS

AD	Advance directives
AHA	American Heart Association
AND	Allow Natural Death
CPR	Cardio-Pulmonary Resuscitation
DNR	Do Not Resuscitate
EOL	End-of-Life
FGD	Focus Group Discussion
HCP	Health Care Professionals(s)
HIV	Human Immunodeficiency Virus
KEHPCA	Kenya Hospice and Palliative Care Association
KNH	Kenyatta National Hospital
KUREC	Kabarak University Research Ethics Committee
NACOSTI	National Commission for Science, Technology and Innovation
PC	Palliative Care
SSA	Sub-Saharan Africa
TMH	Tenwek Mission Hospital
UHC	Universal Health Coverage
WHO	World Health Organization
WPHCA	Worldwide Hospice Palliative Care Alliance

CONCEPTUAL AND OPERATIONAL DEFINITION OF TERMS

Caregivers: Individuals involved in patients' health decision-making or identified by the patient as persons involved in their care. For this study, this includes only unpaid relatives of the patients.

DNR Orders: Directives signed by the patients or their surrogates in the presence of their physicians stipulating that the patient should not undergo resuscitation in the event of a cardio-respiratory arrest. This study's DNR orders involve withholding CPR, intubation, and mechanical ventilation.

Healthcare Professionals: Individuals who deliver medical care to any sick person. In this study, the definition is limited to doctors, clinical officers, and nurses.

DNR Decision-Making: For this study, this is a process where healthcare professionals discuss with caregivers about the patient terminal illness and the idea of not performing CPR or doing it. The caregivers then think and choose the best option for their patient. Negative and positive aspects of the choices are taken into consideration. It ends with a patient code status

CHAPTER ONE

INTRODUCTION

1.1 Introduction

This chapter includes the background, statement of the problem, justification of the study, objectives, purpose of the study, significance of the study, and the limitations of the study.

1.2 Background of Study

1.2.1 DNR and Advance Directives

Patients with terminal illnesses and their caregivers face end-of-life (EOL) discussions frequently. A patient's code status, place of death, and advanced directives are all a part of those conversations. Moreover, do not resuscitate (DNR) orders are a significant consideration in EOL discussions (Ahmed et al., 2015).

DNR, also known as "allow natural death" or "AND", prevents cardiopulmonary resuscitation (CPR) initiation when a patient goes into cardiac arrest (Kaneetah et al., 2019). The concept of CPR was first introduced in 1960 by Kouwen-Hoven, Jude, and Knickerbocker. It was used initially during and after surgeries in the event of a cardiopulmonary arrest. After seeing its benefits, the usage of CPR became widespread among all patients regardless of their conditions (Bishop et al., 2010).

CPR is an "emergency treatment" which constitutes a group of interventions performed to provide oxygenation and circulation to the body during cardiac arrest. The goal of CPR is to maintain perfusion and oxygenation while a reversible cause of cardiopulmonary arrest is identified and treated. CPR is composed of chest compressions and ventilation. Chest compressions maintain blood flow to vital organs, while ventilation facilitates the gas exchange of oxygen and carbon dioxide in the lungs.

Ventilation opens the airway and can be performed by using a variety of methods, including a mask-to-mouth technique, a bag valve mask, and inserting an endotracheal tube. In addition, defibrillation and medications like epinephrine are used to correct certain cardiac arrhythmias (Craig-Brangan & Day, 2020).

CPR effectiveness is not well established, and the outcomes are not always desirable. The American Heart Association's (AHA) consensus published in 2013 found that the outcomes of CPR have been the same even after the advancements made in conducting CPR (Morrison et al., 2013). The general success of CPR was found to be 15.5% (Hanif, 2015). There is a lack of local data on the effectiveness of CPR. A meta-analysis that included 42 studies on CPR success, evaluating four decades, found that less than 2% of patients with haematological malignancy could go home after CPR compared to 7.1 % of solid tumours. The extent of disease in patients with solid tumours also impacted success rates. The survival percentage after CPR was 9.5 % and 5.6% for localized and metastasis tumours, respectively. The same study found that the success rate when CPR was initiated when a patient was in an intensive care unit was better than when it was initiated in a general ward (10.1 % versus 2.2 %). The success rate was 3.7% before 1990 and increased to 6.7 % in 2005 (Reisfield et al., 2006). Multiple deleterious physical and neuropsychological effects were reported following a successful CPR attempt (Yuen et al., 2011). Numerous studies have reported 13-97% of sternum fractures, rib fractures, and soft tissue injuries (Deliliga et al., 2019). In addition, pneumothorax, lung contusion, and hemothorax were documented as physical complications of CPR. The same study found that CPR was associated with liver and left ventricle rupture. Severe encephalopathy and seizures were the neurological side effects associated with the brain hypo-perfusion experienced during CPR. In addition,

resuscitation after a cardiac arrest affected the patient psychologically; amnesia and post-traumatic distress syndrome were mentioned as complications (Kaldirim et al., 2016).

After realizing the sequelae following CPR, it was suggested that all CPR should take place after written informed consent by patients or surrogate decision-makers. That evidence became the DNR orders (Venneman et al., 2008). Respecting patients' decisions and avoiding futile interventions are the main advantages of DNR orders (Yuen et al., 2011).

Code status, including the option of DNR orders, is part of the advance directives (AD), also referred to as a "living will," which is a person's oral or written instructions about their future medical care if they become unable to communicate. It may be in written or oral form (Silveira, 2020). However, worldwide, the completion of AD remains low, with only one-third in America and 8-10 % in European countries (Detering et al., 2019). In Africa, less than 20% of the old population has completed advance directives (Frenchman et al., 2020). In addition, worldwide studies have shown an overall insufficient knowledge of the concept of DNR orders, especially of family and the patient (Pettersson et al., 2018).

There are no national guidelines on AD in Kenya; hospitals create their own policies (Kenya Hospice and Palliative Care Association KEHPCA, 2021). Studies on DNR are limited in Sub-Saharan Africa (SSA). According to a Kenyan study done in a tertiary hospital and in an urban setting, DNR and writing a living will are essential for palliative patients' advanced care. However, the uptake of advanced directives is still low compared to Western countries (Omondi et al., 2017). Cultures, attitudes, and behaviour significantly limit the uptake of ADs.

1.2.2 Palliative Care and End-of-Life Care

The World Health Organization (WHO) defines palliative care (PC) as an "approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering using early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (WHO, 2020 p1). In other words, palliative care uses a holistic approach by addressing patients' physical symptoms and meeting spiritual and psychosocial needs. Palliative care neither expedites nor slows death. Instead, it embraces death as a normal process by optimizing the quality of life, PC works with the patient and the family through the illness journey until death and with the family in the subsequent bereavement period (WHPCA, 2020).

As cited by the Worldwide Hospice Palliative Care Alliance (WHPCA), the medical conditions demanding palliative care for adults are mainly "Alzheimer's and other dementias, arteriosclerosis, cerebrovascular disease, chronic ischemic heart disease, congenital malformation, degenerative central nervous system (CNS) disease, haemorrhagic fevers, HIV, inflammatory CNS disease, injury, leukaemia, liver disease, low birth weight-premature, lung disease, malignant neoplasm, malnutrition, musculoskeletal disorders, non-ischemic heart disease, renal failure, tuberculosis and injury including poisoning and external causes." (WHPCA, 2020, p18).

The right to health and the right to be free from cruel, inhumane, and degrading treatment, as mentioned in the International Covenant on Economic Social and Cultural Rights (ICESCR) Article 12.1, makes palliative care a human rights issue. An emphasis is also present in the Kenyan Constitution Article 43 and the Kenya Health Act 2017. In addition, The UN Committee on Economic Social and Cultural Rights stated that it is

crucial to give "attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity (WHPCA, 2020, p3).

Globally, 56.8 million people require PC services annually, 45% are near the EOL and 78% of those requiring PC live in low- and middle-income countries. The necessity for PCs is preeminent in low and middle-income countries. The most common diagnoses requiring PC are cancers, stroke, AIDS, dementia, and respiratory diseases.

According to the National Institute of Cancer, EOL care is defined as care given to people near the EOL who have stopped treatment from curing or controlling their disease. Furthermore, EOL care includes physical, emotional, social, and spiritual support for patients and their families (Wang et al., 2021).

Good policies, fair education, and adequate resources have been the primary facilitators for PC development. Besides that, psychological, social, and cultural factors are also important. It was also noted to become a hindrance to palliative care implementation. In SSA: Uganda, South Africa, and Kenya lead PC development; however, research in PC remains underdeveloped (Frazer et al., 2017).

In a recent Kenyan PC policy guideline, 800,000 persons need palliative care, but less than 2% can access it. The same body has three main agendas for the next ten years: resolving the structural challenges, increasing early access to PC services, and addressing health scheme issues and sociocultural factors (KEHPCA, 2021).

1.2.3 Role of Caregivers in Palliative Care

A systematic review of global PC research priorities found that less than 20% of studies on PC focused on the patient and the family (Hasson et al., 2020). Nevertheless, families and patients are essential in the palliative care research agenda.

Studies have shown the role of caregivers in decision-making across the world. Chiang et al. agreed with this concept by highlighting the importance of carers in a family-centric culture (2020). In Sub-Saharan Africa, the concept of collectivism influences behaviour and practice. Decisions are made on the family level more than the individual level. Coleman et al. describe how family members in SSA can make decisions even when the patient is conscious when their relative is nearing death. They try to reach the doctors without the patient's consent and knowledge. This can create ethical challenges in developed countries by overstepping patient autonomy, using collectivist practices, and creating confidentiality issues between patients and HCWs (Coleman et al., 2018).

A South African study on end-of-life care found that most participants would want their relatives to be involved in their care and that it would positively impact their mental health (Johnson, 2017). Despite the drastic improvement of palliative care in Kenya, a study done in Kisumu by Johnson found that the role of the caregivers in PC success was overlooked and suggested policy to involve relatives (2017).

KEHPCA has given special attention to person-centered care, which focuses on the patients, including families, rather than disease-centered care, which only focuses on the illness. Family and patients are taken as a unit while giving PC services (KEHPCA, 2021).

It underlines the importance of understanding patients' and their relatives' perceptions of DNR. To the best of my knowledge, no study has been done in rural Southwestern Kenya on the perception of DNR from the family and patient point of view.

1.2.4 Research in Palliative Care

Like all other medical disciplines researching palliative care is essential. Research is needed because new knowledge generated by it is valuable, even without practical

benefits. Besides that, it generates evidence-based content, which is helpful for health care professionals (HCPs) and trainees. It is also essential because it helps address the patient's and family's needs by giving them a voice. Moreover, studies in PC indicate services available and evaluate their success (van der Steen et al.,2021).

Despite the importance of research in PC, it has many limitations and challenges. The main ones include the physical and emotional vulnerability of the participants and bioethics conditions. A study done on the challenges of evidence-based palliative care research found that the ability to obtain consent from patients, their short life expectancy and limited resources, lack of research skills, and the public attitude towards death and dying limits research in palliative care (Khalil & Ristevski, 2018).

Another challenge encountered by researchers when conducting a study on a sensitive topic is low participation, which can undermine the credibility of the research and limit the generalizability of the results. Research in palliative care is controversial and ethically challenging. The primary issue of conducting research is that participants are considered "vulnerable," limiting the designs and methodologies that can be used. It also brings up two more issues, ethics board approvals and informed consent. Consents are often out of culture or have few details because they can bring emotional distress. The greatest hindrance to studies in PC is the research committee clearance. Those boards use the same criteria as other domains, making it harder to approve PC research. Furthermore, researchers often lack knowledge of the legal and ethical framework for conducting research (Gysels et al., 2013).

A systematic review was done on the perspectives and experiences of dying patients themselves to participate in the research. Four major themes emerged from that study. The first one was the "value of research." The vast majority of participants, 85%, stated

that they were happy to get involved in research because it will help future advancement in care. They also thought it was "unethical" to not include dying patients in EOL studies. They also highlighted the notion of expressing themselves freely because they are near death. The second theme was "desire to help." Participants found it essential and fulfilling to have the opportunity to participate in improving future care and scientific advancement. The third theme was "expression of self," Some participants felt valued as humans beyond their illness, and others described it as finding purpose in life. The last theme was "participation preferences." They reported how they would want to be interviewed and expressed a need to be included in the research (Gysels et al., 2013).

1.3 Statement of the Problem

With advances in medical technologies and resuscitation techniques, as well as the rise of the terminal illness burden globally, DNR has been a critical question in the healthcare system and EOL care specifically. Unfortunately, studies involving families and patients are limited.

In Kenya, many challenges can limit patients from making an informed decision about their code status and choosing DNR as their status, particularly. The primary reasons are the ethical and legal limits, the reluctance of the HCP to talk about withholding resuscitation/death, unclear communication about all the treatment choices, and late discussions (KEHPCA, 2021).

A study done with HCPs at Kenyatta National Hospital (KNH) found a similarity with the latter. They stated that not implementing DNR orders was due to the absence of policies regulating them and clinical guidelines to deliver them (Mina, 2020). Cultural, and religious experiences and beliefs can affect healthcare practitioners while

introducing the idea of not attempting resuscitation on a patient and can similarly affect families while deciding on DNR.

This knowledge gap affects patients, families, and the entire healthcare system in low-resource settings. For example, patients might undergo unwanted procedures, families might incur significant financial burdens, and the healthcare system can weaken an already fragile system by using limited resources for futile care.

1.4 Study Justification

With the increased need for palliative care, the shift towards patient autonomy, the limited guidelines and legal framework on EOL care, and the paucity of data on patients and families receiving palliative care, the need for this study in an African context is justified. One of the goals of the WHO in developing PC is to "develop guidelines and tools in PC and to address ethical issues related to it" (WHPCA, p16, 2020). Kenya's vision for 2020-2030 is to achieve UHC, and palliative care has been cited as an integral component of UHC. (Kenya Health Financing Strategy 2020–2030 Republic of Kenya Ministry of Health K).

Additionally, one of the three main agendas of the KEHPCA for the next ten years is to address health scheme issues and the socio-cultural factors associated (2021). Two studies have been done in Kenya on DNR and advance directives in general. Both studies were quantitative in an urban setting in tertiary hospitals. The first study was on AD uptake, and the second one was on the factors influencing HCP DNR decision-making. However, because the perceptions of the DNR concept are dependent on personal factors and are subjective hence unmeasurable, this study will be qualitative.

1.5 Study Significance

The lack of research on patients and caregivers and the lack of adequate training for HCPs in PC were found to be challenges in providing better PC services (Abu-Odah et al., 2020). This has informed the need to do this study. Besides that, MOH, through KEHPCA, has priorities in their 2021-2030 agenda to create and implement guidelines on DNR orders, reinforce continuous medical education for HCPs, and create an ethical framework for resolving ethical conflicts concerning DNR order issues.

From the study's findings, healthcare institutions will be able to create or improve guidelines on DNR requests. New guidelines will help HCPs improve their practice, have more effective code status discussions, and avoid medico-legal pursuits. For patients, it will be a document protecting them and that they can refer to. The result will help also inform KEHPCA, as it seeks to develop and implement policies on AD. Finally, the results of this study will also promote and improve patient-centred care by being able to understand patients and families in EOL.

1.6 Purpose of the Study

The purpose of this study was to gain an understanding of how caregivers perceive the concept of a DNR order. It will also seek to identify what are the major factors and what expectations they have while having a DNR discussion.

1.7 Objectives of the Study

The objectives of this study were:

- i. To understand the perception of palliative care caregivers about the DNR concept
- ii. To describe specific factors influencing DNR decision-making.
- iii. To explore what the expectations of caregivers and patients are while discussing DNR orders.

1.8 Limitations of the Study

The study had two limitations. First, the emotional vulnerability of the participants, the need to care for their relatives at the end of life constantly, and, for some, their grief reduced the rate of participation for this study. The author ensured participants gave their consent; she confirmed through the interview that participants were comfortable and ensured the study reached data saturation. If a participant became emotionally triggered, the interview was stopped and only resumed when the participant wished to. Secondly, our study included only participants from one hospice care among many in the country, which might not represent the whole population; hence, it may not be easy to generalize the findings nationally. However, the research ensured to have diversity in the sampling process.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

In this chapter, we shall review the literature based on the objectives of this study. This section will end with the conceptual framework.

2.2 Perceptions of Caregivers about DNR Orders

Knowing how individuals perceive DNR orders is important because it reflects how the decision-making process will be. Across the world, perception of the DNR code status has been different depending on the culture, religion, society, and level of education. This section will review the literature on DNR knowledge, the sociocultural perception, and the psychological perception of DNR.

2.2.1 Knowledge and Attitude of DNR

A cross-sectional study done in Saudi Arabia found that 32 % had an idea of what DNR is, and more than half had a background in the medical field, followed by a first-degree relative of palliative patients (Kaneeth et al., 2018). Miljković et al. conducted a study with patients with stage IV cancer and found that 84.16% of the participants were conversant with the DNR terms. They also highlighted that patients in this study were willing to have a DNR discussion, and 94.23% wanted to get involved in the DNR decision-making (2015). Kenneth et al., in 2018, while they were assessing the participant's attitudes toward DNR, found that almost half of the participants were not willing to have a DNR order. The reasons given were mainly losing hope and having a religious background. Family issues and obligations were also cited as a hindrance to having a DNR order. The same study also found that the more information patients had about DNR orders, the more likely they were to accept select DNR as their code status.

Shein et al. (2016) agreed with the previous results in their study on the association between caregivers and patients' understanding of the disease with DNR completion. Similarly, in a study done with the general population and with terminal lung cancers and their caregivers, 69.9% of the participants showed interest in participating in DNR decision-making (Kaneeth et al.,2018).

2.2.2 Emotional Perception

Death is a sensitive topic; people have an emotional perception of DNR. According to Oliver et al., participants recognized DNR orders as imminent death; hence, most perceived DNR as a removal or loss of hope. Nevertheless, on the other hand, patients included DNR orders in the progression of natural death, which made DNR policies favourable to all the participants.

A recent study done by Chiang on concerns about and experiences of DNR by caregivers in palliative care found that DNR orders were also synonymous with “giving up.” Accepting a DNR order meant letting go of even the slightest chance of increasing patient days. Also, it might affect the saving life that CPR could give (Chiang et al., 2021).

2.2.3 Socio-Cultural-Spiritual Perception

People from various societies and cultural settings have different perceptions of death. In Taiwan, a study was conducted to identify the relationship between religious and social background and DNR uptake. The paper demonstrated that Buddhists and married participants were less likely to select DNR as their code status. In Buddhism, there was a concept of "filial piety," which was explained by progeny having the responsibility of keeping their kin until the last moment of their lives. On the other hand, in the Daoist

religion, people believed in suffering after someone had passed on. Therefore, they were promoting the delay of death by all possible means. Thus, this belief brought a negative connotation to DNR (Shen, et al., 2016).

The same authors emphasize the idea of “Karma” as a barrier to DNR approval. More religions from different countries showed the association between resuscitation and DNR. In Brazil, for evangelical Protestants, there was hope for supernatural healing. In Poland, in the Roman Catholic Church, CPR was considered treatment, and it was considered a patient’s right to receive it. In addition, the author found that religion impacted DNR refusal in the Orthodox Church. In Pakistan, where most are Muslims, DNR is often taken as having euthanasia (Gibbs et al., 2016).

In the same study, Gibbs et al (2016) found that in Japan, speaking to a patient about death is considered wishing them “bad luck”. In South Africa, when death is brought up, people tend to understand due to the short life span. In Uganda, the sacredness of death makes it impossible to discuss DNR in some regions.

In a qualitative study on bereaved Kenyan families, death was considered culturally taboo. Talking about it allows it to happen, and if a family member introduces a DNR subject, they are considered to be the patient's enemy by the rest of the family (Githaiga & Swartz, 2017). This reinforces the necessity of studying in our context to understand how the population in The Great Rift Valley perceives DNR orders.

2.3 Factors Involved in DNR Decision-Making

The literature has summarized the barriers and facilitators to signing DNR orders into three major categories: personal, family-related, and hospital-related factors.

2.3.1 Personal Factors

One of the four main medical ethics principles is the need to respect patients' autonomy, hence the importance of discussing personal factors related to DNR decision-making. The significant factors to be against or for DNR orders related to the patients were mainly their age, prognosis, the outcome of the intervention wishes, and family composition. Additionally, the title of the document was cited as a factor. Fan et al., in a quantitative study including 524 adults with no comorbidities, found that the likelihood of agreeing on DNR discussions was statistically significant when it was called "allow natural death" instead of "do not resuscitate" (Kaneeth et al., 2018).

In that same study, participants stated that they would consider the patient's desires, wishes, and health status. Another barrier was also the fear of not receiving more treatment. However, the study also highlights that the facilitators to sign a DNR form were to reduce patient pain and lighten family burdens. Other facilitators were when healthcare was giving comprehensive information, and this included the goal of DNR, its success rate, and the possible side effects of CPR when the outcomes were known to be poor. More barriers to making a DNR decision were family worries and uncertainty about the physical conditions.

2.3.2 Family-Related Factors

Syed et al. (2016) conducted a cross-sectional study about the perceptions and barriers in a tertiary hospital in Pakistan. The participants were physicians and doctors in training. They found that the main obstacles to having code status discussions were families. Disagreement, refusal of the diagnosis, and level of education were three main family-related barriers.

Another study from Taiwan found that one of the barriers to DNR discussion was the fear of introducing the topic to a sick relative and knowing the appropriate time (Fan et al., 2018).

Chiang et al. (2021) also emphasized the lack of agreement among family members to make difficult decisions most of the time. In addition, guilt for not doing every possible medical intervention to save their relatives and fear of being blamed by other family members or the community are factors.

2.3.3 Hospital-Related Factors

In this subsection, systems factors will include hospital, doctors, and nurses' factors. One cross-sectional study was done in Taiwan by Syed et al., the objective of the study was to explore the perceived barriers in DNR discussion from healthcare workers' points of view. Four main factors emerged from the research. The first one is the busyness of the hospital, making limits the time attributed to the code status discussion. The second one was the scarcity of guidelines and the absence of hospital backup if the patient or family becomes harmful to the HCP. The third reason was the fear of care withdrawal by the doctors or nurses after code status determination, and lastly, the poor knowledge of the prognostic (Kaneeth et al., 2018).

2.4 Expectations of Caregivers and in the Decision-Making Process

Literature demonstrated that families and patients had expectations, from who should make the decisions, who should introduce the topic, when to have the DNR discussions, and what should later happen after signing a DNR order. Therefore, this objective will bridge the gap by knowing what patients and relatives expect from DNR conversations.

2.4.1 Message Delivery

A study on patients who had already received a DNR order found that how the message was transmitted was very important. Patients and caregivers wanted the physicians to consider their situation and help them. They also reported that patients' autonomy and dignity needed to be respected if they had already signed a will or made EOL instructions clear. Comprehensive, trustworthy information while avoiding medical jargon also arises in patients' DNR decision-making preferences (Ahmed et al., 2015).

Researchers made a similar observation in a study on a healthy population. Furthermore, patients needed to have information on the severity of the illness, life expectancy after DNR, complications of attempting resuscitation, and the outcomes (Fan et al., 2018). Both studies preferred to have DNR discussions with a well-informed and warm-hearted doctor.

2.4.2 Timing of DNR

There was a divergence of opinion on the timing to discuss DNR. Some said earlier when the patient could make their own decisions or late when the need is present. From the literature, discussing DNR orders earlier was recognized to improve quality of life (Mori et al., 2018). Another study done with patients with terminal lung cancer found that the patients equally wanted to discuss diagnosis at EOL (Ahmed et al., 2015).

In a previous study, it was found out that patients had different views of the best time to have DNR discussions. Some participants said they would prefer to choose when to discuss it in this study. They also indicate that these discussions should come up only when the patient chooses to. The reason is that it might be depressing and bring more anxiety about death. However, other participants found that DNR discussions should be held as soon as possible to allow the patients to put their belongings in order. The

remaining thought is that a healthcare practitioner should judge when to discuss DNR. Also, "shared decision-making was the most approved statement by the participant (Olver, et al., 2008).

A different study shows that the majority of the participants showed interest in participating in the DNR decision-making. 72% wanted to have the discussions when they could still make their own decisions with no comorbidities. 15% wanted to have it when they were diagnosed with a terminal illness. The rest did not want to get involved. Another study noted that 59% of the participants wanted to make the DNR decisions at the time of diagnosis (Alsaatiet al., 2020).

2.4.3 Decision-Maker

Making a DNR decision is a crucial component when discussing DNR. Ahmed et al. showed that patients and CGs wanted HCP to be present and another family member while having DNR discussions (Ahmed et al., 2015). Another study also found that most participants wanted their doctors to decide on their behalf. When asked whom they wanted to get involved with, 36% trusted that the family should get involved rather than the patient, and 22% thought that the patient should decide who gets involved. Only 8% believed that the patient should be responsible for his own DNR decision-making (Alsaati et al., 2020). Studies in African communities, where the assumption is that the general preference is to make decisions as a community, are still needed.

2.4.4 Future Care

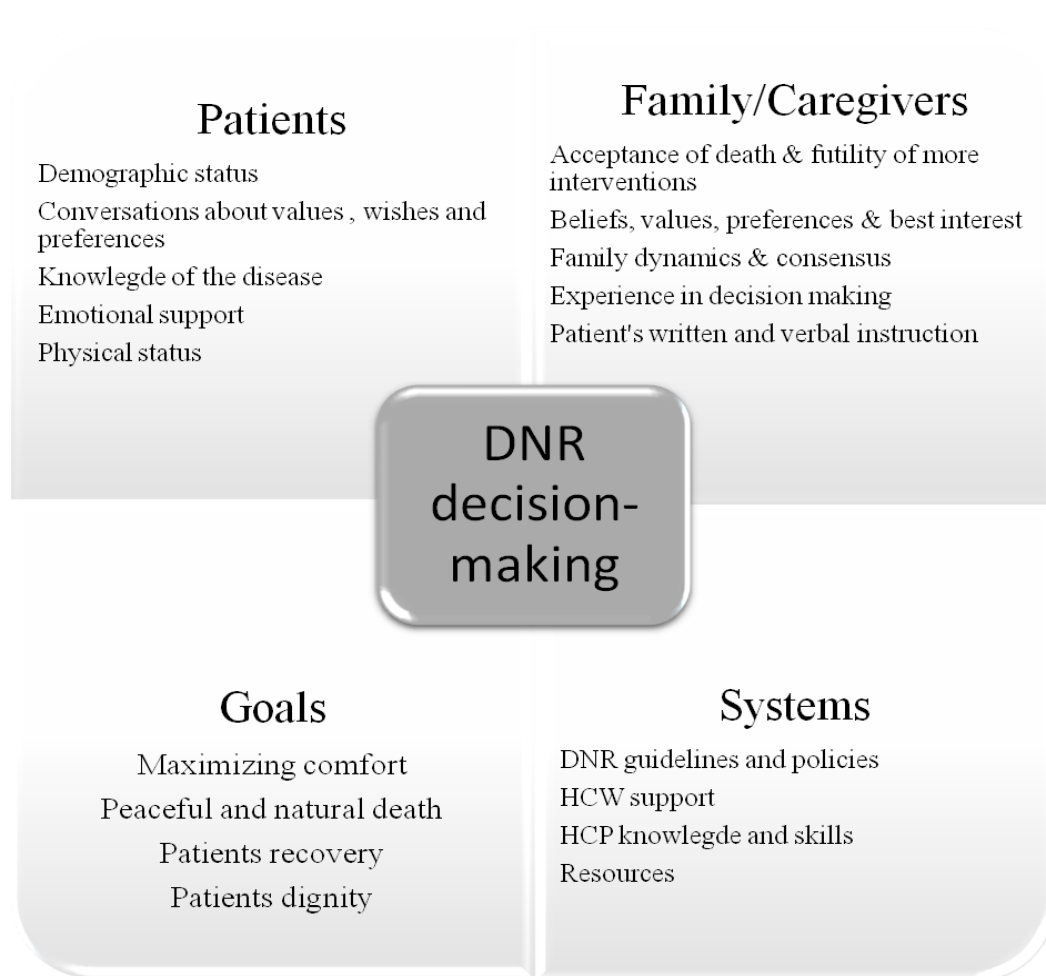
Few studies have been done on the expectations of medical treatment after signing a DNR order. However, in their study done in Korea, Kang et al. (2014). found that most participants expected that the best care would continue to be given even after a DNR order

2.5 Conceptual Framework

This conceptual framework illustrates what we expected to find through our research. It defines the relevant variables for our study and maps out how they might be related to each other. This conceptual framework is similar to that espoused by Kim et al. (2016).

Figure 1

Conceptual Framework



CHAPTER THREE

RESEARCH DESIGN AND METHODOLOGY

3.1 Introduction

The following chapter will outline the research design, the location of the study, the study population, the selection criteria, the sampling method and sampling size, the data collection procedure, data analysis, ethical considerations, rigour and trustworthiness and conflict of interest statement.

3.2 Research Design

This study adopted a qualitative design with a descriptive phenomenological approach. Evidence demonstrates phenomenology as an effective research method to understand people's experiences in health and illness and the perceived caring needs of patients and those caring for them (Polit & Beck, 2017). The design choice was also justified because we sought to deeply understand the DNR discussion perceptions from the caregivers' perspectives. In addition, the study explored their expectations in the DNR decision-making process and described specific factors involved in DNR decision-making. In this study, DNR perception included the caregiver's knowledge and interpretation of the DNR concept, the information they received about it, and their feelings about it.

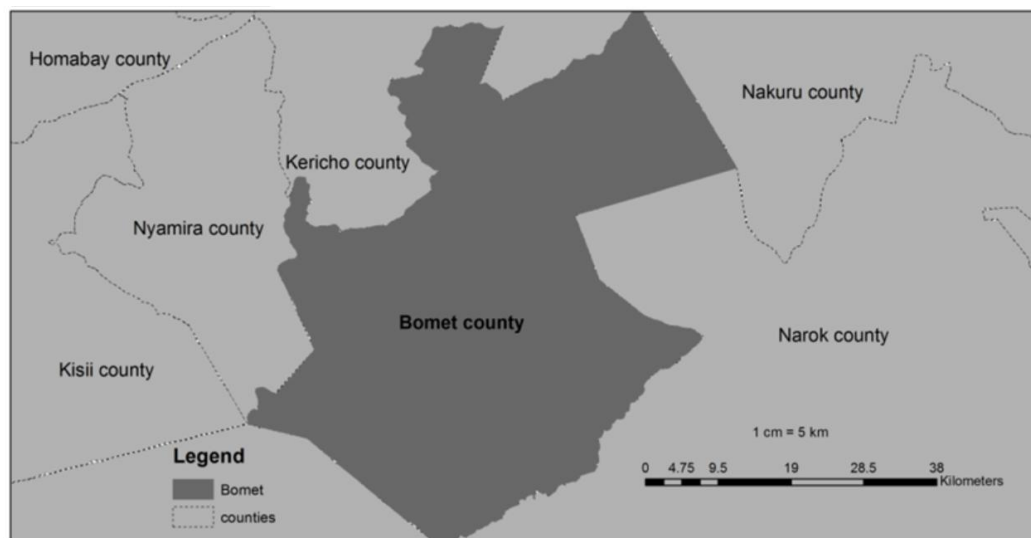
3.3 Location of the Study

The study was conducted in Bomet County. Interviews were conducted at the participant's home and Tenwek Hospital. TMH is a 361-bed capacity, level five B, non-profit and faith-based hospital in the greater South Rift region in Bomet County. It is 150 miles northwest of Nairobi, the capital city, and five miles east of Bomet Town. The number and variety of patients visiting the institution explain our choice. People from Bomet, Kisii, Kisumu, Narok, Nakuru, Nyamira, and Kericho seek healthcare services in

TMH. Two of those counties, Kisii and Nakuru, have been listed among the top ten counties in Kenya leading in cancer burden, and Bomet is in the region with the highest prevalence of oesophageal cancer in Africa (Maithya, 2022; Odera, 2017). Oesophageal cancer was also Kenya's leading cause of cancer-related mortalities (Uhlenhopp et al., 2020). In addition, TMH runs a palliative care program created in 2012 that aims to ensure easy access to PC services for every patient. DNR discussions are conducted by a multi-disciplinary team, HCPs, nurses, chaplains, and counsellors are involved in the discussion. Due to the late presentation of patients, DNR discussions are done with caregivers. Every DNR discussion is followed up by signing a DNR form clarifying the choice caregivers made for their loved ones.

Figure 2

Map of Bomet County



Source: "Spatial Modelling of Maize Lethal Necrosis Disease in Bomet County, Kenya" (Osunga et al., 2016).

3.4 Population of the Study

The study population included caregivers of patients with a terminal illness and healthcare professionals involved in DNR discussions. The primary researcher chose

caregivers because of their role in health decision-making, especially in family-centric cultures and palliative care (Jazieh et al., 2018). Caregivers were in two categories. The first category was relatives living with a patient on home-based palliative care. The patients were followed up with the Tenwek Hospice department. The second category of caregivers was caring for an admitted patient and had had DNR conversations with clinicians at the time of the study.

This study also recruited healthcare professionals from different adult wards at TMH to increase our understanding of caregivers' perceptions. They were individuals who had been involved in DNR discussions with caregivers. The choice was motivated by DNR decision-making involving clinicians and caregivers. This approach provides a more comprehensive picture of the DNR discussions than interviewing only caregivers.

3.5 Sampling

3.5.1 Sampling Procedure

In recruiting caregivers, purposive and convenient samplings were used to select eligible participants for the study. The purposive sampling method helped to obtain a sample representing a broad spectrum of home-based caregivers based on gender, age, economic status, educational levels, cultural backgrounds, religion, and diagnoses. The principal researcher contacted a hospice nurse to select participants who met the study's criteria. After confirming eligible participants, the researcher called them individually to obtain verbal participation consent.

To recruit hospital-based caregivers, we used a convenient sampling method. The motivation was that DNR discussions happened when patients were very sick, which put the caregivers in a position of inability to participate. The researcher used that method because of its cost and logistics advantage and because participants were accessible to

the researcher. We recruited caregivers who were in the hospital during the study period and who had had DNR discussions. The FGDs used a purposive sampling procedure.

The healthcare professionals were recruited from various adult wards, units, and hospice care personnel. The choice of sampling methods is justified because we wanted a variety of HCPs with different encounters, work experiences, and taking care of patients with different conditions.

3.5.2 Sample Size

According to Guest et al. (2020), the median number of attaining data saturation is 12. Hennick and Kaiser (2021) found that data saturation can be attained between 9-17 interviews. Our study had an initial target of 12 interviews. The interviews continued until they reached the redundancy of theme and data saturation. We conducted 18 interviews; data saturation was attained at the 16th interview. To ensure that there was no other new information; the researcher conducted 2 more interviews and no additional data was obtained. For the FGD, Nyumba et al. (2018) found that 4-8 participants in FGD are enough most of the time; however, they recommend over-recruiting due to the uncertainty of all the patient's participation Hennick and Kaiser (2021) also agreed with that. One FGD was held in this study, including 6 participants.

3.6 Study Subjects

3.6.1 Inclusion Criteria

The inclusions for caregivers were:

- i. Caregivers of patients who have enrolled in the Tenwek palliative care program with a life-limiting condition and/or caregivers of patients who had been involved in a DNR discussion.
- ii. Caregivers who speak either English, Kiswahili or Kipsigis.

The inclusion for HCP was.

- i. HCP that has been involved in DNR discussions.
- ii. HCP with a minimum of one year of experience

3.6.2 Exclusion Criteria

This study excluded the following population;

- i. Paid caregivers
- ii. Caregivers of paediatric patients
- iii. HCPs working in the paediatric department.

3.7 Data Collection

3.7.1 Instrumentation

The study used a semi-structured interview guide for data collection for interviews and FGDs. The researcher developed the questionnaire based on the literature review and knowledge of the topic field from clinical experience. The questionnaire contained questions about the study's objectives and probes to keep the conversation going. The interview guide was in English and Swahili. Only one participant needed a translation in Kipsigis. To ensure data accuracy translation, a graduate multi-linguistic research assistant went through the audio to confirm that the interview was similar to the other participants' questionnaire.

3.7.2 Pilot Study

The interview guide was piloted on two caregivers accompanying patients visiting an oncology outpatient clinic one week before data collection. The pilot study results were not included in the data set. The objective of the study pilot was to test the research tool, check if the questions were clear, and confirm the cultural relevance of the tool. The

study pilot led to some adjustments to the interview guide and some improvements to the questionnaire.

3.7.3 Procedure

Data was collected from May to July 2023. Face-to-face interviews and FGDs were used to collect data. Due to the study's sensitivity and the participants' vulnerability, a palliative care nurse who had experience conducting research was recruited to be a research assistant and help conduct the home-based interviews. The researcher trained the research assistants. This choice was motivated by the literature that recommended that before conducting interviews in PC, a researcher-participant relationship should be created to allow the participants to come forefront quickly hence recruiting a familiar research assistant (Sivel. et al., 2019).

The research assistant purposively selected home-based caregivers that fit the study's criteria from the Hospice care program office registry. We obtained the participants' contacts from the same registry. The primary researcher contacted the participants, explained the study's objectives and the data collection methods, and asked their willingness and availability to participate. Caregivers willing to participate in the study were considered to have given verbal consent. The home-based interviews were held at the caregivers' homes at the usual palliative care outreach after the routine care had been provided to the terminally ill patients. A palliative nurse, a chaplain counsellor, and the researcher did the visits. Interviews were conducted in a quiet space of the caregivers' home and lasted less than 30 min.

For the hospital-based caregivers, the researcher briefly described her study to clinicians and nurses in the different adult wards and intensive care units and asked them to note down caregivers involved in DNR decision-making regardless of the outcome of the

discussions and to contact the investigator about DNR discussions. After the HCPs call, the investigator would talk to the caregivers, explain the study's objectives, and ask for consent. If the caregiver agreed, it was also considered verbal consent. The interviews happened in a quiet meeting room at the discretion of other people at Tenwek Hospital. The caregivers determined the time of the meeting.

On the day of the interviews, the researcher explained again the study's objectives and the data collection methods. Furthermore, the primary researcher guaranteed privacy, confidentiality, voluntary participation, the right to withdraw from the study, and dissemination of findings. After that step, participants were given time to ask for clarifications about the study. After that, the researcher obtained written consent from all participants. All the interviews were conducted in English and Swahili, apart from one in the local language in which the research assistant was fluent. All the interviews began with a very general question concerning the patient's diagnosis and conditions and the caregiver's current quality of life. Followed by: "Have you ever heard about DNR?" Or "In the event your relative's heart would stop have you thought of what else could be done?" Those who answered "No, I have no idea or a similar answer" were described the resuscitation techniques (CPR and mechanical ventilation) and what DNR orders are. Then the researcher moved on to more specific questions exploring the study's objective. Probes and follow-up questions (e.g., Kindly elaborate? Tell me more about it? What do you mean by that? Give me an example) were added to encourage discussion and clarify answers. At the end of the interview, the interviewer asked: "Do you have a question for me? Or is there anything else you want to add, which I did not ask? Furthermore," Interviews lasted less than 30 min, audio-recorded with participants' permission, and notes were taken. Each participant was assigned a number, and the transcripts were without personal information to ensure data confidentiality.

All the approached participants gave consent to be part of the study. The primary researcher was present at all interviews. Two caregivers got emotional during the interviews but continued answering the questions. Two interviews were cancelled due to the loss of patients that the caregivers cared for. There was a recording failure with one focus group; however, detailed notes were taken by the researcher. The FGD was held in the doctors' meeting room at Tenwek Hospital after working hours on a weekday. The clinicians and nurses that fit the study's criteria were sent an invitation via WhatsApp text and asked to confirm their availability to participate twenty-four hours before the scheduled date of the FGDs. Twelve HCPs were sent invitations to participate in the study. The invitation included the name of the primary research, the study objectives, the time, the date, and the venue of the FGDs. Six HCPs came on the day of the FGDs, four apologized for being held up by their work, and two did not communicate. The objectives of the study were mentioned again. The investigator showed an approval letter from the hospital ethical committee and a NACOSTI permit allowing her to conduct the study. Time to ask questions was given, and consent was signed after that. The researcher conducted the FGD. English and Swahili were to be the languages of the discussion, but English only was used. Probes were used to keep the conversations going (e.g., Do you have an example in mind? Or please elaborate?). Participants were given equal chances to talk by allowing them to share their experiences. Participants were ensured of voluntary participation, the right to withdraw from the study, and the right to remain silent if they wanted to.

3.8 Data Analysis

Data was analyzed using an inductive thematic analysis. The primary researcher and one researcher assistant did the data analysis. To increase the trustworthiness of this study, an independent reviewer with expertise in qualitative research went through the transcript

and came up with her team. After discussions, we had a consensus on the main themes. We used six steps described by Braun and Clark (2006) to provide authentic results.

The first step was familiarization with the data. A trained transcriber transcribed the audio recordings verbatim. At the same time, the primary researcher was listening to the audio recorder cross-checking the transcriptions. They were translated into English after verifying the transcript's accuracy. With the final transcripts, the researcher started reading and rereading them to immerse in the data.

The second step was to create initial codes. We gathered data with the same patterns and meaning and created codes. The primary researcher underlined and highlighted with various colours and made notes in the margins of the transcripts.

The third step was to generate initial themes. The researcher identified common patterns from the data-created codes and then looked for initial significance which was called themes.

The fourth step was to review the themes. This step was for refining the themes. The researchers reviewed the themes and compared them with the collected data. The researcher adjusted themes by adding or subtracting some according to the conceptual framework.

The fifth step was defining and naming themes. This stage consisted of identifying each theme's particularity, meaning, and relevance for this study.

The final step was to write a report. The study was then summarized into the following sub-sections; the objectives, data collection, and the process, closed by reporting the findings.

3.9 Ethical Considerations

Ethical approval to conduct the study was sought from NACOSTI and Tenwek ISERC. Participation in the study was voluntary. Participants had the right to withdraw from the study. Verbal and written consent were obtained from all the participants before the interviews and FGD. The consent provided information on the study's objectives, the possible risks and benefits, the period length of the research, and contacts for the researcher and Kabarak University. Participants had identifiers only known by the primary investigator to ensure anonymity and confidentiality. Furthermore, voices in the audio were distorted. Participants will be given pseudonyms for the data report. The audio recorded and transcripts will be kept in a locked file drawer with a password with the access of the researcher and Kabarak University. The data collected will be destroyed after five years.

3.10 Conflict of Interest Declaration

The researcher would like to acknowledge that there was a pre-existing relationship between the research assistant and some participants. However, the researcher would like to ensure that professional objectivity was not compromised, and that care was continued to be given to patients regardless of the caregivers' participation in the study. Furthermore, no financial connections were involved in this study.

CHAPTER FOUR

DATA ANALYSIS, PRESENTATION AND DISCUSSION

4.1 Introduction

This chapter will deal with the presentation of data analysis, findings, and the discussion related to the study. This was done in line with the specific objectives of this study which were:

- i. To understand the perception of palliative care caregivers about the DNR concept
- ii. To describe specific factors influencing DNR decision-making.
- iii. To explore what are the expectations of caregivers and patients while discussing DNR.

Analysis of data was performed using the framework for content analysis that was espoused by (Erlingsson & Brysiewicz, 2017) Manual coding was done where the participants' views were assigned codes, categories and themes and viable conclusions were drawn from the same.

4.2 General information and Socio-Demographic Data

4.2.1 General Information

The total number of participants was twenty-four. Eighteen caregivers participated in the interviews, and six healthcare professionals participated in the FGDs. The focus group lasted 49 min. The average time for all interviews was 15 minutes. One patient died the day before our visit, and we had to cancel the interview. Twelve healthcare professionals were invited to participate in the FGD, but only six were available; the remaining six could not avail themselves. None of the caregivers refused to consent to participate in the study. Two participants got emotionally triggered during the interview but were willing

to continue. A translator helped conduct one interview; the remaining were conducted in the language the primary researcher was fluent in.

4.2.2 Socio-demographic Data

4.2.2.1 Age of Caregivers

Table 1

Age Distribution for Caregivers in in-Depth Interviews

Age of Caregivers in Years					
21-30	31-40	41-50	51-60	61-70	Total
4	6	5	2	1	18
22%	33%	28%	11%	6%	100%

A total of 18 caregivers participated in the interviews. The majority of caregivers were in their thirties representing 33 %, followed by 28% participants in their forties. Only one participant was in his sixties and represented 6% of the participants.

4.2.2.2 Gender of Caregivers

Table 2

Gender of the Participants in in-Depth Interviews

Gender		
Male	Female	Total
10 (55.5%)	8(45.5%)	18

The majority of the participants in the in-depth interview were male representing 55.5% and female participants were 45.5%.

4.2.2.3 Period of Provision of Care to Patients

Table 3

Caregiving Period in Months

Period of Provision of Care to Patients In Months					
0-2	3-6	7-12	13-18	19-24	Total
1	5	4	6	2	18

The longest period for caregiving was twenty-four months and the shortest period of caregiving was only two months.

4.2.2.4 Age of Patient under Palliative Care

Table 4

Age of Patients Under Palliative Care

Age of Patient in Years						
21-30	31-40	41-50	51-60	61-70	71-80	Total
2	3	2	3	4	4	18

The youngest patient was 22 years and the old patient was 75 years old. The majority of the patient under palliative care were in their sixties.

4.2.2.5 Data on Patient Diagnosis

Table 5

Patient Diagnosis

S/N	Patient Diagnosis
1.	ASV/VSD Congenital, Stage 4 heart failure
2.	Esophageal Cancer Stage 4
3.	Esophageal Cancer
4.	metastatic breast ca
5.	Advanced colon cancer
6.	Lung cancer
7.	Lung cancer
8.	SCC of the lower limb
9.	Leukaemia
10.	Prostatic cancer
11.	Multiple sclerosis
12.	Gastric cancer
13.	Extensive haemorrhage stroke
14.	Multiple organ dysfunction
15.	Hypoxic-ischemic brain injury
16.	Metastatic esophageal cancer
17.	Metastatic gastric cancer
18.	Metastatic esophageal cancer
Total	18

4.2.2.6 Whether DNR Discussions have been held or Not

Table 6

Participants who had DNR discussions or not

Whether The Dnr Discussions Have Been Held Or Not		
Yes	No	Total
8 (45,5%)	10(55,5%)	18

This table shows that 45.5% of our participants have had a DNR conversation compared to 55.5% that had not had a DNR conversation.

4.2.2.7 Level of Education of the Caregivers

Table 7

Level of Education of the Caregivers

Level of Education	
No Education	3
Primary	5
Secondary	6
College and Degree	3
Masters	1
Total	18

The majority of the participants had a primary and a secondary level of education. Only one participant had no education. Four participants had a high-level education with one that had a masters.

4.2.2.8 Demographic Data for Health Care Providers

Table 8

Socio Demographics Distribution of HCPs

Participant	Position	Department	Year Experience	Number of DNR Discussions
FG001	Consultant	Family medicine	5	>10
FG002	Clinical Office	Medicine	2	>10
FG003	Medical Officer intern	Surgery	1	>10
FG004	Nurse	Palliative care	12	5
FG005	Medical Officer	Medicine	4	>10
FG006	Resident	Family medicine	3	>10

4.3 Findings

This section of the chapter discusses the findings in alignment with the objectives. The findings will therefore focus on the Perception of Palliative Care Caregivers about the DNR Concept, Specific Factors Influencing DNR decision-making, and the Expectations of Caregivers and Patients while Discussing DNR.

4.3.1 Perception of Palliative Care Caregivers about the DNR Concept

Figure 3

Thematic Representation of the Perception of Palliative Caregivers of the DNR Concept

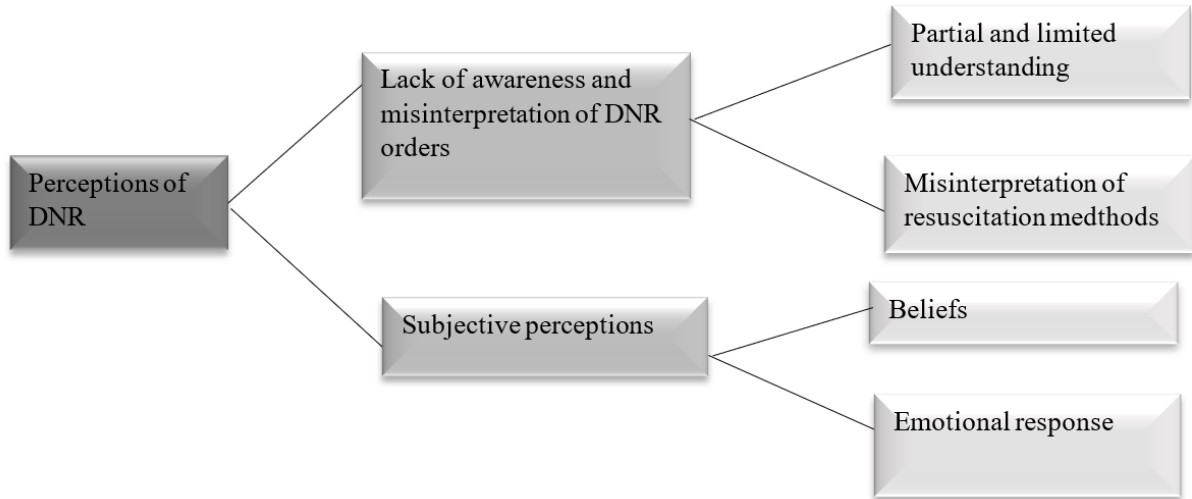


Table 8

The Transition from Code to Category on Objective One

Codes	Categories
Unaware of the DNR concept	Partial/Limited understanding
Knowledge from experience	
Misinterpretation of Intubation with oxygen	Misinterpretation of resuscitation methods
Misinterpretation of the mechanical vent and pacemaker	
Negative Attitude regarding DNR and Resuscitation Methods.	Beliefs
The feeling of imminent death	
Easy way to introduce death.	
Discontinuation of care	
Feeling overwhelmed	Emotional response to DNR orders
Loss of hope/ Sadness/Anxious	
Giving up on my person	
Difficult decision	

4.3.1.1 Lack of awareness and misunderstanding of DNR orders

Limited / Partial Knowledge of DNR and Resuscitation Methods

There was an indication of limited understanding of the DNR and the resuscitation methods. This was depicted in instances where participants in the CGs were asked if they had ever heard about the DNR concept or if they had ever thought about what would happen in the event their loved one heart stops and most of the participants attested that the concept of DNR and resuscitation methods was new to them. The responses below are evidence of their limited understanding of DNR and patient resuscitation.

“No, I have never heard about it.” CG 004

“No, I have never. What is it” CG 007

Misconceptions about Resuscitation, CPR, and Mechanical Ventilation

After assessing the participant's understanding of the DNR concept, participants have explained DNR orders and the various methods of resuscitation. Even after that some misconceptions still came out. The resuscitation methods were still confused with other medical practices. There was confusion between giving oxygen intranasally and intubation as well as mechanical ventilation with the insertion of a cardiac pacemaker. For instance, these participants reported:

*“I have heard it is something that slowly brings back the heart, but if it has gone, it has gone. But it does not treat, isn't it? Or am I wrong? Did I get it right?”*CG

002

*“I was told it is a device "a battery" they put inside so that the heart continues beating, mostly in older people, and the patient goes home, and sometimes they go to recharge it.”*CG **004**

4.3.1.2 Subjective Perception

Beliefs

Participants' perception of the DNR concept was equally influenced by their beliefs. After being taught what resuscitation methods were, they showed a negative attitude towards resuscitation methods. For example, this caregiver said:

"... try to understand when someone's heart has stopped. It means they are gone. Isn't it? So why put things on someone who is already gone? That is not good"

CG 003

Furthermore, this study found that participants believed that DNR orders meant imminent death, or that DNR discussions were an easy way to introduce death. In addition to that, some participants believed that signing DNR orders meant to discontinue care. This was indicated by participants in the FGDs by the following responses:

"...the caregivers feel that when you say you don't resuscitate it is the end of everything and you do not continue to give care." **FG003**

"The minute you start talking about this ... it would seem like you are already predicting death." **FG004**

"...whenever you initiate a discussion on a potential DNR, people start feeling like their patient will not make it out of the hospital. They lose hope and feel like it is the end. It feels like it is discussing what will happen after the patient dies. Most often they'll ask you, "Daktari wewesematu vile iko, usiogope," (doctor, just tell us as it is, don't be afraid). We will accept." **FG002**

The Emotional Response of Caregivers

Participants reported multiple distressing feelings when asked about how they felt after having DNR discussions; or even how they would feel if the conversation was brought up. There was a wide range of feelings from bitterness, loss of hope, anxiety, and even sensations of feeling overwhelmed. For instance, this participant whose child had a non-operable cardiac condition said:

“I felt bitter. I prayed to God to intervene. That day she was very sick; her heart was beating so fast.” **CG 001**

Additionally, other caregivers reported being shocked, devastated, and helpless by the news that nothing else could be done to save the lives of their relatives as evidenced by the responses below.

“He (The doctor) said that there was nothing else he could do. I was like, how come there is nothing else you can do? What do you mean, doc? I even had to call another doctor for a different opinion. Even that one told us that his bleeding was extensive, and his other disease made his body weak. And that there was no benefit to taking him to ICU. I was devastated. My brother was devastated as well.” **CG 013**

“(in a soft laughter) You get into shock but what else can you do? Then you also try to be calm so that the people back at home can be calm as well”. **CG 016**

“.... sure, it was something shocking because it was something we were not expecting. The results came there, and I was surprised because it was like his body was getting worse and worse”. **CG 018**

“After being given the report, I moved aside with my in-laws who had accompanied us... We tried the best we could not to break down”. **CG 017**

Another participant in the FGD reported that the DNR discussions were overwhelming, especially with the responsibility that accompanied decision-making and feelings of guilt that were associated with giving up on the state of a loved one as attested by their response below,

“...sometimes they feel overwhelmed. For instance, we had this patient admitted to the ICU and we had multiple discussions with the families. We knew there was nothing we going to achieve if we continued with the intubation. But for them to make the decision was very difficult because they felt we were giving them the responsibility to decide for their patient whether they live or die.” FG004

4.3.2 Factors Influencing DNR Decision Making

Figure 3

Thematic Representation of the Factors Influencing DNR Decision-Making

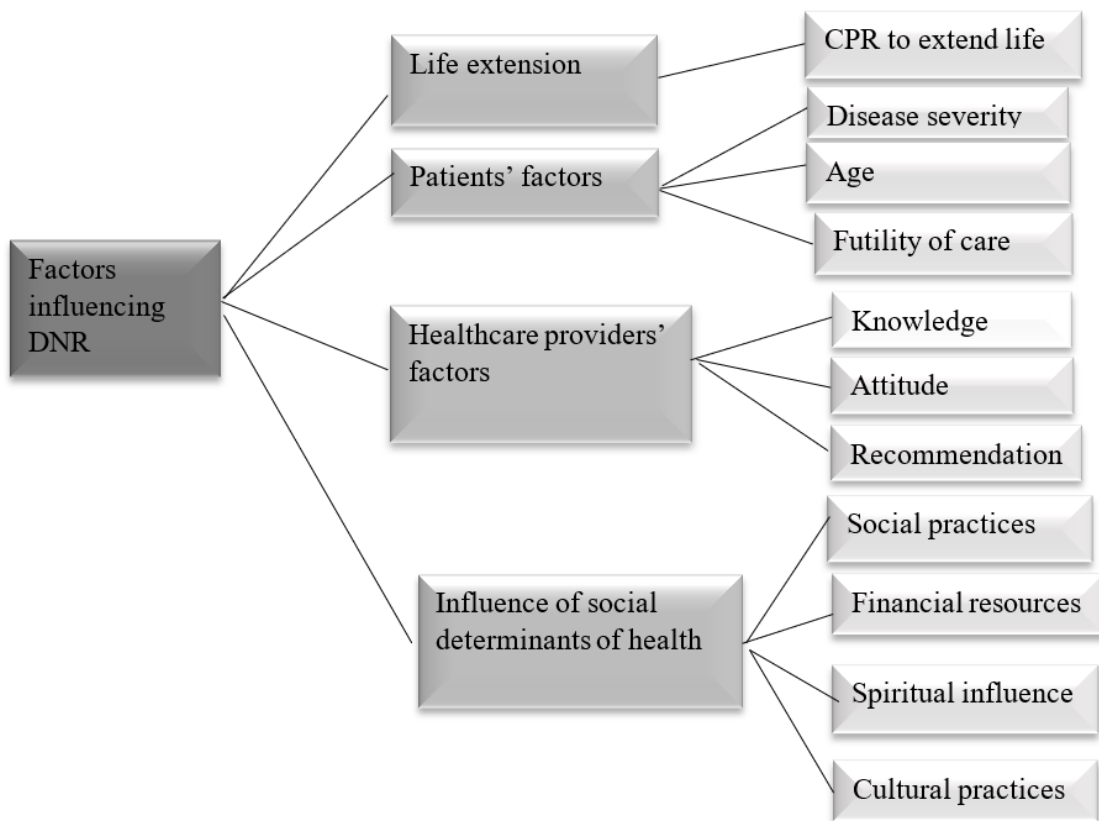


Table 9*Transition from Codes to Categories on Objective Two*

Code	Category
Life extension	CPR as a means to prolong life
Stay with us	
Be here longer	
Acuteness vs chronicity	Patient condition
Disease stage	
Futility of care	
Patient's current situation	
Patient choice	Healthcare provider's knowledge and recommendation
Preparation of family	
Doctors' recommendation	
A doctor who knows all the patient's details	
Social support	
Family dynamics	Influence of Social Practices on DNR
HCP in the family	
The cost involved in resuscitation	Financial resources
Belief in a higher power	Spiritual- religious influence
Religious practice	
Adherence to cultural norms	Cultural practices

4.3.2.1 Life Extension

One of the overarching factors that influenced decision-making among caregivers was the desire to extend the life of a loved one. Most of the people who took part in our study wanted their loved ones to stay, no matter what. They believed that by enabling resuscitation and rejecting DNR orders, the life of the person they cared for could have been prolonged, even if just shortly.

*“Sometimes, like humans, we have expectations that will force us to choose to take him on the mechanical ventilation because I want him to live longer. In my view, I will choose that.”***CG 004**

*“I think I will choose to have it (resuscitation methods), (long silence) I want her to stay.”***CG 007**

“I will choose at least for them (Doctors)to do the resuscitation for his life to be pushed off a few more days.” **CG 005**

*“I will ask them to go ahead and resuscitate the patient, at least so that it helps him a little.”***CG 010**

Despite being aware that resuscitation cannot improve a patient's condition, some participants insisted on having their families undergo resuscitation, rejecting DNR orders.

“If their heart has stopped and I am told that CPR might help, I would give them that chance. Even if I am told it will not help, I will still try; everything is about trying. If it works, it is good, if it doesn't at least I would have tried my best.” **CG 012**

4.3.2.2 Patients Factors

Patient's Current Condition

It came to light that patient factors play a major part in DNR decision-making. The duration and severity of the patient's condition, either helped or hindered the implementation of DNR orders. Many HCPs brought up the impact of the length of illness during the focus group discussions.

“This will depend on the acuteness or chronicity of what they have. I will give an example of a patient who has been managed for CLL since 2018 but has been deteriorating. The family was prepared for these eventualities. Having that DNR discussion didn't come as a surprise to them. In as much as the conversation of not escalating care was hard for them, they have come to terms with that decision. Yes, they are sad but they kind of understand.”FG 005

Another participant in the FGD concurred with the viewpoints of the previous respondents,

“She mentioned something about the acuteness or chronicity someone has been battling something a long time. People look at it like “Let him rest, he has suffered.”. But someone who presents with upper GI bleeding and then the next thing he is dead, and they'd be like “Hey, how?”FG006

“Caregivers on their side had already anticipated what would be next by just seeing how the relatives were doing or how they were progressing. On the question of why they had agreed for their relatives to be DNR, these were the responses.

“You know I have been with him for long. I know he is old, but you can anticipate some things. I could see he was deteriorating. We have been coming in the hospital severally, I knew that day would come at some point.”CG 014

Patient Age

Patient age was also another factor that determined the decision of the caregivers toward DNR and other resuscitation methods. Participants described old age as a facilitator to DNR orders and young age as a barrier.

“I remember we had an advanced-aged grandmother in her mid-90s. We discussed with the family, and they were like, "It's okay, if you see she's not doing well you can just turn off the oxygen. They never got scared.” **FG002**

“It's quite different for somebody who is elderly to someone younger. For someone who has not lived his or her life well, it's quite hard but for a grandmother who is 100 years or above 90 even the people around will appreciate God. (Joint laughter).” **FG004**

Futility of Care

Caregivers reported that the futility of resuscitation was a facilitator of DNR orders. The following statements were in support of DNR after acknowledging that resuscitation was no beneficial and ineffective.

“Well, there is no need now. At the end of the day, she will still die. If it is something helping her, they should put it, but if it is not helpful there is no need.

CG 002

“Isn't it maintenance? It is just like uh.... (pause). It is like lying to life (Laughs), but the reality is you are dead. They are just trying to keep you alive, but you are gone. What I think is even if you are resuscitated and intubated you will still die.”

CG 011

Even those other measures you know even if they perform on her. You know that after some time she will die. But as I told you, I am very optimistic but will not cheat. I will not lie even to my family. I will let them know that the patient will not make it for long, so there is no need to put machines. I will suggest releasing her so that she may rest. **CG 009**

4.3.2.3 Healthcare Providers Factors

Healthcare Care Knowledge and Recommendation

Healthcare professionals have an important role in DNR decision-making. The findings in this study indicated how caregivers of palliative care patients trusted doctors to make decisions on their behalf. As alluded to by these different participants who had not had a DNR conversation.

“I will depend on the doctors' decision if all interventions bring the same results.

I do not think we will refuse the doctor's decision. If the doctor has said, we will follow” **CG 007**

“You know me, there is nothing I am choosing. It is the doctors who decide. We will just accept. If I decide to refuse the DNR orders, It is like I am not the one who knows better. I want the doctors to try everything, even undergoing resuscitation but the doctors are the ones who know better.” **CG 008**

The same findings were presented with caregivers who had already signed DNR orders in the hospital. They show understanding of doctors' decisions but also trust that they can make good decisions on their behalf.

“I asked them to do what they know. When I was explained I gave consent because they said that there is nothing that could be done.” **CG 001**

“Of course, the doctors had already said. We just accepted.” **CG 013**

Additional factors that contributed to HCPs influencing DNR orders included the information's content and delivery approach. Furthermore, how well they understand the patients' conditions.

*"If you explain to them(caregivers) appropriately and they have all the information and possible management, they are likely to agree or disagree if they think there's something that can be done. They need to understand the diagnosis."***FG005**

*"How you make the relatives understand the condition of your patient matters. Like how well you know the patient's details, how you package the story and how you make them understand your thought process to that decision."***FG006**

4.3.2.4 Socio-Economics Factors

Influence of Social-economics Factors

The outcomes of the DNR conversations seemed to be influenced by social factors. Family dynamics, the caregiver-patient relationship, the caregivers' education—especially if they are HCPs—and the absence of a family spoke-person were all social factors that influenced DNR conversations. Respondents in the focus group discussion stated that it was more difficult for them to make decisions the closer the caregivers were to the patient and vice versa.

*"...the relationship between the patient and the caregivers affects how easily that decision is made. Sometimes, the immediate family let's say it's a parent, a daughter or a son may be quite reluctant to sign, but when you call an uncle, they decide faster. So, most of the time the people who end up making the decision are not the immediate people. They are the extended family members."***FG005**

*"We had a similar case where the patient was brought in by the shemeji (in-law). The husband and the parents of the patient had died. So, they had it easy in making decisions."***FG001**

The study also showed a contrast in outcomes when caregivers are HCPs. The participants gave examples of when it was a barrier and when it was a facilitator.

“...sometimes the caregivers are medical personnel who understand how badly their relative is doing. When you talk about DNR status they are sad of course but they understand. They are a kind of link between you and the family and can be an easy way to break the news on putting the patient in a DNR status.” **FG004**

“But then there’s also the medical personnel who would want you to still go ahead and do everything. I think it varies and hard to predict what’s going to happen.” **FG004**

Another family factor highlighted in the study both in the FGDs and interviews was when the caregiver is alone and cannot make decisions alone. They had to wait for a bigger quorum to make decisions collectively as an entire family.

“It is very difficult to sign a DNR form because they have to consult so and so who may be like the elder son. And the discussion ends up going for a whole week.” **FG002**

Financial Resources

The cost was also a major factor in denying or agreeing to a DNR order. The findings in this study from the interviews showed that the cost factor was a hindrance to resuscitation procedures. The findings from the Focus Group Discussions concurred with the above findings however it also showed a contrast in economically stable families. It shows that those relatives were ready to try everything regardless of the outcome.

“...it depends on the cost; if we can gather the amount of money required for him to undergo resuscitation, we will choose that, because everyone would like their friends to live long, but if we cannot afford it we will let him rest.” **CG 004**

".... may be to add on the issue of resources, we've had relatives who have enough resources and feel they can do anything for their patient. So regardless of how their patient is they want ICU care and everything possible to be done for them. We had a patient recently where the family wanted everything done for him including ICU care and surgery despite the mortality risk being high. Eventually, he died the day after surgery." FG001

4.3.2.5 Spiritual and Cultural Factors

Spiritual Influence

This study found that most caregivers' spiritual background was a facilitator to acceptance of DNR status. From the interviews, it is evident that caregivers believed in a higher power to protect and heal their loved ones without resuscitation. They also attributed people's last breath to their Maker, making resuscitation go against God's will. Some participants reported that doing resuscitation was to compete with God's power in the life of an individual.

"I will leave her like that she will get healed. God will heal her without any machines connected to her or resuscitation done on her. They will give her medications only."CG 006

"Today the doctor told us that her brain is dead, only the lungs and heart functional. But we all leave it to God because we cannot object to his will." CG 015

"I asked them to do what they know. When I was explained I gave consent because they said that there was nothing that could be done. I left it in God's

*hands. He knows why, even when the doctors are trying everything, God already know what is next."***CG 001**

*"... another issue is about spirituality. Sometimes you talk to them, and they are like trust God and he will heal this patient. "Those forms you are giving us to sign we will not sign because we trust God to do a miracle."***FG003**

Cultural Practices

One of the factors for DNR decision-making was the influence of culture. Participants from the focus group discussion attested that death was a difficult topic of discussion among some communities. Others reported some cultural practices that were hindering DNR. Some of those practices were related to marriage.

*"... culturally, the Kalenjin's don't want to be associated with death. When it comes to deciding for someone, some people would feel like they gave up early and would feel like the decision will have bad consequences for that."***FGD 003**

"We had a lady who had been married and separated later. All her siblings and uncles came but they were unable to decide for her. They wanted to involve the husband who was married to someone else. The husband was unavailable, and they were now saying they'd have to look for a clan elder to come help to avoid the curse to follow them. Funny enough they had been separated for 15 years."

FGD 002

4.3.3 Expectations of Caregivers and Patients while Discussing DNR

Figure 4

Thematic Representation of the Expectations of Caregivers and Patients while Discussing DNR

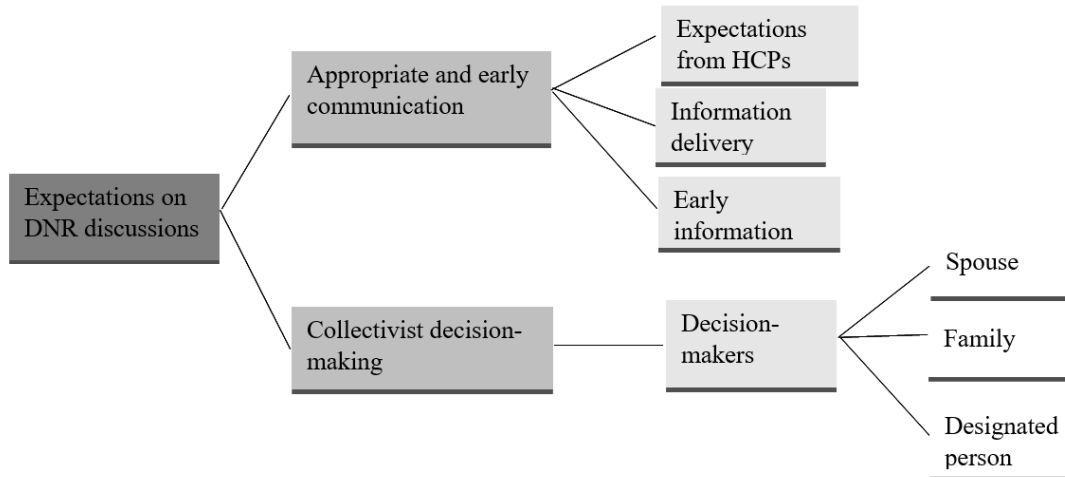


Table 10

Transition from Codes to Categories on Objective Three

Code	Category
Compassionate HCW Availability Involve caregivers in the discussion. Allow for questions	Expectations from healthcare professionals
Non-medical jargon Languages Comprehensive message Know all the patient details No conflicting information	Information delivery
Early information	Appropriate timing for DNR discussion
Family decision Spouse decision Designated person	DNR decision-makers

4.3.3.1 Appropriate and Early Communication to Caregivers

Expectations from Healthcare Professionals

One of the sub-themes in this study was what people expected of healthcare providers. Participants anticipated that compassionate healthcare professionals would bring up the topics. In addition, they wanted to be allowed to express their concerns and ask questions. Finally, they anticipated that the HCPs would always be accessible in case they needed an update for their family members.

"... when talking about such sensitive information, sometimes they (caregivers) want you to talk multiple times to different people who keep showing up every day. You know according to them their patient is the only patient in the ward that you should be concerned about. And it's like they just want to hear it again and again until they are comfortable with the decision." FG005

"Try understanding what they are going through. Be empathetic and show some love. Don't give the whole information at once. Allow for a break as they process the rest of the information, be ready to answer questions." FG005

"Sometimes, we try to do these discussions in a hurry which I don't think is very fruitful. I think time is one of the expectations I see they need from us. Just sit them down and give them time to understand, internalize what you've said then eventually come up with a decision." FG002

Information Delivery

Another sub-theme that emerged from the data was how the information on DNR code status should be delivered. Respondents said that they would like the HCPs to give a comprehensive message sharing all patients' details. They were also expecting that the

message would be delivered in an easy language some wanting the message to be in their local language.

“I had a discussion with a family about the state of their mother. I had about 20 relatives. Before I could explain anything, they already had questions. They wanted to know the diagnosis and progress of their patient and the outcome. I started speaking in Swahili, but they insisted I speak in the local language since among them were people who didn't understand Swahili. They wanted to hear it directly from me rather than from someone translating.” **FG001**

“They expect you to give them actual information so that even if someone else talks to them they'll give the same information...and then they also expect us to know everything about the patient.” **FG006**

On this information delivery, this study found that there were conflicting opinions on the extent to which truth should be told. Some participants did not want any false hope others wanted an encouraging message even if it was a lie.

“I would like to be told everything. That is good. I like it like that It is better to know the truth. Without giving me false hope” **CG 012**

“They should comfort you. They should tell you he will get healed even if they will not get better. Not to ask you to give up on them.” **CG011**

“I stood for him until he died. He had leukaemia, just like my wife. But we were not informed earlier about it. We were only told:“ Let us fundraise; let us donate blood” but the medics held the information they had from us. Like the reason, the patient was losing blood. They knew that even if we donated any amount of blood for him to be transfused, blood would still end. They lied to us.” **CG 009**

DNR Appropriate Timing

The timing for DNR consent remained an issue of concern. It was evident that most participants wanted the DNR consent to be sought early from the caregivers as well as the patients,

"They (doctors) should tell us early that she is not doing well." **CG 003**

"Early is best." **CG 005. CG 012**

Various reasons were given on why they wanted an early conversion from preparation to trying to improve the patient's quality of life and also to reconcile with God and others.

"Definitely early; imagine if you have, for example, HIV. Isn't it better to know it earlier than being told late? They should say it so that I prepare myself. I would also like the patient to be told so that he asks forgiveness to God." **CG 010**

".. like my brother's case. I got angry at the doctors. I complained. I told them You should have told me earlier so that I decide because it was something I was also responsible for. So, I told them if you had told me earlier, I would have made a decision earlier. I would have told people at home to relax instead of waiting. You know it also involves an expense like being told to go back home and bring people to donate blood. You see, that is an expense. And people will be panicking; they used to come running because they were told it was about to save someone's life. When you know at the end it is not helping. So I was complaining about it. Anyway (breathing loudly), we were increasing their blood bank, which can help others, but they would have told me early." **CG 009**

"He (the doctor) talked to us late. I wish he should have discussed this with us earlier. I came to terms with it first. It was so hard to make everyone else around me understand that in such a short time. I was still processing everything myself,

and I could not help others who hoped that the medic in the family could be of help." CG 013

4.3.3.2 Collective Decision-making

DNR Decisions Makers

To come up with this sub-theme, participants were asked who should be involved in the DNR discussions or if they were comfortable making decisions alone. Findings in this study indicated that most of the participants were expecting the whole extended family to be involved in the DNR decision. These responses show that participants were reluctant to make decisions alone. Another reason was that the rest of the family would question the caregiver's choice if they made an individual decision on the patient. Besides, decision-making seemed a huge responsibility.

"...oooh no, you know, the minute she gets admitted, all her children are showing up. Even when we were last admitted, that's what happened. We sat together and discussed it. Again, if that day comes, you know me, I am her in-law. It will be a must for all her sons to be present, but if I must inform them, I will do it..." CG 002

"We will have to discuss this first. First, we must see how she (the mother) is doing. Even when I am about to be taken to the hospital, I call my sisters and brother." CG 003

"In my case, it can be me, the children, and some family members. I will not make the decision alone." CG 005

“Not myself. I will call his brothers so we can all hear because if I hear alone, it will look like I am happy about what is happening. But if we hear it, all of us, they will hear and understand by themselves”. **CG 010**

"I can call other people. I am not the only one relying on this person. There are many others. I will call my brothers, my sisters, and his brothers (patients' brothers) for them to help me. There are some situations you need help to decide. It becomes hard. You can choose alone, and people will start questioning your choice. Especially when it is about someone's life." **CG 011**

"Our homes are far. I was born in Homabay County while my husband comes from Migori but works in Kisumu. I told the doctor I couldn't make the decisions on my own. I needed to involve my in-law who could have other ideas. We waited for him." **CG 015**

One participant thought that the decision to agree to disagree with the DNR order was also to be done by the patient confidant. A confidant in this case would be someone the patient has given the power of will. One participant responded that,

“... close relatives or someone this man trusts can make the decisions. Someone he has been discussing his health status with.” **CG004**

Another expectation that emerged was those men, as spouses, were very comfortable in making decisions on behalf of an ailing wife. On the contrary, women found it hard to make such decisions and tended to involve the extended family. This highlighted the patriarchal influence on DNR decision-making.

“... it is me. There is no one else who is going to make that decision. If I am available and this mum (the patient) is available. Who else should be involved???? It is me. No one else. (Laughs).” CG 006

“If the patient is attached to me directly, I will respond. For example, for my wife. That one is a direct relative, but if it is something about the family, I will involve family members who are around.” CG 009

Another finding was that young people wanted adults to be the ones involved in decision-making. This was evidenced by the following two participants in their responses about who they think should be involved in decision-making for the patient under palliative care,

“That old man, (His dad, the patient's husband).”CG 007

“Mzee (My father-in-law in Law). I am just her in-law.” CG002

4.4 Discussion

4.4.1 Perceptions of DNR Orders

Lack of Awareness and Misunderstanding of DNR orders

Several participants alluded to being unaware of the DNR consent form and the other resuscitation procedures. On the contrary, some were aware but had a negative attitude towards the resuscitation procedures that the hospital facilities avail during end-of-life care for their patients in the event of a cardiac arrest. These findings were consistent with the findings of Alrimawi et al. (2018), which indicate that the Palestinian participants appeared to have a negative attitude toward the DNR concept. On the other hand, it lacks an understanding of DNR meaning and confuses it with the removal of life-sustaining machines. It was evident that most participants needed more information and education on DNR and other resuscitation procedures to be able to express how they were

perceiving DNR orders. We think that lack of understanding might be explained since death is a taboo topic and the reluctance from HCPs to introduce death. This data also supports the extensive evidence that there needs to be more understanding of the DNR concept (Alsati et al.,2020). These findings are similar to the findings of Vranick, Sanghavi, Torp, and Stanton (2022), who suggest that every facility with palliative care facility should have a DNR policy in place.

Further, they should be educated about its importance to the patient's wellness. Hence, from the findings, there is a need for health education and awareness to be made a priority for both caregivers and palliative medical personnel. This way, the attitude towards DNR as a whole and other resuscitation procedures will improve and change significantly from a negative to a positive attitude. Consequently, with more health education on DNR and other resuscitation methods, the misconceptions around the same will be reduced since there will be more clarification.

Subjective Perception

From the findings, it is evident that most of the participants depicted feelings of despair and even, in some cases, emotional downcast. This is because death remains a super sensitive topic of discussion among most persons in the cultural setting. The DNR concept seems to elucidate many negative emotions associated with the death of an ailing loved one since most perceive the DNR as an easy way to introduce death or as preceding the death of their loved one. Olver et al. (2019) aver that participants associate DNR with imminent death. Thus, most perceive DNR as consenting to a loss of hope and even progression toward the actual death of an individual.

In some cases, it was evident that DNR consenting seemed like automatic despair towards the patients' ailing state. Thus, there was a need to improve the pre-counseling

and post-counseling for caregivers and patients under palliative care. This will change their perception of DNR and resuscitation methods from negative to positive, it will also prepare caregivers to consent to DNR orders.

4.4.2 Factors involved in DNR decision-making

Life Extension

This objective's overarching theme was the caregiver's loved one's life extension. These results differ from what Qi et al. found in their qualitative study. Most participants agreed with DNR orders because they did not want to see their loved ones suffer and found CPR meaningless (2021). The contrast in the findings should be explained by the fact that our participants had limited knowledge of the outcome of CPR and how it is performed. The study provides a new insight into the relationship between understanding DNR orders and their implementation. These results will help the healthcare workers explain to relatives that a DNR order is not a synonym for death and that CPR does not necessarily mean the patient will stay longer.

Patients' Factors

From the findings of this study, the severity of the patient's conditions, age, and futility of care were the main patients' factors involved in DNR decision-making. These findings concur with what was found by Mockford et al. in their study on barriers and facilitators of DNR orders (2014). The author of the last study found that the severity of the disease was a relevant factor in deciding on the code status. Regina et al. also found that the patient's age had an essential influence on signing a DNR form, with older age being a facilitator (2017). These findings suggest that HCPs should consider the severity of the disease, the period of sickness, and the patient's age when they want to engage in a DNR conversation.

Healthcare Factors

Participants in this study indicated that doctor's suggestions had an essential role in DNR decision-making. The HCP's knowledge of the patient's condition, availability, attitude, and information delivery were also HCPs-related factors. This was similar to a qualitative study in Taiwan by Chiang et al. that found doctors' recommendations were foundational to relatives' decision-making process (2021). HCPs should be trained on how to hold end-of-life discussions to be able to have smooth conversations and to be able to support caregivers emotionally.

Socio-Economic Factors

It was evident that decision-making regarding whether or not to embrace DNR, as well as other resuscitation procedures, was influenced by the social and economic background of the participants. The family dynamics, like the relationship between the caregivers and the patients and the education of the caregivers, influenced DNR decision-making. The findings support Syed et al. results attest that families' disagreement, refusal of the diagnosis, and level of education were the main barriers to embracing DNR (2016). Chiang et al. also emphasized the lack of agreement among family members as a barrier to making DNR decisions. This study found that having an HCP in the family could be both a barrier and a facilitator to withhold CPR. It is explained by the fact that HCPs understand what DNR orders are and what ineffective treatment is. They have probably experienced successful resuscitation, adding to the emotional challenge of losing a loved one.

Additionally, other factors from the findings that were linked to decision-making by the caregivers included the ability of both financial and material resources of families. These findings were consistent with other studies that showed that the cost of some medical

interventions was an essential burden in lower- and middle-income countries (Chuan-Qi et al., 2021).

Spiritual- Cultural Factors

From the findings, it was evident that beliefs and culture had a crucial role in deciding whether to embrace DNR. Also, from the findings, it was evident that most people from the South Western region did not wish to be associated with the death of a patient. From the respondents, it was evident that some people would not want to be associated with death and, hence, not with DNR discussions. These findings concur with Gibbs et al. (2016), who observed that the sacredness of death in Uganda made it impossible to discuss DNR. The same scenario was the case in South Africa and Japan, where discussing the possibility of death was considered wishing the dying patient lousy luck. Further, Githaiga and Swartz (2017) observed that discussions around death have always been considered taboo in Kenyan communal settings. Hence, the reason most people fear discussing the subject. It infers that even discussions around DNR and other resuscitation methods like CPR and mechanical ventilation would be done reluctantly. This study confirms the theory that death is a taboo topic in African societies. Furthermore, these results suggest that HCPs should consider the caregivers' socioeconomic, spiritual, and cultural backgrounds before discussing DNR.

4.4.3 Expectations While Having DNR discussion

Appropriate and Early Communication

This study showed that most participants had expectations on how and when the message was delivered. An overarching finding from this study was early communication from HCPs to relatives. The participants hoped that this way, they would be able to make decisions concerning their loved ones on time and come to terms with the situation. A study is still needed to understand exactly when or how early they would like to have a

DNR decision, from when the non-reversible diagnosis is made to when death is imminent. These findings are similar to a study done on caregivers of patients with lung cancer, where the majority choose to have a DNR conversation early at the time of the diagnosis (Ahmed et al.,2015).

Besides that, the participants expected that the medical personnel should show more empathy when dealing with caregivers of patients under palliative care. Participants also indicated that they always anticipated discussing with a well-informed doctor and being compassionate toward patients' concerns. These findings agree with the findings of Ahmed (2015), who suggests that end-of-life instructions should be made clear so patients can maintain autonomy and clarity in decision-making regarding their patients in good time and that physicians should always consider their patients' situation and endeavour to help them. The same study found that how the message was transmitted was very important. Patients and caregivers wanted the physicians to consider their situation and help them. They also reported that patients' autonomy and dignity needed to be respected if they had already signed a will or made EOL instructions clear. Comprehensive, trustworthy information while avoiding medical jargon also arises in patients' DNR decision-making preferences (Ahmed et al., 2015).

There is a need for the provision of information to patients by healthcare providers on the severity of illness, life expectancy after DNR, the complications of attempted resuscitation, and the outcomes of such medical practices (Fan et al., 2018).

Collective Decision-Making

This study revealed that participants wanted the DNR decision-making process to be a family decision with the whole family present. These findings concur with the Chuang-Qu study that stipulated that the Chinese population chooses to make a joint decision

(2021). Alsaati et al. also agreed with their findings. The same study also found that most participants wanted their doctors to decide on their behalf. When asked whom they wanted to get involved with, 36% trusted that the family should get involved rather than the patient, and 22% thought that the patient should decide who gets involved (2018). A particular finding in this study was how husbands were comfortable making DNR decisions for their wives but not vice-versa. These findings are explained by the study happening in a patriarchal society.

CHAPTER FIVE

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

This final chapter includes the summary of the findings, recommendations by the researcher, and the conclusion. It also includes the areas that the researcher has recommended for further research.

5.2 Summary

This was a qualitative study whose main objective was to understand how caregivers perceive the concept of DNR. Further, this study sought to identify the significant factors and expectations of caregivers of patients under palliative care while having DNR discussions.

On caregivers' perception of the concept of DNR, it is evident that there is a general lack of awareness and misconceptions of the DNR concepts. Further, there was a subjective perception based on belief and emotion. Life extension was an overarching factor for making a DNR decision. Besides that, patient factors, healthcare providers' factors, socioeconomic background, and spiritual-cultural influence were found to be factors involved in the DNR decision-making process. Participants expected appropriate and early communication while having a DNR discussion. Furthermore, decision-making was to be done in a collectivist manner.

5.3 Conclusion

In conclusion, this study shows the need to increase awareness of the DNR concept alongside resuscitation methods like CPR and mechanical ventilation for better and more successful DNR conversions. It also highlights the need for counselling and caregivers' preparation during DNR discussions. It emphasizes the evaluation of the patient's

condition and the assessment of the background of the decision-maker. Finally, this study shows a need to empower healthcare providers to hold DNR discussions.

5.4 Recommendations

5.4.1 Policy Recommendations

a) Hospital level

The following are the recommendations at the hospital level;

- i. To provide continuous medical education to HCPs on end-of-life discussions to be able to hold DNR discussions.
- ii. To offer counselling sessions to all caregivers involved in the DNR decision-making process.
- iii. To organise group discussions for caregivers of patients under palliative care regarding advance directives.

b) National level through KEHPCA

The following are the recommendations at the national level through KEHPCA

- i. To create a framework on legal issues surrounding DNR discussions that protect both the HCPs and the caregivers.
- ii. To create a framework that will resolve DNR discussions related to ethical issues.
- iii. To establish a national policy on DNR orders
- iv. To raise awareness of advanced directives at the community level

5.4.2 Recommendations for Further Study

The following are the recommendations for further studies.

- i. The perceptions and preferences of patients on palliative care
- ii. The understanding of DNR orders and challenges from HCPs

- iii. The Impact of end-of-life discussion on the emotional wellness of the primary caregivers
- iv. The impact of health education on the role of the primary caregivers in palliative care
- v. The role of pre-counselling and post-counselling on caregivers of patients under palliative care in hospitals
- vi. The cultural relevance of renaming DNR to AND and its impact on our setting

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APPENDICES

Appendix I: Research Instrument

Demographic Characteristics

1. Age: years
2. Sex: Female Male
3. Education level: Primary Secondary Tertiary
4. Relationship with the patient: Spouse Sibling Child In-law Others specify.....
5. Faith: Christian Muslim Others Specify
6. Care giving duration: years months Days
7. Patient's age:....years
8. Patient's diagnosis:

In-depth Interview Guide

A) For homebased caregivers

1. What do you know about your patient condition?
2. From what you were told by their medical team, what are the expected outcomes?
3. Knowing you are taking care of a patient with life limiting illness, have you ever had a discussion on what will happen in the event their heart stops or they stop breathing?
4. Has anyone ever talked to you about not trying to restart when it stops, or trying to restart it? If yes please elaborate
5. Please tell me your feelings on not attempting to restart someone heart? Is it something would like your relatives to have or no to have?

6. How would you want to have this discussion? ... if you do not want to get involved who would like to get involved?

B) For hospital based caregivers

1. How did you understand DNR?
2. How did you arrive at your decision? What helped you decide about the DNR status? What are the main factors that facilitated or hinder you in making your decision?
3. Please explain to me how the HCP discussed the subject with you.... If it was up to you, how would you want the subject discussed?

Focus Group Discussion

A) For Hospital Based Caregivers

1. What are the feelings of caregivers when you are having a DNR discussions?
Please give examples/ case scenarios if you can.
2. How do caregivers arrive at making the decision? What helped them decide about the DNR status? What are the main factors that facilitated or hinder them in making your decision?
3. Please explain to me if there is any expectations/preferences that caregivers usually bring up while having a DNR discussion? (Probe: Language, content of information...)

Appendix II: Informed Consent Form

This consent form is an invitation for caregivers of patients on follow up with the Tenwek Palliative Care Program and the caregivers of patients with terminal illness admitted at Tenwek Hospital to participate in research titled:

Caregivers' perceptions towards decision-making for Do Not Resuscitate Orders: Qualitative study in rural Southwestern Kenya

Principle Investigator: Alida Iradukunda

Organizations: Kabarak University/ Tenwek Hospital

This document has 2 parts: Information sheet and the Certificate of Consent

Part I: Information Sheet

My name is Alida Iradukunda. I am a Family Medicine Master's student at Kabarak University. I am doing a study on caregivers of patients with life-limiting illness on home-based care and in the hospital. The study is about how they perceive Do Not Resuscitate. We want to know the factors considered to make that decision or deny it. We also would like to know your expectations regarding when healthcare providers will bring up that topic or what your experiences were when you had the Do Not Resuscitate discussions. This research will involve your participation in a face-to-face interview or a focus group discussion with the principal investigator and / or a research assistant. The interview will take about thirty to forty-five minutes of your time, while the focus group discussions will take forty-five minutes to one hour. The interviews will be recorded and your voices will be distorted to allow confidentiality. Your participation in this study will help us improve how patients with life-limiting illnesses are treated by knowing what their caregivers wish. The study is voluntary, and you are free to participate or not. You will be free to leave at any point. If you do not want to answer some questions or wish to stop the interview or focus group discussions, you are free to do so. No explanations will be required from you unless you offer them. Your name will not appear anywhere, and your identity will be known by the primary investigator and the researcher's assistant only. You will be communicated the findings of the study after it is done. Feedback from this study will also be shared with people involved in your care, trainees in health sciences, policymakers, religious and local leaders. You are free to ask questions if you

want clarity or further explanations. You can also contact me. Dr Alida Iradukunda on 0705248106. You can also contact Tenwek Hospital ISERC on ierc@tenwekhosp.org. This proposal has been reviewed and approved by the different Ethics and Research Committees.

Part II: Certificate of Consent

I..... have been invited to participate in a study called: **Caregivers' perceptions towards decision-making for Do Not Resuscitate orders: Qualitative study in rural Southwestern Kenya**. I have read the above information (or it has been read to me). I have been given the opportunity to ask questions about it, and any questions I had have been answered to my satisfaction. I consent to be a voluntary participant in this study.

Name of Participant.....

Signature/ Thumb print of participant Date / /
2023

Research/ Research Assistant.....

Signature/ Thumb print Date / /
2023

Appendix III: Fomu Ya Makubaliano

Fomuhiiyamakubalianoinawaalika wale

wanoatunzawagonjwawaowanaofuatiwanahospitaliya Tenwek

kwenyeidarayamagonjwayasionatiba (Tenwek Palliative Care)

nawanaotunzawagonjwawalionamagonjwayazionatibaambaowamelaswakatikahospitaliy

a Tenwek iliwashirikikwenyeutafitiwenyemada:

**“Mtazamowawanaotunzamagonjwayasionatibakatikakufanyamaamuziinaposemek
anahawawezikushugulikiwawanapobadilishahaliyaoyaafya:
Utafitiwamtazamokatikaeneo la kusinimagaribiya Kenya”**

Anayefanyautafitini: Alida Iradukunda

Chuo husika: Chuo Kikuu Cha Kabarak / Hospitaliya Tenwek

Nakala hiiinasehemu Mbili: Habari inyohusunacheti cha makubaliano

Sehemuya kwanza: Maelezokuhusumtafiti

Jina langu ni Alida Iradukunda. Mimi nimwanafunziwacheti cha pili

katikatibayajamiikwenyechuokikuu cha Kabarak. Ninalenga wale

wanaotunzawagonjwayanayofupishamaishanawanaopatautunzajinyumbani au

hospitalini. Utafitihuuunlengamtazamowaokuhusu **‘usawekejuhudi pale**

ambapomgonjwaanapobadilihaliyaakeyaafyakuwambaya Zaidi.

Tunatakakujuavipengelevinavyohusiswakatikakufanyamaamuziyakukubali au

kukataamtazamohuowadaktari.

Tunatakakujuamatarajioyako pale

ambapowahudumuwaafyawanapoletamazungumzokamahayo au

yanayopitiakwenyemawazouliposikiakuwawahudumuwaafyahawatawekajuhudi pale

ambapohaliyamgonjwautakapokuwambayasaidi.

Utafitihuuutakuhezishamajokwamajokatikakukuhoji au

majadilianonawahusikakatikamajadilianonamtafitimkuu au msaidizi wake.

Mahojianoyatachukuanususaahadidakikaarobaininatano au wakatimwinginesaamoja.

Mahojianoyatarekodiwanasautiitabadilishwailikulindasiriyaanayetoahabari.
Kuhusikakwakokutasaidiakuboshajinsiyakuwashugulikiawagongwawalionamagonjwa
yanayofupishamaisha pale ambapotutajuamtazamowawanaotunzawagonjwawao.

Mahojianoniyahiarinaunaruhusiwakukubalikuwamhusika au la.
Unawezakujiondoawakatiwowote. Endapohutakikujibubaadiyamaswali au
endapoungependakusimimishamahojianoyabinafsi au
kwenyekikundiunayohusizwaticamajadiliano, ukonahurukufanyahivyo.
Hutaulizwakutoamaelezokuhuzuuamuziwakoisipokuwaukitakamwenyewakufanyahivyo.
Jina lakoalitaonekanapopotenautatambuliwatunaanayefanyautafitihuunapenginenzaidizi
wake pekee. Matokeoyautafitiutafahamishwabaadayautafitikumamilika.
Ripotiyautafitihuuutatolewa pia kwawatuhusikakatikautunzajiwawagonjwahusika,
wanaochukuasomoyamatibabu, waunda sharia, viongoziwadini and
viongoziwasehemuhusika. Unahurukuulizawaswalilote au kamaunatakaufafanusiwaziada.
Pia wawezakuzungumzanamimi Daktari Alida
Iradukundakitanambariyasimuyarununu 0705248106. Pia
unawezakuwasiliananaidarayautafitihospitaliya Tenwek katikaanwani pepe
ierc@tenwekhosp.org.

Utafitihuuumechunguzwanakupitishwanakamatitofautiyautafiti

SEHEMU YA PILI : CHETI CHA MAKUBALIANO

Mimi.....

Nimekualikamhusikakatikautafitiwenyemadahi:

Mtazamoyawanaotunzawagonjwakwenyemaamuziyakukubali au

kukataakutofanyajuhudiyakuokoamaisha:

**Utafitiwamtazamouliofanywakusini makaribimwa Kenya. Nimesomamaelezo
(uanimesomewamaelezo).**

Nimepewanafasiyakuulizamaswalikuhuzumaelezo hayonamaswali yote
yamejibiwananimeridika. Ninafanyamaamuziyakuwamhuzikakwenyetafitihuu.

Jina la mhuzika

Sahihi/ Alama yakidolewamhusika Tarehe.... / / 2023

Anayefanyautafiti/


Msaidizi

wake

.....

Sahihi/ Alama yakidole Tarehe / /
2023

Appendix IV: Ethical Approval Letter



TENWEK HOSPITAL
A Ministry of Africa Gospel Church

P.O. Box 39-20400
Bomet-Kenya
Postal Address:

Telephone: (254) 728-691900, 20-2045542
E-mail: info@tenwek.org
Website: www.tenwekhospital.org

Date: April 20th 2023

Dear Dr. Alida

RE: 2023-0007; “Caregivers’ Perceptions Towards Decision-making for Do Not Resuscitate Orders: Qualitative Study in Rural South Western Kenya”

This is to inform you that the Tenwek Hospital ISERC Executive Committee has reviewed your submissions and accepted your responses and corrections and now approves your proposal titled above. This approval period is from **20th April 2023 to 19th April 2024**.

This approval is subject to compliance with the following requirements

- i. Only approved documents including informed consent, proposal, and study instruments to be used.
- ii. All changes including amendments, deviations, and violations are submitted for review and approval by the Tenwek Hospital ISERC.
- iii. Death and life-threatening problems and serious adverse events or unexpected adverse events whether related or unrelated to the study must be reported in writing to the Tenwek Hospital ISERC within 72 hours of notification.
- iv. Any changes anticipated or otherwise that may increase the risk affected the safety or welfare of study participants and others or affecting the integrity of the research must be reported to the Tenwek Hospital ISERC within 72 hours.
- v. Clearance for export of biological specimens must be obtained from relevant institutions if applicable.
- vi. Submission of a request for renewal of approval at least 60 days prior to the expiry of the approval period. Fill out an annual renewal form from the website and attach a comprehensive progress report to support the renewal.
- vii. Submission of an executive summary report within 90 days upon completion of the study to the Tenwek Hospital ISERC.

Prior to commencing your study, you will be expected to obtain a research license from National Commission for Science, Technology, and Innovation (NACOSTI) <https://research-portal.nacosti.go.ke> and any other relevant clearances needed.

Blessings in your study.
Sincerely,

TENWEK HOSPITAL
ISERC CHAIR
21 APR 2023
P. O. Box 39-20400
BOMET

Dr. Miriam Wanjala
ISERC Chairperson on behalf of the ISERC Committee.

Tenwek Hospital is a Christian community committed to excellence in compassionate healthcare, spiritual ministry and training for service.


Appendix V: NACOSTI Research Permit



NATIONAL COMMISSION FOR SCIENCE, TECHNOLOGY & INNOVATION

RefNo: 478917
Date of Issue: 11/May/2023

RESEARCH LICENSE




This is to Certify that Dr. Alida Iradukunda of Kabarak University, has been licensed to conduct research as per the provision of the Science, Technology and Innovation Act, 2013 (Rev.2014) in Bomet on the topic: Caregivers' perceptions towards decision-making for Do Not Resuscitate orders: Qualitative study in rural Southwestern Kenya for the period ending : 11/May/2024.

License No: NACOSTI/P/23/25727

478917
Applicant Identification Number


Director General
NATIONAL COMMISSION FOR SCIENCE, TECHNOLOGY & INNOVATION

Verification QR Code



NOTE: This is a computer generated License. To verify the authenticity of this document, Scan the QR Code using QR scanner application.

See overleaf for conditions

Appendix VI: List of Publication



KABARAK JOURNAL OF RESEARCH & INNOVATION

Private Bag - 20157
KABARAK, KENYA
Email: editorial@kabarok.ac.ke

Tel: 254-51-343234/5
Fax: 254-051-343529
www.kabarok.ac.ke

OUR REF: KABU01/KJRI/07/07/35

05th December, 2023

Dear I. Alida,

SUBJECT: PAPER ACCEPTANCE

We are pleased to let you know that your submission to Kabarok Journal of Research & Innovation (KJRI) has been accepted for publication. Details of the submission are as follows:

TITLE

CAREGIVERS' PERCEPTIONS OF DO NOT RESUSCITATE ORDERS: A QUALITATIVE STUDY IN RURAL SOUTHWESTERN KENYA

AUTHORS

Iradukunda A, Nthusi J and Eli H

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Congratulations on this achievement and thank you so much for choosing KJRI.

Thank you.

Sincerely,

Dr. Michael N. Walekhwa
Editor in Chief

As members of Kabarok University family, we purpose at all times and in all places, to set apart in one's heart, Jesus as Lord. (1 Peter 3:15)

Kabarok University is



ISO 9001:2015 Certified

Appendix VII: Evidence of Conference Participation

