DEVELOPMENT OF COMPETENCY GUIDELINES FOR END-OF-LIFE NURSING CARE UTILIZING A MODIFIED DELPHI PROCESS

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DECLARATION

I, Gladys Warindi Machira, declare that this project; entitled **'Development of competency guidelines for end-of-life nursing care utilizing a modified Delphi process'** is completed as an independent work. I declare that the material in this project report has been appropriately cited. The material has not previously been submitted or approved for the award of a degree by any University.

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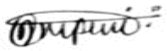
   Signature:  Date: 1st November, 2021

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DEDICATION

I wish to dedicate this thesis to my children, Gareth Metian, Gian Mayiani, and Glenys Milanoi, who at the time of my PhD journey were quite young. You have helped me to remain focused and taught me to appreciate every little thing in life. I consider you my greatest achievement.

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Table of Contents

LIST OF TABLES

Page

LIST OF FIGURES

Page

LIST OF ABBREVIATIONS AND ACRONYMS

AIDS – Acquired Immunodeficiency Syndrome

Ads – Advance Directives

BI – Bamako Initiative

BScN - Bachelor of Science in Nursing

BTM - Benner's Theoretical Model

CBD – Central Business District

CCUs - Critical Care Units

CDP - Continuing Professional Development

CINDP – County Integrated Development Plan

DT – Delphi Technique

EBP - Evidence Based Practice

EBNP - Evidence Based Nursing Practice

ED - Emergency Department

EOL - End-of-Life

EOLC – End-of-life care

EOLNC-CG- End-of-Life Nursing Care Competency Guidelines

ELNEC - End-of-Life Nursing Education Consortium

FBO – Faith Based Organizations

FGD - Focus Group Discussion

GOK – Government of Kenya

HDU – High Dependence Unit

HFA – Health for All

HIV – Human Immunodeficiency virus

HSRS – Health Sector Reform Secretariat

ICU - Intensive Care Unit

KHPF – Kenya Health Policy Framework

KHP – Kenya Health Policy

KNH - Kenyatta National Hospital

MDG – Millennium Development Goals

mDT – Modified Delphi Technique

MOH – Ministry of Health

MRC – Ministerial Reform Committee

MTP – Medium Term Plan

NACOSTI - National Commission for Science, Technology and Innovation

NCD – Non Communicable Disease

NCK - Nursing Council of Kenya

NGO – Non-Governmental Organizations

NHIF – National Hospital Insurance Fund

OR - Operating Room

PCU - Palliative Care Unit

PhD - Doctor of Philosophy

QOL – Quality of Life

SCU – Specialized Care Unit

SD – Standard Deviation

SDGs – Sustainable Development Goals

TB - Tuberculosis

UHC – Universal Health Coverage

UoN - University of Nairobi

UNHCR – United Nations High Commissioner for Refugees

WHO – World Health Organization

OPERATIONAL DEFINITION OF TERMS

Attitude – Nurses' viewpoint regarding personal and institutional effectiveness in provision of end of life care.

Competency – Overall knowledge, attitude, and practice skills that enable nurses to assess health needs, provide end of life care, educate patients and support individuals/families to manage their health holistically up to death and including bereavement.

Competency guidelines - A best practice document with a list of required knowledge, attitude and practice abilities to enhance high quality end-of-life nursing care standards

End-of-Life – This is the period when body systems shut down and death is imminent. It normally lasts from a matter of days to a couple of weeks. During this period a person may exhibit various changes as the body shuts down.

End of Life Nursing Care – Care given to a patient admitted in an acute care hospital whose body has begun to shut down. It includes physical, emotional, social, and spiritual support for patients and their families.

Good death –This is when the body systems completely cease to work and there was no avoidable distress and suffering for patient, family, and caregivers; and one that occurs in accordance to patient's and family's wishes.

Knowledge – Awareness by nurses of facts pertaining to end-of-life care gained through experience or education by perceiving.

Nurses' preparedness – It is the readiness by nurses to effectively provide end of life nursing care. This encompasses knowledge, attitude and practice domains.

Palliative Care – It is the assessment, diagnosis, and implementation of interventions that support or modify human responses in patients with acute or chronic, potentially life-limiting illnesses and their families to improve quality of life and alleviate suffering.

Practice – What nurses do or ought to do to provide good quality end of life nursing care

Special Care Units– These refer to units in the Kenyatta National Hospital that provide intensive care. These are Intensive Care Unit, High Dependence Unit, Oncology Unit, Burns Unit, Renal Unit, Emergency Department, Oncology clinic, and Palliative Care Department at Kenyatta National Hospital

ABSTRACT

Background: Most acute care hospitals are increasingly facing an upsurge in patients with chronic conditions as well as an aging population and thus patient hospitalization is quite common at the end of life (EOL). This study therefore, sought to understand Kenyan nurses' perceived level of preparedness to provide EOL nursing care; identify nurses' perceived training needs in EOL; identify and validate core & sub competencies for nurses in Kenya requisite for provision of EOL nursing care. **Methods:** The study was conducted in a government national referral hospital and was executed in two phases. Phase one research design was cross-sectional using self-administered questionnaires (SAQ). Simple random sampling was used to identify the 174 respondents who participated. Phase two utilized a modified Delphi process using SAQs. A total of 20 panel members responded. Ethical approval was obtained from the National Council of Science and Technology (NACOSTI) and Kenyatta National Hospital/ University of Nairobi Ethics and Research Committee (KNH/UON-ERC). **Results:** Findings: a) Phase I: The overall mean score was 2.7 in a scale of 4 with 4 being 'no knowledge'; In the attitudes dimension, participants indicated that they were somewhat effective (mean<2/3) in provision of EOL nursing care; and finally, in the practice dimension, it was observed that all the items examined were identified as barriers to provision of good quality EOL nursing care; and b) Phase II: two rounds of the modified Delphi process were conducted and consensus reached. **Conclusion:** Nurses had deficiencies in the level of EOL care knowledge, attitudes and practice. Further, the existing basic nursing curricula was noted to have gaps pertaining to nursing students' clinical experience for dying patients. Finally, the study identified eight core competencies and 92 sub competencies. **Recommendations:** This study provides a starting point for understanding EOL care clinical competencies for nurses in Kenya. The competencies identified in this study need further examination in practice and in actual educational settings. Finally, a large-scale survey to examine the appropriateness of the identified competencies during clinical application; as well as the relationship among these competencies, ongoing evaluation of competence, and the actual performance of nurses.

CHAPTER ONE: INTRODUCTION

1.0 Introduction

Globally, most hospitals are increasingly facing an upsurge in patients with chronic conditions as well as an aging population and thus patient hospitalization is quite common at the end of life (EOL) (Glover et al., 2017). EOL is a term that was originally applied to patients with a terminal illness (Pinto et al., 2019). However, this term has now been expanded to comprise those patients with a life threatening illness not responsive to curative treatment and who are not certainly imminently dying (Stewart-Archer, Afghani, Toye, & Gomez, 2015). However, it was noted that there was no consensus as to the duration: whether hours or months (Condon, Grimsley, Kelley, & Nissen, 2013). Nonetheless, there seem to be a change on the location of death with a shift being noted from people dying at home, to dying in institutional settings (Kobewka et al., 2017) such as acute care hospitals or nursing homes. This chapter therefore, provides some background information regarding end-of-life; statement of the problem; justification of the study; significance of the study; research questions; the hypothesis to be tested and finally, highlights the research objectives.

1.1 Background Information

Acute care hospitals have traditionally focused on the diagnosis, treatment and management of serious and chronic illness, however, they are increasingly the place where care is provided at EOL and the location of death (Kobewka et al., 2017). Globally, there is an increasing concern about quality of EOL care provided in acute care hospitals (Blakemore, n.d.; Costello, 2006; Ó Coimín et al., 2019). Literature has highlighted substantial deficits and poor care provided to patients in their final hours and their families in this setting (Rawlings et al., 2019), Conversely, the role of acute care hospitals in provision of high quality EOL care is well documented in literature (Blakemore, n.d.; Ó Coimín et al., 2019).

Irrespective of the location of death, people ought to receive decent quality EOL care regardless of the conditions that cause the death (Brighton, et al., 2017). Stewart-Archer, Afghani, Toye, & Gomez (2015) indicated that good quality EOL care is characterized by, for instance, autonomous decisions: those that reflect the self who makes them (patient). Additionally, comfort was highlighted as a key indicator to good quality EOL care (Glover et al., 2017) as well as the presence of family during

provision of EOL care (Brighton et al 2017) just to mention a few. Brighton et al (2017) indicated that, in the context of EOL care, f*amily* meant any person who was perceived to be significant to the patient and not necessarily the immediate family members. Since nurses are the frontline health care professionals who are noted to spend much time with patients (Hendricks-Ferguson et al., 2015), it is therefore important for them to be skilled. That is, they are not only expected to know their jobs but to also do their job well.

It is therefore very critical for both new and experienced nurses working in acute care hospitals to be comfortable providing EOLNC. Conversely, according to Glover, et al (2017) few nurses have the essential education or experience to provide optimal EOLNC to patients and their families. These sentiments were also highlighted in a different systematic review study whose findings supported the fact that nurses have inadequate knowledge on EOLNC (Pulsford, Jackson, O'Brien, Yates, & Duxbury, 2011). Condon *et al* (2013) indicated that this is likely to have occurred due to the fact that views and beliefs surrounding EOL and beyond are overwhelmingly distinctively individual. Additionally, they noted that views and beliefs surrounding EOL are habitually related more to experience than actual teaching.

Globally, a large percentage of the population live and die with little or no end of life care which results in extreme suffering. In 2015, approximately 56.2 million adult deaths were recorded with approximately 25.5 million (45%) experiencing suffering. Of the 25.5 million, more than 80% of them came from developing regions and the vast majority lack access to end of life care and pain relief. The scenario is not any different with the pediatrics as approximately 2-5 million children die annually with a lot of suffering. In Kenya, more than 200,000 people die annually (*CDC Kenya Annual Report - CDC Global Health*, 2019). Additionally, the population is ageing and the number of cases of non-communicable diseases (NCDs) is also on the increase (Cain & McCleskey, 2019; Ó Coimín et al., 2019; Sutherland, 2019). As the proportion of older Kenyans grows, it is likely that the numbers of people requiring end-of-life (EOL) care in the acute setting will rise. This implies that a good number of patients spend their end-of-life (EOL) days in acute care hospitals (Ó Coimín et al., 2019). These situations ensue alongside a back-ground of insufficient hospices/palliative care facilities.

Due to the aforementioned situations, nurses working in specialized care units in acute care hospitals are required to provide high-quality EOL care to augment the quality of life of patients

and their families during their final hours. The quality and safety of EOL care has important implications to the society as a whole. Potentially preventable physical, emotional and spiritual distress can occur if care is less than optimal. Invasive investigations may continue beyond the point where they are effective, and may contribute to suffering at the EOL (Bylicki et al., 2019). Communication and care planning with patients and families may be poor; psychosocial and spiritual needs may be neglected; and patients may have suboptimal control of symptoms and pain at the EOL. These have been documented to lead to suffering at EOL and as such lead to a 'bad death' (Peicius et al., 2017; Pinto et al., 2019; Ramelet et al., 2020).

The inadequate knowledge reported in literature, may be due to the fact that nursing curricula are deficient in didactic content on EOL (Condon *et al*, 2013; Glover *et al*, 2017). As was observed by Yoshioka, Moriyama, and Ohno (2013) training programs have helped educate nursing workforce in EOL care concepts. Therefore, it is vital that beside classroom-based education, hospital-based EOL programs be initiated to promote patient-centred care. It is therefore undisputable that nurses have the capacity to help most patients achieve a 'good death' in the hospital setting, yet these nurses require appropriate competencies in EOLNC. As such, nurses must and are required to provide comprehensive care that meets patients' and families' complex and divers needs irrespective of work setting (Nedjat-Haeim, et al., 2016). To accomplish this, it is important for nurses to improve their nursing care competency and utilize in their daily practice. This study therefore, sought to understand the Kenyan nurses' perceived level of preparedness to provide EOLNC; identify nurses' perceived training needs in EOL; identify and validate core competencies for nurses in Kenya for EOLNC; and identify and validate sub competencies for EOLNC for nurses in Kenya.

1.2 Statement of the Problem

Generally, acute care hospitals focus on diagnosis and treatment with a view to cure and discharge of the patient. In this context, recognition of the fact that a patient may be approaching the EOL and in need of interventions is often delayed (Bloomer, 2015). Common interventions during EOL include but not limited to: conversations about goals of care with a shift from cure to palliation (Bylicki et al., 2019); elimination of pain and other symptoms; and promotion of comfort in all aspects including psychosocial and cultural (Gayoso et al., 2018). Ensuring that patients who deteriorate receive appropriate and timely care is a key safety and quality challenge (H. Y. L. Chan

et al., 2020). All patients should receive correct care regardless of their location in the hospital or time of day.

Nurses are present throughout the trajectory of care including at the beginning and EOL, and they play a key role in caring for patients in their final hours. There is evidence that, despite the frequency of deaths in acute care wards, not all nurses are comfortable in caring for the dying patient (Park & Oh, 2019; Sedillo et al., 2015). Therefore, educating nurses to improve EOL care is critical. The End-of-life Nursing Education Consortium (ELNEC), is one such programme whose primary aim is to educate nurses on EOL care (Barrere & Durkin, 2014). ELNEC was developed with an aim of improving EOL care in the United States. However, over the years, it has been rolled out to other continents, Africa, included (Malloy et al., 2011).

In 2008, an ELNEC training was conducted in Kenya which attracted participants from various health care settings as well as those from nursing training institutions. Majority of the participants were nurses, and upon completion of the ELNEC training, the participants noted that the ELNEC competencies are pertinent to the Kenyan setting (Malloy et al., 2011). Following this training, the Nursing Council of Kenya (NCK) in 2013 recommended the integration of palliative care (PC) content into the basic nursing curriculum at certificate, diploma and undergraduate level. The integration of the PC content, was undertaken by individual institutions.

As such, it was observed that there are numerous variations in nursing schools on the amount and type of EOL care instruction students receive. Specifically, there are significant differences in students' clinical experience as far as EOL care is concerned. This can be attributed to the fact that the required EOL care instructions in all nursing schools is limited to didactic sessions which are primarily conducted in the senior years. Additionally, there are no hours allocated for EOL care clinical exposure for nursing students. For that reason, six years post ELNEC training and integration of PC content into the basic nursing curricula significant deficiencies in EOL nursing care still exist (Sedillo et al., 2015).

The ELNEC competencies seem to have been integrated in the theoretical component in the nursing curricula in Kenya but is lacking students' EOL clinical exposure as there are no hours allocated for this. Since the integration of the ELNEC content into the nursing curricula, many students leave nursing school without a structured clinical experience for provision of care to patients at their final hours. The lack of a structured clinical exposure by the nursing students in

Kenya could have led to inadequate preparation of nurses to provide EOL care in acute hospital in Kenya.

1.3 Justification of the study

In Kenya at the moment, there are limited long-term health facilities, and as such patients requiring EOL care are admitted in the acute care hospitals. This therefore means that, patients requiring EOL care are attended to by non-specialist palliative care nurses. Hence, there is need to equip these nurses with EOL care competencies to enhance their efficacy in provision of EOL care. This is critical considering the gap identified earlier, where nursing students in Kenya lack a structured clinical exposure for provision of care to patients in their final hours during their nursing training. As such, this study aimed at developing and validating clinical competencies requisite for nurses in Kenya to provide high quality EOL nursing care. This is imperative for this group of nurses who are non-specialist palliative care nurses but are critical in provision of high quality EOL care in Kenya.

In Kenyatta National Hospital (KNH), approximately 8-12 patients die in the SCUs weekly (KNH records, 2017). This suggests that KNH which is an acute care hospital cares for patients and/or their families at EOL. Therefore, nurses are required to offer high-quality EOL care to improve the quality of life (QOL) of patients and their families. For instance, it is the responsibility of the nurses to improve and maintain the physical appearance of the patients even when the body begins to shut down. That is, not only washing them and changing their clothes; but also ensuring that the patients are well groomed. Additionally, nurses are required to support the dying process by for instance, allowing family presence during the final hours which is critical for the dying patient.

However, nurses at KNH experience challenges towards provision of high quality EOLNC. This was highlighted in an unpublished descriptive study that was conducted in the critical care unit at KNH that sought to determine nurses' level of knowledge and practice in palliative care, it was noted that nurses had difficulty in provision of quality EOL care(provide reference). Specifically, psychosocial care, especially support for families with a patient at EOL. Some of the barriers that were highlighted towards attainment of high quality EOLNC included, but not limited to, nurses' anxiety about death, undesirable views of life and death, and inadequate knowledge on symptom management at EOL.

Moreover, in the same study, it was reported that nurses felt that the presence of family at the final hours was interfering with nursing care. Hence, nurses need to be brought abreast with the reality that presence of family at the final hours is crucial to patients; and as such empower nurses to accommodate the family during this time. Therefore, this study intended to develop evidence-based clinical competency guidelines for EOLNC for nurses in Kenya. Clinical competency guidelines facilitate the transfer of research evidence into practice (McDonald et al., 2019; Norris et al., 2019; Tetreault et al., 2019). This is so because the guidelines describe the required behavior by the professional which contributes to improved care when the guidelines are effectively implemented. The positive impact of clinical competency guidelines in care provision is documented in literature (McDonald et al., 2019; Tetreault et al., 2019). The study results could be useful in enhancing the quality of medical services provided to this group of patients.

1.4. Significance of the Study

Globally, most hospitals are increasingly facing an aging population as well as a population with life threatening illnesses; thus patient hospitalization is quite common at the end of life (EOL). Additionally, diseases are constantly mutating which compromises the patient's QOL. This too has led to overcrowding of patients in acute care health institutions requiring EOL care. As such, nurses in acute care hospitals provide EOL care as part of their role. This is not to mention the fact that the nurses in these units are non-specialist PC nurses yet they are vital for provision of high quality EOL care. Over and above, access to good quality EOL care is at best limited and in some circumstances non-existent for majority of the patients with life threatening illnesses and/or their families.

Given the huge number of deaths in the acute care hospitals, nurses in these units are expected to provide high-quality EOLNC. However, barriers such as lack of experience in communicating with patients and their families on EOL matters have been reported by nurses. The following barriers were also reported to exist: nurses possessing inadequate knowledge on EOLNC, negative attitude towards EOLNC and nurses' anxiety about death. The said barriers were reported to have resulted due to inadequate training.

In Kenya, there are countless obstacles to the realization of good-quality EOLNC. But majorly, the current curricula place more emphasizes on the theoretical teaching without emphasis on the students' clinical experience in EOL nursing care. This therefore means that many nurses have left nursing training institutions without undergoing a structured clinical experience in caring for the dying. This study therefore sought to address the gaps in EOLNC practice by identifying and validating core and sub competencies for EOLNC practice for nurses in Kenya. It is hoped that the identification of the competencies will enhance continuous professional development (CPD) that will equip nurses with requisite competencies for provision of EOLNC.

Findings from the first phase of this study will benefit the nurses in that understanding the nurses' level of preparedness and their training needs provided baseline information on the status of EOLNC training and practice in Kenya. The information generated maybe useful in harmonizing EOLNC training as well as ensure that the EOL training program for nurses in Kenya is contextualized in order to incorporate the unique aspects of the Kenyan population. This in turn will lead to improved quality of EOLNC leading to high quality EOLNC and eventually a '*good death*' for patients as care provided during their final days will preserve their dignity. Findings from phase II, which is a list of core and sub competencies requisite for provision of high quality EOLNC may be useful to institutions in developing strategies to improve EOLNC such as develop continuous professional development programs (CPD) for nurses to update their competencies. Additionally, it could form the basis for competency assessment within the clinical setting which is currently missing.

Additionally, findings from this study will also inform policy on EOL care as well as nursing education and practice in EOLNC. That is, a formal policy framework needs to be developed shading light on the national methodology to EOL care comprising but not limited to procedures for advance care planning; regulation of medical treatment; referral for expert palliative care advice and services; and finally, alignment with systems for recognizing and responding to clinical deterioration. In the end, there will be improved care for all patients at or nearing their EOL as nurses will become more comfortable with the concept of death and issues surrounding death. Acceptance of finality of death by nurses will intensify their comfort to embrace death and dying as fundamental to practice and advocate for palliation.

1.5 Research Questions

1.5.1. General Research Question

What nurses' competencies are appropriate for End of Life Nursing Care in Kenya?

1.5.2. Specific Research Questions

1. What is the perception of nurses on their level of preparedness to provide End of Life Nursing Care in Kenya?
2. Is there a relationship between nurses' perceived level of preparedness to provide End of Life Nursing Care and work station?
3. What are the nurses' perceived training needs for End of Life Nursing Care in Kenya?
4. Is there a relationship between nurses' perceived training needs for End of Life Nursing Care and work station?
5. Do nurses' perceived training needs in End of Life Nursing Care affect nurses' perceived level of preparedness to provide End of Life Nursing Care.
6. Are the End-of-Life Nursing Education Consortium core competencies suitable for Kenyan nurses?
7. What sub competencies would be appropriate for each of the core competencies for End of Life Nursing Care for Kenyan nurses?

1.6. Hypothesis for the study

a) H0: There is no statistically significant relationship between nurses' perceived level of preparedness to provide End of Life Nursing Care and nurses' perceived training needs.

b) H1: There is a statistically significant relationship between nurses' perceived level of preparedness to provide End of Life Nursing Care and nurses' perceived training needs.

1.7 Research Objectives

1.7.1. Broad Objective

The overall objective of the study was to develop and validate clinical competencies for End of Life Nursing Care for Kenyan nurses

1.7.2. Specific Objectives

The study was conducted to specifically achieve the following objectives based on the two phases:

Phase I: Nurses' preparedness to provide EOLNC

1. To establish the perception of nurses on their level of preparedness to provide End-of-Life Nursing Care in Kenya.
2. To determine if there is a relationship between work station and nurses' perceived level of preparedness to provide End of Life Nursing Care.
3. To identify nurses' perceived training needs for End-of-Life Nursing Care in Kenya.
4. To establish if there is a relationship between work station and nurses' perceived training needs for End of Life Nursing Care.
5. To explore the effect of nurses' perceived training needs in End of Life Nursing Care to nurses' perceived level of preparedness to provide End of Life Nursing Care.

Phase II: Delphi Process

6. To validate the End-of-Life Nursing Education Consortium core competencies for end-of-life nursing care in Kenya
7. To identify the sub competencies within the core competencies for End of Life Nursing Care in Kenya.

1.8. Expected Outcome

The end results of this two phase research work are clinical competencies requisite for provision of End of Life Nursing Care in Kenya.

CHAPTER TWO: PHILOSOPHICAL UNDERPINNINGS IN NURSING RESEARCH

2.0 Introduction

In order to understand the nursing profession and discipline, it is important to appreciate a nurse's philosophical stance since it influences his/her everyday nursing practice. Nurses' philosophical position includes paradigms and theories, which reflects the nurse's values, and puts forth significant influence over the nursing practice (Burton, 2016). The major paradigms within the nursing profession are: empiricism (positivism & post-positivism), interpretive, and critical social theory (Scotland, 2012). However, pragmatism is another paradigm that is gradually being considered in nursing (Reed, 2018). Each paradigm has distinctive principles, and contributes to the profession and discipline of nursing in different ways.

When conducting research of any kind, a consideration of the philosophical stance or worldview is important (Rosa et al., 2017). Investigators may consider these differences so enormous that a single paradigm is incommensurable with another. On the other hand, investigators may ignore these differences and either unknowingly combine paradigms inappropriately or neglect to conduct required study. Education in nursing is facing numerous reforms (Burton, 2016), to realize the mission of developing nursing knowledge to be utilized in the nursing profession, it is imperative that investigators possess adequate knowledge on the paradigms used for nursing inquiry.

Hence, as a researcher, it was paramount to understand the underlying ontological and epistemological assumptions behind each research. Therefore, in order to enrich the researcher's understanding of the philosophical underpinnings in nursing research better, the researcher shall discuss the paradigms separately though in reality they are all interrelated and intertwined. An in-depth understanding of these philosophical underpinnings enabled the researcher to better comprehend research and research results.

This chapter therefore, explores the interrelationships between each paradigm's ontology, epistemology and methodology. It further discusses some of the fundamental assumptions behind the empirical (scientific), critical, interpretive, and pragmatic paradigm; and provides an overview of the content in each paradigm. Additionally, it shades some light on the contributions, limitations

and implications in research for each. Finally, the chapter provides a discussion regarding the researcher's ontological, epistemological and methodological standpoint.

2.1. The paradigm of inquiry

Paradigms are sets of beliefs and practices, common among communities of researchers, which orders inquiry within disciplines (Al-Saadi, 2014). A number of paradigms are characterized by ontological, epistemological and methodological differences in their tactics to conceptualizing and conducting an investigation, and in their role towards disciplinary knowledge construction (Schick-Makaroff et al., 2016). A paradigm entails the following components: ontology, epistemology, methodology, and, methods. Details of each component are explained and the relationships between them are explored. To begin with, *Ontology* is the study of being (Crotty, 1998 see Scotland 2012).

Ontological assumptions explain what constitutes reality, in other words *what is* (Al-Saadi, 2014). Investigators need to take a position regarding their perceptions of how things really are and how things really work (Al-Saadi, 2014; Stanley & Wise, 2002). The principle concerned with the nature and forms of knowledge is *epistemology* (Scotland, 2012). Epistemological assumptions are interested in how knowledge can be created, acquired and communicated, rightly put, they are interested on what it means to know. Investigators from the epistemology perspective ask the question, what is the nature of the relationship between the would-be knower and what can be known? (Burns et al., 2018).

Every single paradigm is centered on its own ontological and epistemological assumptions. As all assumptions are guesswork, the philosophical foundations of each paradigm are not empirically proven or disproven (Greason, 2018). Different paradigms innately contain differing ontological and epistemological views; and so, they have differing assumptions of reality and knowledge which underpin their particular enquiry method (Al-Saadi, 2014). The paradigm position of the investigator is reflected in their methodology and methods, where methodology is the strategy/plan of action which guides a scholar on the choice and appropriate methods to utilize (Sutton & Austin, 2015).

Therefore, according to Sutton and Austin (2015), methodology is concerned with what, why, when, from where, and how data is gathered and examined. Hence, the key question in

methodology is, how can the investigator go about finding out whatever they believe can be known? On the other hand, methods are the exact techniques and procedures used to gather and examine information (Nassaji, 2015). The information gathered will either be quantitative or qualitative. Both quantitative and qualitative data can be utilized in all the paradigms.

It is important to note that study methods can be traced back, through methodology and epistemology, to an ontological position. Hence, an investigator ought not to conduct an inquiry without declaring their ontological and epistemological positions (Al-Saadi, 2014). Investigator's differing ontological and epistemological positions frequently lead to different study methods towards the same phenomenon (Groenewald, 2004).

Therefore, the ontological and epistemological assumptions made by an investigator are crucial in the justification of choice of methodology and methods for their study. In a nutshell, the investigator's choice of how data will be collected, analyzed and interpreted should be guided by, and understood through, the ontological and epistemological assumptions and arguments being made. The following discussion provides an overview of two major paradigms, precisely, positivist and interpretive.

2.1.1 Positivist Paradigm

The positivist paradigm takes the ontological position of *realism*. This is the view that objects have an existence independent of the knower (Al-Saadi, 2014). Hence, according to Al-Saadi (2014) a discoverable reality exists independently of the investigator *(etic)*. A good number of positivists assume that reality is not mediated by our senses. That is, language fulfills a representational role as it is connected to the world by some designative function; consequently, words owe their meaning to the objects which they name or designate (Reed, 2018).

On the other hand, the positivist epistemology is one of *objectivism*. Scotland (2012) indicated that positivists venture out into the world objectively, finding out in totality the knowledge about an impartial reality. The investigator and those being investigated are independent units *(etic)*. This position emphasizes the fact that meaning exclusively exists in objects, not in the conscience of the investigator, and as such, it is the duty of the investigator to find out this meaning.

2.1.2 Interpretive Paradigm

The interpretive paradigm takes the ontological position of *relativism*. This is the view that reality is subjective and individualized, thus it differs from person to person (Dory et al., 2017; Guba & Lincoln, 1994). Guba and Lincoln (1994) observed that our realities are mediated by our senses and as such our consciousness gives meaning to the world (Dory et al., 2017). Dory and colleagues (2017) indicated that truth materializes when consciousness engages with objects which are already filled with meaning. Truth is individually constructed, as such there are as many truths as individuals. This means that language does not inertly label objects but keenly outlines and forms what truth is (Al-Saadi, 2014). Consequently, truth is created through the interaction between linguistic and facets of an autonomous world.

On the other hand, the interpretive epistemological position is one of *subjectivism* which is grounded on the real world phenomena (Groenewald, 2004). Groenewald (2004) observed that the world and our knowledge of it are interrelated and coexist. That is, different people may construct meaning in different ways regarding the same phenomenon, but reality is harmoniously made by co-constructors (Scotland, 2012). As a result, knowledge has the trait of being culturally imitative and historically placed (Rosa et al., 2017). Hence, an investigator within the interpretive paradigm does not question ideologies but rather he/she accepts them.

2.1.3 Critical Paradigm (CP)

An additional paradigm of importance in nursing is the critical paradigm, which focuses on social struggles, domination, and institutions, with the intent to bring about an equal society. Thus CP aims at eliminating oppression in society. CP highlights the fact that knowledge is a product of societal values and influences; and as such, it is not enough to observe or study power inequalities in society; action must be taken to correct them. The ontological position of the CP is *historical realism*: the view that reality has been shaped by social, political, cultural, economic, ethnic, and gender values. Realities are socially constructed entities that are under constant internal influence. Reality is constructed through the interaction between language and aspects of an independent world. Critical epistemology is one of *subjectivism*: knowledge is both socially constructed and influenced by power relations from within the society.

Social *constructionism* (we are born into a world in which meaning has already been made; we are born into culture) is of the position that pre-existing system consists of consensuses about knowledge that have already been reached and are still being reached. Reality is alterable by human action. The CP seeks to address issues of social justice and marginalism, thus knowledge is not value free (it is culturally derived, historically situated and influenced by political ideology). CP blends well with the nursing profession's emphasis on promoting justice through equitable nursing care and allocation of resources. Nurses often practice with an aim of changing patients' beliefs in order to change their health. Instead, a wider view is required to appreciate the antecedent factors that influence a client's behaviors and health. Thus, nursing practice takes into consideration a wider influence of societal factors and how to practice in relation to those factors. Advocacy is a key consideration of the nursing profession, and stems from an understanding of a client's circumstances and the impact of the same.

2.1.4 Pragmatism

In addition to the three major paradigms, pragmatism is also an important philosophical consideration. Pragmatism favors tolerance, respect for the opinions of others, and collaboration. As such, it reflects the astute appraisal of options and selection of the course of action that will best serve the client. The variety of phenomena investigated by nursing research is so diverse that a pragmatic approach is necessary to advance the understanding of the discipline. Adhering to only one paradigm limits the understanding of a phenomenon because contextual factors and influences are not as widely explored. A pragmatic approach is advantageous because it enables nurses to address research questions with appropriate guiding methodologies.

Additionally, a pragmatic approach to nursing theory selection implies a humble and inclusive nursing practice. A nurse has the opportunity to critically evaluate a range of theoretical options, and determine what will be the most effective and appropriate course of action for the client. The pragmatism promotes respect for the individual, as it appreciates each person has unique needs. Additionally, it promotes critical thinking and flexibility in nursing practice, as nurses can explore a range of options without negating a particular paradigm. These considerations make pragmatism a natural way forward in nursing practice.

This perspective evaluates an idea not by the criterion "is it true?" but rather by the question "what difference does it make?" For practice-based discipline such as nursing this is the ultimate question. If a particular paradigm does not address fundamental questions of how to improve health care for clients, it does not serve nurses. The problems addressed by nurses are so diverse that multiple approaches to problem-solving are necessary. A pragmatic approach to theory development through synthesis of cumulative knowledge relevant to nursing practice requires that inquiry start with assessment of existing knowledge from distinct studies to identify key substantive content and gaps.

Table 2.1: Summary of key philosophical underpinnings in nursing research

Paradigm	**Ontological**	**Epistemological**	**Approach**	**Methodology**	**Methods**	**Type of data & analysis**
Empirical/ positivist/ scientific	Realism	Objectivism	Deductive	Experiments Correlational	Closed-ended questionnaires Standardized tests Standardized observation tools	Quantitative data Descriptive and inferential statistics are used Research have internal and external validity, it is replicable and reliable
Interpretivism	Relativism	Subjectivism	Inductive	Case-studies Ethnography Phenomenology : a) Hermeneutics (lived experiences) b) Empirical/trans	Open-ended interviews and/or questionnaires Focus groups Role-play Open-ended observations	Qualitative data Thematic interpretation Research have- internal validity/credibility, external validity/transferability, and

				cedental/psychological (no researcher interpretation its purely objective)		reliability/dependability
Paradigm	**Ontology**	**Epistemology**	**Approach**	**Methodology**	**Methods**	**Types of data & analysis**
Critical theory	Constructionalism/historical realism	Subjectivism	Inductive	Critical discourse analysis Critical ethnography Action research Ideology critique	Open-ended interviews Focus groups Open-ended questionnaires Open-ended observations	Qualitative data Thematic interpretation with allocation of values Research have-catalytic validity
Pragmatism	Realism Relativism	Objectivism Subjectivism	Deductive Inductive	Mixed method (looks at the best approach)	Closed-ended Standardized tests Open-ended observations	Quantitative Qualitative

2.2. Linking Philosophy to Research

The following discussion shades some light upon which the researcher's own thinking about and understanding of the world and its phenomena rest. Specifically, it discusses the researcher's ontological and epistemological assumptions that form the bases for this study. These assumptions also informed the development of the research methodology and methods adopted in this research.

2.2.1. The researcher's ontological assumptions

Actually, as a Christian person, the researcher's ontological and epistemological positions have arisen mostly from the researcher's beliefs which come from the holy Bible and the proverbs and behaviors of Jesus Christ. Nonetheless, the researcher's readings in the area of epistemology and ontology have largely added to the development of the researcher's understanding of such

philosophical opinions and helped me to relate them to and critically think about the end of life nursing care (EOLNC) situation in the researcher's context.

The ontological and epistemological positions which support this study are based on the belief that there exists an ultimate or outright truth or knowledge which has been shown to us through the holy Bible. Additional knowledge and truths do exist, but these cannot be claimed as ultimate truth. The ultimate truth about existence, nations and events of the past, present and future is of a divine origin and has been revealed to us through the holy Bible.

Nevertheless, not all truth and knowledge have been revealed to mankind and so, it is upon mankind to discover the truth in order to seek explanations of the laws that govern thoughts and human behaviour. Jesus says: "Beloved, believe not every *spirit*, but try *the* spirits whether they are of God: because many false prophets are gone out into *the* world" (Good News Bible-King James Version: 1 John chapter 4, verse 1). In fact, the trinity (God, Son and Spirit) inspires us to think about the world around us and envisage its existence through finding explanations of the creation and eventually we become knowledgeable.

So this shades some light to the existence of other knowledge and truths which are autonomous of our beliefs or understanding and we have to discover them. But as a positivist thinker, finding of explanations can only be based on 'careful observation'. Additionally, hypotheses are derived first from theories and then tested empirically against observations rather than being understood through testing propositions.

Furthermore, just like the positivists, the researcher maintains that ultimate truth can be known precisely. This means that reality is actualized in the people being investigated and this impartial truth can be revealed if we go about it in the right way (Al-Saadi, 2014). In other words, as was reported by Scotland (2012) natural science can employ the following means and methods for gathering and interpreting data: hypothesis testing, causal explanations and modelling. Therefore, the researcher's ontological assumptions view truth as real and it is autonomous of our beliefs or understanding. As such, since the researcher is of the view that truth can be observed directly and accurately the study collected data that was quantifiable rather than exploring inner xperiences which are subjective. This supports the researcher's view that truth is something fixed awaiting discovery; happenings have causes which are influenced by other circumstances.

2.2.2. The researcher's epistemological assumptions

Having looked at the researcher's ontological assumptions that are based on positivism paradigm, the researcher's ontological position is that of realism. Regarding the nature of knowledge and how it is acquired (epistemology), the researcher took a positivist view which emphasizes no relationship between the investigator and the world, i.e., an *etic* epistemology. Specifically, in the research process, the investigator detaches him/herself from the study process. In contrast, an *emic* epistemology approach has the investigator continually constructing meanings and interpretations guided by their experiences and reflection, over and above those of their participants (Al-Saadi, 2014). In this regard, knowledge of the world and social phenomena, for example caring as is the case in this study, is founded on our understanding which arises from our senses and careful observation as supported by the positivist view. Essentially, the researcher thinks that objective and value-free inquiry is possible as results are not influenced by investigator's values and perspectives.

Furthermore, the researcher believes that knowledge about the social world can be acquired through understanding and making sense of people's behaviour, perceptions and interpretations of the world as opposed to only observing and explaining these perceptions and interpretations. And so, the researcher thinks that the methods of natural science are appropriate for the study of social phenomena such as caring– hence the research methods utilized in this study to discover (survey) participants' understanding of EOLNC competencies.

Moreover, because the role of social research is to explain than explore reality, it embraces the qualities and principles of quantitative research (Scotland, 2012). One of the relevant characteristics of quantitative research that is applicable to our discussion here is that, it uses a process of 'deduction' to prove or disprove an already established theory from the data gathered instead of using the data to develop theory and new knowledge (Groenewald, 2004). Therefore, the researcher considered scientific method and deduction, which are common in natural science, as appropriate methods in social research, and in this study in particular.

As mentioned earlier, social science places emphasis on the fact that a clear distinction exists between our beliefs about the world and the way the world is. In this view, findings of social research highlight that life is defined in quantifiable terms instead of inner experiences (Rosa et al., 2017). Therefore, the researcher does not see caring as a purely subjective phenomenon which

exists dependently of the human mind and socially constructed meanings but rather as a product of an active process of gathering facts. Such a process is informed by the causal links between happenings and their causes which can in the long run be discovered by science. The researcher also appreciates the critical importance of respondents' own interpretations of the issues this study sought to explain while at the same time believe that their diverse perspectives will produce hard, tangible and objective explanation of the human behavior; thus disputes will be resolved through observations.

Therefore, the researcher's epistemological assumptions of the nature of knowledge and how it is acquired view the world as autonomous of and unaffected by the investigator; disputes are resolved through observations; facts and values are distinct; objective and value-free inquiry is possible; knowledge is produced through the senses based on careful observation; methods of natural science are appropriate for the study of social phenomena; and only phenomena confirmed by the senses can be genuinely regarded as knowledge. Hence, the characteristics of knowledge are that it is: hard, tangible and objective and it can be attained through gathering of facts. Therefore, this study gathered quantitative data since the researcher believes that social world can be approached through the explanation of human behavior in this case the competencies requisite for nurses to provide high-quality EOLNC..

2.3 Theoretical perspectives

Investigators utilize theories to explain, describe, and predict phenomena in nature and to provide understanding of relationships between phenomena (McEwen & Wills, 2014). McEwen and Wills (2014) further noted that within the nursing profession, theories aid in setting professional boundaries as they define and clarify nursing and the purpose of nursing practice bringing out its uniqueness. Additionally, theories challenge and validate intuition, a characteristic of a proficient nurse, and in the long run promote rational and systematic practice. As such, theory utilization in nursing is not a new concept.

The first modern nursing theorist was Florence Nightingale (Raymond-Seniuk & Profetto-McGrath, 2011). She was the first to prescribe nursing's goals and practice domain, she believed the role of the nurse was one of facilitation. She was reported as having said that the nurse places the patient/client "in the best condition for nature to act upon him" (see McEwen and Willis pg 26). Therefore, theory utilization aids the nurse to understand practice in a more complete and

insightful way and hence supports nursing as a profession build on scientific evidence (McEwen & Wills, 2014). This study utilized Parse's Human becoming theory (2015) and Kolcaba's Theory of Comfort (2001).

McEwen and Wills (2014), documented that Parse's theory initial publication was in 1981 by the name *Man-Living-Health* and revised as was deemed necessary. In 1992, Parse changed the name to the Theory of Human becoming. The theory emphasizes the importance of the nurse walking together with the person and the family in their experiences. The paradigm according to McEwen and Wills (2014) clearly stipulates the role of the nurse as "guides humans toward ways of being, finding meaning in situations, and choosing ways of cocreating their own health" (p 209), the nurse's presence is ratified through practices that support patients and/or families to 'freely choose' within their EOL situations, and to shade meaning and marshal wholeness as they move through the course of EOL. Parse's theory of human becoming has several congruent elements consistent with health and well-being. These are: being fully present and attentive to the patient; understanding the whole person, not reducing the patient to parts; and the importance of focusing on the subjective experience of quality of life (McEwen & Wills, Theoretical Basis for Nursing, 2014). Therefore, this theory emphasizes on the importance of the physical presence of the nurse during care provision.

While the Theory of Comfort was first published in 1994 and modified in 2001 (McEwen & Wills, Theoretical Basis for Nursing, 2014). It emphasizes on the importance of the nurse identifying a person's and/or family's comfort needs and intervening towards promotion of comfort in traumatic health care situations. It provides a guide for promoting three forms of comfort particularly relevant to EOL care and decision-making, namely: *ease* as a state of calm or contentment; *relief* as a state of having a specific comfort need met; and *transcendence* as the state in which one can rise above problems or pain (Gayoso et al., 2018). It also guides the nurse on the four contexts in which comfort needs to be addressed: specifically, psychosocial, physical, environmental, and sociocultural (McEwen & Wills, Theoretical Basis for Nursing, 2014).

2.4 Methodological Approaches

Prior to commencement of a study, an investigator lays out the plan of action that will promote successful completion of the study. This plan of action is referred to as methodology, it lies behind the choice and use of particular methods (Moch et al., 2016). It is thus concerned with what, why, when, from where, and how data is gathered and analyzed. While methods are the exact approaches and procedures used to gather and analyze data (Maltby, Day, & Williams, 2007). Maltby and colleagues (2007) noted that the data gathered is either qualitative or quantitative but all paradigms can use both qualitative and quantitative information. As such, as was noted by Al-Saadi (2014) research methods interrelate with the methodology and epistemology enabling one to understand the ontological position of the investigator.

For that reason, the ontological and epistemological assumptions made by or held by an investigator are crucial in the sense that they justify the choice of methodology and methods of the research (Scotland, 2012). Therefore, the investigator's choice of gathering, analyzing and interpreting information should be informed by, and understood through, the ontological and epistemological assumptions and arguments he/she is making (Nassaji, 2015). To conclude, this study focused on the scientific paradigm (positivism): specifically, the ontological position of realism and the epistemological assumption of objectivism.

2.5 Conclusion

Ontology is the study of being and its assumptions are interested in what constitutes truth. Investigators need to take a position regarding their perceptions of how things really are and how things really work. While epistemology is concerned with the nature and forms of knowledge. Epistemological assumptions are concerned with how knowledge can be created, acquired and communicated (*what it means to know)*. Study methods are interrelated among methodology, epistemology, and ontology. It is impossible for an investigator to engage in any form of research without clearly articulating the ontological and epistemological positions. This explains why investigators may examine the same phenomenon but have differing ontological and epistemological positions.

In brief, various philosophical views and debates exist about the kind and nature of knowledge and truth and, as such, there exist numerous methodologies and frameworks utilized in the study and understanding of this knowledge. As such, the ontological and epistemological assumptions which

are made and/or embraced by the investigator are important as they explain the choice of methodology and methods of the research. For this study, the ontological and epistemological positions discussed are of significance to the researcher's work as the researcher commits here to explain EOLNC in her context through the eyes of the nurses themselves. The ontological and epistemological positions and views explained much earlier in this chapter, vividly manifest themselves in the researcher's methodology and overall research design. Therefore, the philosophical underpinnings for this study take realism as the ontological position and objectivism as the epistemological position of positivism.

CHAPTER THREE: LITERATURE REVIEW

3.0 Introduction

This chapter offers a detailed discussion of the literature reviewed on: nurses' preparedness to provide end-of-life nursing care (EOLNC); training on end-of-life nursing care (EOLNC); and common core competencies for EOLNC. A review of the theoretical and conceptual model that was used as a framework for this study is also provided. The literature search was restricted to studies conveyed in English and peer reviewed. This was due to the fact that the subject being investigated is one that has extensively been studied.

In order to obtain more depth of the existing evidence related to the subject under study, the researcher focused on high quality research studies such as systematic reviews. The literature search was enabled by use of databases namely SAGE and Medline; and one publisher site: Science Direct. The following key words were used: long-term care; life limiting illnesses; palliative care; terminal illness; end-of-life care; nurses; nursing; guidelines; barriers; competency; education; curriculum, and knowledge. Key words were combined in order to enhance the literature search further. Such as, end-of-life care + nursing; and so on and so forth until all keywords were combined exhaustively.

3.1 Nurses' preparedness to provide EOLNC

Nurses' preparedness in this study means the possession of requisite competencies by nurses to enable them to provide high-quality EOLNC. The aspects that constitute the preparedness are EOLNC knowledge, attitudes and practice. Regarding knowledge, it was noted that barriers to quality EOLNC exist across the trajectory of life threatening illness from diagnosis to long-term and hospital-based care. One major barrier that was highlighted was nurses' lack of knowledge on EOLNC particularly regarding pain management (Dubois & Reed, 2014). Nurses indicated that cognitive changes in patients often made it difficult to assess the level of pain the patient was experiencing.

These sentiments were also highlighted in a different systematic review study whose findings supported the fact that nurses have inadequate knowledge on EOLNC (Pulsford, Jackson, O'Brien, Yates, & Duxbury, 2011).Lack of adequate EOLNC knowledge was also noted to exist in undergraduate nursing students. This was confirmed in a study conducted among nursing students

to determine their knowledge on end-of-life (EOL) care. Findings indicated that majority of the nursing students had inadequate knowledge (Glover, Garvan, Nealis, Citty, & Derrico, 2017). This was so especially in areas on palliative care (PC) philosophy, symptom management, communication and grief.

Nurses were noted to have inappropriate attitude as far as provision of EOLNC was concerned. This was reported in a study that was conducted to explore the views of health care professionals (HCPs) as far as initiation of EOL communication was concerned. The study noted that majority of nurses felt that initiating EOL discussions was mainly the role of the doctor (Nedjat-Haeim, et al., 2016). They emphasized that their role was mainly supporting the patient (being the patient's ear). That is, clarifying information provided by doctors to patients and their families while being supportive and comforting to patients as they internalize the bad news.

Inappropriate attitude by nurses towards EOL care was also reported in yet another study by McConnell, Scott, and Potter (2016). The study noted that the Health Care Professionals (HCPs) among them nurses, reported feeling anxious when talking with family about death or even using the word *dying*. Thus, the HCPs distanced themselves from patients at or nearing their EOL as a way of protecting themselves from becoming too involved. Interestingly, even the more experienced nurses distanced themselves arguing that, that, would help them to avoid burnout (McConnell, Scott, & Porter, 2016).

Self-efficacy which is the nurses' belief on their ability to promote a 'good death' is very critical in provision of EOLNC. This is because self-efficacy plays a critical role in how nurses think, feel and behave (Montagnini et al., 2012). The person nearing EOL may be disregarded by family, friends, and the healthcare members as they all seek for ways to prolong life. But Condon et al (2013) noted that caring for one on the verge of dying should incorporate honoring living quality while recognizing the dying person as a cocreator of the emerging now. Therefore, nurses need to always remember that EOL is expected and being at easy with this view will make EOLNC a good experience that would lead to a 'good death'.

This was also echoed by Young, Froggat and Brearley (2017) in their study that was conducted among staff working in a nursing home. They noted that good experience by the staff towards EOLC led to a *'good death'* while bad experience led to a *'bad death'*. For instance, effective

communication within the team of care at EOL was observed to lead to a *'good death'* while poor communication led to negative experience by the staff which in turn led to a *'bad death'*.

Additionally, values for the staff within the team were also noted to affect the staff behavior (Young, Froggat, & Brearley, 2017). For instance, when the staff values within the team were congruent with each other, staff believed that a patient had a *'good death'* as the staff was able to '*to do the right thing*'. Interestingly though, when the staff values within the team were incongruent with those of the patient, the staff felt that this too led to a *'good death'* because they felt they were fulfilling the patient's wishes by doing what the patient preferred. That notwithstanding, nurses felt unprepared to provide EOLNC.

A number of studies supported the fact that nurses felt unprepared to provide EOLNC and they were apprehensive about caring for patients who are dying and communicating with these patients and their families (Young, Froggatt, & Brearley, 2017; Glover *et al*, 2017). Additionally, nurses often felt frustrated and stressed with the nursing care they provided to dying patients (Yoshioka, Moriyama, & Ohno, 2013). Some nurses have even gone as far as expressing deep concerns about caring for the dying. Nurses' professional sovereignty is an essential component in the care at EOL (Paganini & Bousso, 2015). This is because when nurses feel they are self-directed even while providing EOLNC, they begin to think critically and independently. This enhances the planning and delivery of nursing care. As a result, there is improved quality of EOLNC.

The discussion above highlighted some of the shortcomings as far as nurses' preparedness to provide EOLNC is concerned. That is, it was noted that nurses had inadequate level of EOLNC knowledge, inappropriate attitudes towards EOLNC; and inadequate skills requisite for provision of high quality EOLNC. However, this was not the case as was reported in some studies which indicated that nurses were adequately prepared. For instance, in a study conducted in the united states of America, it was reported that nurses/nursing students had adequate knowledge on EOLNC especially on areas surrounding general nursing such as ethics and ethical principles (Glover, Garvan, Nealis, Citty, & Derrico, 2017).

Further, in a study conducted in England involving two acute hospitals, findings indicated that majority (79.6%) of the bereaved relatives rated care provided by nurses as exceptional or excellent in comparison to the other health care providers such as doctors (Coimín et al., 2019) an indication

that nurses were better prepared for provision of EOLNC. Additionally, another study conducted in Japan, reported that nurses had positive attitudes towards EOLNC (Okamura et al., 2018). Finally, in a study conducted in acute care hoapitals in 5 states namely: England, Belgium, Ireland, Spain & Finland; findings indicated that nurses had the requisite competencies for provision of high quality of care as substitution of nurses by other health care providers had negative impact on patient outcomes and quality of life (Aiken et al., 2017). In a nutshell, literature indicated that there were occasions where nurses were adequately prepared for provision of EOLNC while some highlighted that nurses were inadequately prepared for provision of EOLNC.

3.2 Training needs for provision of End-of-Life Nursing Care

EOL experiences are unique. Most people can clearly recall the feelings they had during those times. However, the beliefs of teaching staff arising from those unique experiences can change the attitude and meaning of what students are actually taught (Condon, Grimsley, Kelley, & Nissen, 2013). Dillard and Siktberg (see Condon *et al,* 2013) observed that teaching staff may be uninformed of what students learn through faculty expressions, priorities and interaction with them but students are very cognizant of this; and these gestures from the faculty craft a more lasting impact on the students than what is actually taught.

The implications of these sentiments shed light to the fact that there is need for education regarding EOL and the care involved. Opinions as to what ought to be included in this EOL education may differ between schools of nursing as well as among teaching staff within the same training institutions (Glover *et al,* 2013). Such disparities in beliefs could unintentionally surface as hidden curriculum (Condon, Grimsley, Kelley, & Nissen, 2013).

Regarding nurses' training needs, it is clear that in nursing schools, nurses are taught to relieve pain and sufferings of a patient. However, the interventions required to relieve pain and suffering at EOL are different from the curative approach interventions. For instance, in EOL pain management ought to consider the concept of total pain which highlights the importance of a comprehensive assessment of a patient in order to diagnose the kind of pain that a patient may be experiencing (Nedjat-Haeim, et al., 2016). That is, is the pain physical, spiritual, psychological or social. This is a concept that is not taught in nursing schools and as such nurses in practice have a deficit in this aspect of pain

management. As a result, a major gap in the physique of scientific knowledge and clinical education exists regarding EOL care (Guo & Jacelon, 2014).

In a systematic review by Pulsford *et al*, (2011) on training courses in EOL care, findings indicated that deficiencies existed in aspects of EOL care especially in communication, symptom management, psychosocial care, and working with families. As such, the study recommended that: advanced care planning skills, principles of symptom management, communication skills (to highlight various levels), and skills in assessing a person's needs and preferences be incorporated in education and training. It is important that nurses are trained in advanced care planning (ACP) particularly in the usefulness of ACP, the legal status of ACP, and how to implement ACP (Glennon et al., 2019).

This therefore, does not mean that EOLNC education should be neglected but that much still needs to be done to equip educators with EOLNC competencies which can then be transferred to students. The need for training in EOL was supported by yet another different study that was conducted on novice nurses to explore their experiences with EOL care especially in the area of communication with children (Hendricks-Ferguson, Sawin, Montgomery, Phillips-Salimi, & Haase, 2015).

EOL care education was not only wanting in the nursing field alone but also in the medical field. This was confirmed by a study that was conducted on resident physicians attached to an intensive care unit. The study noted that the residents had inadequate EOL skills at the point of entry, however, they gained the skills through progressive experiences (Chen, McCann, & Lateef, 2015). As such, the study highlighted the importance of role modelling for EOLC skills, and increasing formal EOLC teaching throughout the medical education system.

Additionally, Connolly and colleagues (2019) in their study on education and EOL options, noted that medical students supported the importance of training in EOL care. The study further highlighted that the EOL training should incorporate pain and symptom management, patient and caregiver counselling; and EOL options among other dimensions. From the study it was clear that training students in EOL prepares them for provision of good quality EOL care. Formal training in EOLC is not a new concept.

End-of-Life Nursing Education Consortium (ELNEC) is an example of what is being done towards improving quality of EOLNC through formal training. This is a national initiative in the United States of America to improve education about EOL care (Glover, Garvan, Nealis, Citty, & Derrico, 2017).

The didactic content contained in ELNEC was developed by PC experts and is regularly reviewed and updated by an advisory panel (Glover, Garvan, Nealis, Citty, & Derrico, 2017). ELNEC is an education program that consists of eight basic components: nursing care at the EOL, preparation for and care at the time of death, pain management, symptom management, communication, cultural considerations in EOL care, ethical/legal issues, grief, loss and bereavement (Glover, Garvan, Nealis, Citty, & Derrico, 2017).

In Kenya, a program such as ELNEC does not exist. However, in 2008, an ELNEC training was conducted in Kenya by the ELNEC project officers from City of Hope (Malloy et al, 2010). The five day ELNEC training course had participants (49) who were drawn from various health settings and nursing training institutions. Majority (45) of the participants were nurses. The participants who attended the training indicated that the ELNEC competencies were relevant and appropriate in the Kenyan setting. Therefore, following the ELNEC training, the Nursing Council of Kenya (NCK) in 2013 recommended that palliative care (PC) content be integrated in the basic nursing curriculum at certificate, diploma and undergraduate levels. The ELNEC competencies seem to have been integrated in the nursing schools but students' clinical experience is not structured as there are no hours allocated in the basic nursing curricula for this. Since the integration of the ELNEC content into the nursing curricula, many students leave nursing school without a structured clinical exposure to death and dying patients.

Moreover, in the year 2013, NCK approved a post-basic training in palliative care which has content pertaining to EOL care. The course is allocated theory and practical hours which are 680 and 1440 respectively (*Palliative Care Syllabus June 2013.Doc*, n.d.). Of the 2120 hours allocated for this program, EOL content is allocated 10 theoretical hours (0.5%) but no provision for clinical experience in EOL care. The basic nursing programs namely certificate and diploma in nursing also have 0.2% and 0.1% content in palliative care concepts but none specified for EOLC.

Table 3.1: EOL content in the existing basic nursing programmes in Kenya

SNo.	Program	Theory Hours	Palliative Care (PC)	Hours allocated to EOL Content	Practical hours	Hours allocated to EOL	Total hours for the programme	% of hours allocated

			Content in hours			**Clinical experience**		**for EOL content**
1	Bachelor of Science in Nursing	2645	45	23	355	0	3000*	0.87
2	Post-basic diploma in Palliative Care nursing	680	680	10	1440	0	2120	0.5
3	Diploma in Nursing	1200	6	2	3120	0	4320	0.17
4	Certificate in Nursing	1050	6	2	2640	0	3690	0.19

** PC content in Kenya has some overview on EOL care Total hours for the bachelor of science in nursing excludes hours allocated to common university courses*

Despite the fact that there is provision for PC content in the nursing syllabi, individual institutions are left to oversee the implementation of the integration of the PC concepts with EOL care being one of the areas to be covered. Therefore, every institution develops their own curriculum, as such, there is no standardization and hence much still needs to be done to harmonize what is being taught across all nursing training institutions in Kenya.

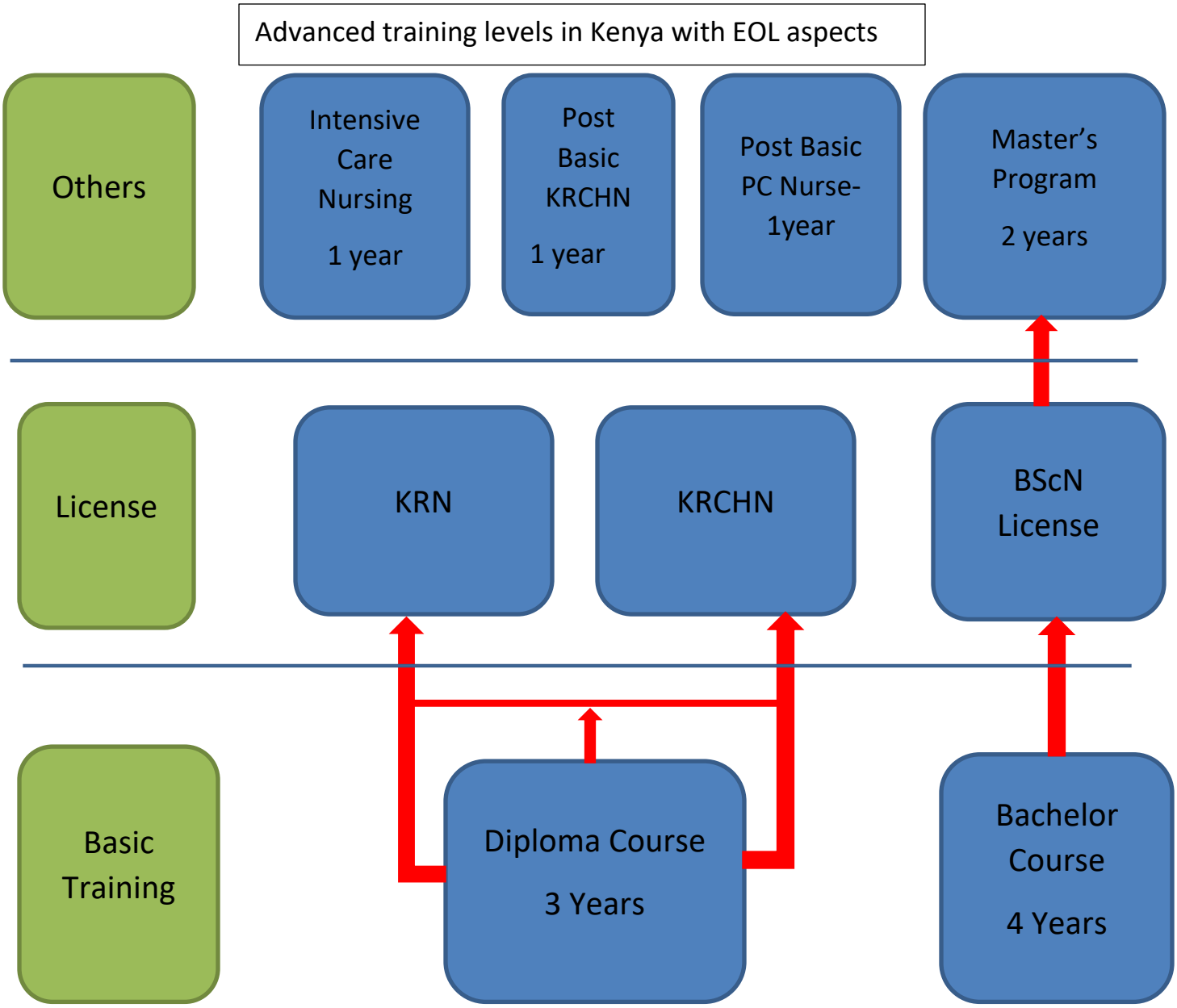

Figure 3.1: Kenyan education system for nurses

3.3 Competencies for EOLNC

3.3.1 Background

Nurses find themselves in complex situations especially where EOL is concerned. In these situations, a more complex dilemma also exists as to whether nurses are adequately prepared to

provide EOLNC. This highlights the difficulty in determining whether nurses' competence to manage such delicate situations is sufficiently evidence-based, or simply a combination of spontaneous, intuitive responses based around life experience. It can be said that good practice by nurses at the bedside in such situations is a combination of both.

With this understanding, it is critical to note that learning is a complex issue and there are a number of ways to describe how nurses attain competence. Bloom's (1956) taxonomy can be used alongside a variation of Benner's (1984) 'novice to expert' theory. Additionally, Carper's (1978) four patterns of knowing, which should be present in each nursing act are: empirical knowledge; aesthetic knowledge; personal knowledge; and ethical knowledge. This emphasized the influence of nurses' values, beliefs and life experience.

Looking back in literature, only few authors have attempted to define the skills and competencies used by nurses when caring for dying people (Taylor et al, 1997; Degner et al, 1991; Davies and Oberle, 1990; Heslin and Bramwell, 1989). Most of the competencies documented in literature contribute to a competent practitioner's collective expertise, however, it is important to consider the elements that standout as essential to end of life nursing care (EOLNC). The Canadian Association of Schools of Nursing (CASN) is one such example that highlights the competencies required by nurses for provision of EOLNC to include but not limited to pain & symptom management; communication skills; psychosocial support and grief & bereavement.

These competencies were also reported by ELNEC. Finally, living matters dying matters also developed a palliative and end of life care competency assessment tool. The competencies highlighted in living matters dying matters also had similarities to those documented by CASN and ELNEC. As such, there seems to be a similarity on what EOLNC competencies entail.

3.3.2 Appropriate competencies for EOLNC

People suffering from life-threatening illnesses have numerous technological advances obtainable to them to elongate and support their life. Sometimes the difference between hope for a cure and the acknowledgement that an illness is incurable is unclear. The society has many concerns regarding the incurable phase of life (Bülbül et al., 2015), particularly due to the fact that advanced medical technology is being used towards EOLNC which prolongs life and postpones death

(Burstin & Johnson, 2017). As a result, moral and ethical concerns have arisen especially in patients whose life span has been extended at the cost of the quality of their life (Goel, et al., 2014).

When the decision is made to relinquish high-tech life-sustaining treatment in exchange for a peaceful death, a major gap in the physique of scientific knowledge and clinical education exists regarding EOL care (Guo & Jacelon, 2014). In nursing schools, nurses are taught to relieve pain and sufferings of a patient. However, nurses frequently find themselves in conflict with their nursing teachings, patient desires, cultural values, spiritual beliefs, or family demands (Bijnsdorp et al., 2019). These conflicts occur due to the fact that to respect a person, one must reverence their choices. A good example surrounds the role of advance directives.

Nurses are the frontline caregivers for those nearing the EOL (Hendricks-Ferguson, Sawin, Montgomery, Phillips-Salimi, & Haase, 2015). Nevertheless, shortfalls are apparent in the professional and continuing education of nurses (Nedjat-Haeim, et al., 2016). In a systematic review by Pulsford *et al*, (2011) on training courses in EOL care, findings indicated that deficiencies existed in aspects of EOL care especially in communication, symptom management, psychosocial care, and working with families. As such, the study recommended that: advanced care planning skills, principles of symptom management, communication skills (to highlight various levels), and skills in assessing a person's needs and preferences be incorporated in education and training.

Advance directives are legally binding forms that record decisions made while a person is cognizant and can make decision regarding the treatment and care that he/she should be given in the event of becoming incapacitated (Jones, et al., 2016). Advance directives are advantageous because they allow the patients to express prospective autonomy in the future (de Arruda et al., n.d.). However, advance care planning (ACP) was identified as an area requiring further training (Chan et al., 2019). The need for training in ACP was clearly highlighted in a literature review that noted most HCPs, nurses included, experienced challenges in discussing and developing ACP. The HCPs identified the following as areas of uncertainty: the usefulness of ACP, the legal status of ACP, and how to implement ACP (Glennon et al., 2019).

Nurses skills in advanced care planning were noted to be wanting as was observed in a study that highlighted the fact that nurses found it challenging to follow advance directives (Foo, Zheng, Kwee, Yang, & Krishna, 2012) or advocate for their implementation due to conflict between what

the patient had expressed as their wish and what the nurses believe (Goel, et al., 2014). Young, Froggatt, and Brearley (2017) contradicted this in their study on moral distress among nursing staff. They noted that nurses rarely developed conflict with what the patient wished but rather with their colleagues' values and beliefs.

At EOL, nurses are expected to conduct a patient assessment and identify patient's care needs and preferences in order to intervene accordingly (Nedjat-Haeim, et al., 2016). This would mean that nurses need to be conversant on what assessment tools to use to get as much information as possible from patients in order to plan for their care appropriately. Additionally, detailed patient assessment would ensure that miss opportunities to introduce EOL discussions would be minimized as patient wishes would be well stipulated way in advance before the patient is incapacitated (Bussmann, et al., 2015).

Issues surrounding patients' wishes at EOL seem to be an area of great challenge for nurses (Guo & Jacelon, 2014). This was clearly highlighted in a study by Foo *et al* (2012) that explored on factors that contributed to HCPs decision making at EOL. Findings suggested that the HCPs would respect a competent patient's wishes over the family's requests when there was a conflict on goals. Nevertheless, most of the HCPs would stand by the family's requests when patient loses capacity even in the presence of an advance care directive.

Deficiency in effective communication at EOL was supported further by Hendricks *et al*, (2015) in their study on novice nurses experience with PC/EOL. Findings confirmed that the area that was found wanting in nursing at EOL was issues surrounding communication. They attributed this to inadequate or lack of preparation in EOL care. As a result, there is a pool of practicing nurses who are unprepared to participate in EOL discussions.

Policy making, leadership, and management in EOLC is also wanting. For instance, the number of people with chronic illness in Kenya is increasing. This means that a significant proportion of the Kenyan population requires or will require EOL at some point. However, to the best of the researcher's knowledge, there is no policy on EOL in Kenya; the benefits of an EOL policy are well highlighted in a systematic review on effect of an EOL policy within nursing care homes. The study noted that there was improvement in patients' outcome as well as patient assessment by the staff (Kinley, Froggatt, & Bennett, 2011).

Additionally, having a policy would be an effective means of providing EOL counselling since this wants a plan that is organized to comprise the relevant and fully informed team of individuals (McRee & Reed, 2016). The team would be fully informed empirically about the patient's health status, but then again, be ethically informed such that each member is sensitive to the values and treatment preferences of the patient. Therefore, if nurses are empowered with appropriate competencies they will be able to contribute to hospital-level and even national-level EOL policy development.

3.4 Development of Competency Guidelines (CG)

Healthcare and care provider systems are changing rapidly for various reasons among them being an aging population (Finucane et al., 2019; Glover et al., 2017) and mutation of disease causing agents (Bloomer, 2015). For instance, in the presence of an acute medical condition, the hospital is expected to provide short-term, intensive care. When the treatment is completed, home care is required to support for treating the patient with dignity and respect until the EOL. Therefore, nurses must and are required to provide comprehensive care that meets patients' and families' complex and divers needs irrespective of work setting (Nedjat-Haeim, et al., 2016). Nurses are always challenged on how they can contribute to society as professionals.

They are expected to take professional responsibilities for continuously providing direct care, protecting individual lives and supporting activities of daily living (Juma et al., 2014; Wagoro & Rakuom, 2015). To accomplish this, it is important for nurses to improve their nursing care competency and utilize in their daily practice. In nursing practice, nurses are required to apply their acquired knowledge, skills and attitudes to each situation and be able to adapt that knowledge and those skills to different circumstance (Finucane et al., 2019; Glover et al., 2017; Wagoro & Rakuom, 2015). EOL nursing care included. Within the EOL nursing care context, the aim is to minimize suffering and promote a 'good death'.

However, while the concepts surrounding EOL nursing care competency are important for improving nursing quality, in Kenya, they are still not yet completely developed. Thus, challenges remain in establishing structures for EOL nursing care competency, competency levels necessary for specialists and non-specialists' PC nurses and training methods. As such, this study endeavored to develop EOLNC clinical competency guidelines (EOLNC-CCG) for nurses in Kenya. The

EOLNC-CCG provide guidance for the knowledge, attitudes and skills required for non-specialist PC nurse(s) to deliver high quality EOL care in an acute setting. In a nutshell, it includes core abilities that are required for fulfilling one's role as a nurse (Gupta et al., 2019; Pettersson et al., 2018; Sade & Peres, 2015).

The development of competency guidelines (CG) utilizes various approaches and this section discusses three approaches. To begin with, it can be developed through undertaking and utilizing systematic/literature reviews to inform the development (McDonald et al., 2019). However, McDonald et al (2019) noted that developers have raised concerns particularly regarding the time spent and resources required to undertake reviews; as such, these obstacles limit the contribution and uptake of CGs. This especially possess a challenge of keeping up to date with the rapid evidence being generated. Developing a CG using this approach is paramount as it promotes the transfer of research results into actionable components that can be implemented (Anderson et al., 2008).

Further, CG can be developed through a consensus process involving subject matter experts (Albetkova et al., 2019) and/or involving the direct users/beneficiaries (Carter et al., 2017). Carter and colleagues (2019) for instance, involved the admiral nurses to develop the CG with them rather than for them. This began with focus group and telephone interviews to understand the competencies that this group of nurses wanted included in the CG. This process ensured that the developed CG was both evidence-based and practice-based.

Finally, CG can be developed through a combination of literature review and a consensus process involving subject matter experts. This approach was for instance used by Deacon et al (2017) while developing a CG for registered nurses in adult critical care. The study developed a CG for clinical practice for critical care nurses in order to ensure that what is taught in critical care courses is also practiced at the point of provision of care. The study commenced with a list of competencies identified from existing educational competencies. This was followed by a validation process that aimed at obtaining professional consensus on the developed CG.

Successful implementation of CG ensures the best possible outcomes for patients (de Almeida Vieira Monteiro & Fernandes, 2016; Gupta et al., 2019; Sade & Peres, 2015). As such, irrespective of the approach utilized, it is prudent that the process of developing CG is both efficient and cost-effective (McDonald et al., 2019) especially bearing in mind the time and resources spent in

developing them. In this study, the researcher utilized a combination of literature review and a consensus process involving subject matter experts for validation of the CG.

In conclusion, Competency guidelines outline the knowledge, attitudes and practical skills necessary for nurses to deliver EOLNC services efficiently and effectively. Literature indicated that nurses have inadequate knowledge on EOLNC (Abate et al., 2019), inappropriate attitudes (Hendricks-Ferguson et al., 2015) and inadequate practical skills (Rodgers et al., 2016) to deliver good quality EOLNC. Thus it is paramount that nurses are trained on EOLNC. As was highlighted earlier on, the Kenyan basic nursing curricula lack adequate content on EOL nursing care. This poses challenges because nurses are frontline caregivers to patients and their families and as such they are required to be well equipped to provide EOLNC (Abate et al., 2019). Nursing as a profession has endorsed competency development as a means of strengthening the nursing workforce. Competencies improve the workforce by providing a guiding framework for producing education and training programs (Lee et al., 2015). They also clarify nursing roles and responsibilities which makes assessment of individual performance and organizational capacity easy to undertake.

Competencies are action-oriented statements that delineate the essential knowledge, attitude, and practical skills that are critical to the effective and efficient performance of work. They should be observable and measurable (Maijala et al., 2015). Competency guidelines have been developed in different professions. For instance, the public health fraternity developed competency guidelines through a consensus process with experts (*Welcome to CDC Stacks .Pdf*, n.d.). The nursing profession too has a number of guidelines developed in support of patient care (Bostwick & Linden, 2016). However, the researcher noted that most of these guidelines were developed through conducting systematic reviews only unlike through a combination of literature review and a consensus process as was the case in this study.

3.5 Theoretical Framework

In order to better explore the problem identified in this study, it is imperative to consider utilizing theories. Theories according to McEwen and Wills (2014), clarify the research problem making it much easier for the researcher to undertake an in depth exploration of the problem. They further indicated that, theories in research enrich the interpretation of findings by the researcher as they

act as the structure for the study. Theory-based EOLC knowledge unique to nursing is widely available. It is particularly suited to inspire and guide nurses in the EOLC conversations.

The researcher utilized a combination of two theories as the underlying competency theories. Specifically, Rosemarie Parse's Human Becoming (2015) and Katherine Kolcaba's Theory of comfort (1994) were used. Parse's theory was first published in 1981 by the name *Man-Living-Health* and has had several revisions. The latest revision was that done in 1992 that saw Parse change the name to the *Theory of Human becoming*. While the Kolcaba's Theory of Comfort was first published in 1994 and in 2001, it was modified to its latest version (McEwen & Wills, Theoretical Basis for Nursing, 2014).

Parse's human becoming paradigm is well aligned to EOL decisions for care. The paradigm according to McEwen and Wills (2014) clearly stipulates the role of the nurse as "guides humans toward ways of being, finding meaning in situations, and choosing ways of cocreating their own health" (p 209), the nurse's presence is ratified through practices that support patients and/or families to 'freely choose' within their EOL situations, and to shade meaning and marshal wholeness as they move through the course of EOL. This paradigm provides an empirical base of research as well as models for practice with patients and/or families in critical situations. Interestingly, it can as well address the ontology of human beings facing EOL decisions, and the ethical scopes of nursing presence in facilitating patients choosing and then living their 'value priorities' with dignity.

In a nutshell, Parse's theory of human becoming has several congruent elements consistent with health and well-being. These are: being fully present and attentive to the patient; understanding the whole person, not reducing the patient to parts; and the importance of focusing on the subjective experience of quality of life (McEwen & Wills, Theoretical Basis for Nursing, 2014). Therefore, this theory emphasizes on the importance of the physical presence of the nurse during care provision. Additionally, it emphasizes on the need for patient involvement in care provision due to the subjective nature of health. Finally, there are emphasis on provision of holistic care.

The aforementioned elements are critical particularly for nurses providing EOL care. This is because death and dying elicits a lot of emotions in nurses (Ingebretsen & Sagbakken, 2016) and as a result possess a challenge to nurses in that they struggle to separate their personal role from their professional role. However, experience in caring for the dying has been noted to increase

awareness and new insight to health care professionals' own life (Anderson et al., 2008); as he/she journeys along with the patient. This indicates the pivotal role that clinical experience plays in nurses' development. That is, there is some symbiotic relationship between the patient and the nurse in the journey towards high quality of life for the patient and/or family.

Kolcaba's comfort theory on the other hand, provides a guide for promoting three forms of comfort particularly relevant to EOL care and decision-making, namely: *ease* as a state of calm or contentment; *relief* as a state of having a specific comfort need met; and *transcendence* as the state in which one can rise above problems or pain (Gayoso et al., 2018). It also guides the nurse on the four contexts in which comfort needs to be addressed: specifically, psychosocial, physical, environmental, and sociocultural (McEwen & Wills, Theoretical Basis for Nursing, 2014).

Psychosocial comfort has mental and spiritual components. It encompasses emotions that are associated with concepts that give the individual's life meaning such as self-awareness. For instance, as the disease progresses, patients become anxious which alters their psychosocial comfort (Cipolletta & Oprandi, 2014; Kobewka et al., 2017). Physical comfort is related to bodily perceptions and it encompasses physiological factors such as response to disease and homeostasis that affect an individual's physical condition. For instance, physical comfort can be compromised by the presence of pain (Machira, 2013). Environmental comfort includes external factors and circumstances and their effects on the individual. That is, the individual's external environment such as lighting, noise and safety of the environment, affects the individual's environmental comfort (Coyle et al., 2015). Finally, is the sociocultural comfort which refers to the individual's social and cultural environment. Components of sociocultural care include providing care that is sensitive to the individual's family traditions, habits, and religious beliefs; and interpersonal communication (Hu et al., 2019; Kobewka et al., 2017) the theory highlights the importance of patient-led decisions in identifying comfort outcomes.

3.5.1 Rationale for the chosen theoretical framework

The main goal of nursing as a professional discipline is to provide patient care, and one of the pillars of nursing practice is providing comfort interventions (Lewis, 2013). Comfort is an important element of quality of life, and many interventions performed by nurses focus on promoting comfort. Hence, for nurses to provide comfort to patients they are required to be

physically present which is in line with Parse's Human Becoming theory. That is, nurses guide individuals and/or families in choosing possibilities in changing the health process. As such, the nurse supports the client and/or family as they navigate through the experience of EOL.

While the theory of comfort by Kolcaba guides nurses in the process of promoting comfort. Hence, nurses identify comfort needs of patients and/or family members and they design and coordinate interventions to address these needs. Therefore, nursing care should be planned holistically and should embrace the four dimensions of comfort. By means of such comprehensibly planned care, patients can experience relief, ease, and transcendence. To realize the goal of promoting comfort, nurses should possess the right competencies. This study therefore, aimed at identifying requisite competencies for provision of high quality EOL nursing care in Kenya in light of the theoretical framework described above.

3.6. Conceptual Framework

A researcher is required to synthesize literature in relation to his/her phenomenon under investigation, this is diagrammatically represented in a conceptual framework (Imenda, 2014). Basically, it indicates the scholar's understanding of how the particular variables in the study relate with each other. Therefore, it identifies the variables necessary in the research study. In figure 3 below, the independent variables are a) nurses' preparedness to practice, b) nurses' perceived training needs; and c) EOLNC core and sub competencies. While the dependent variable is the evidence-based competency guidelines.

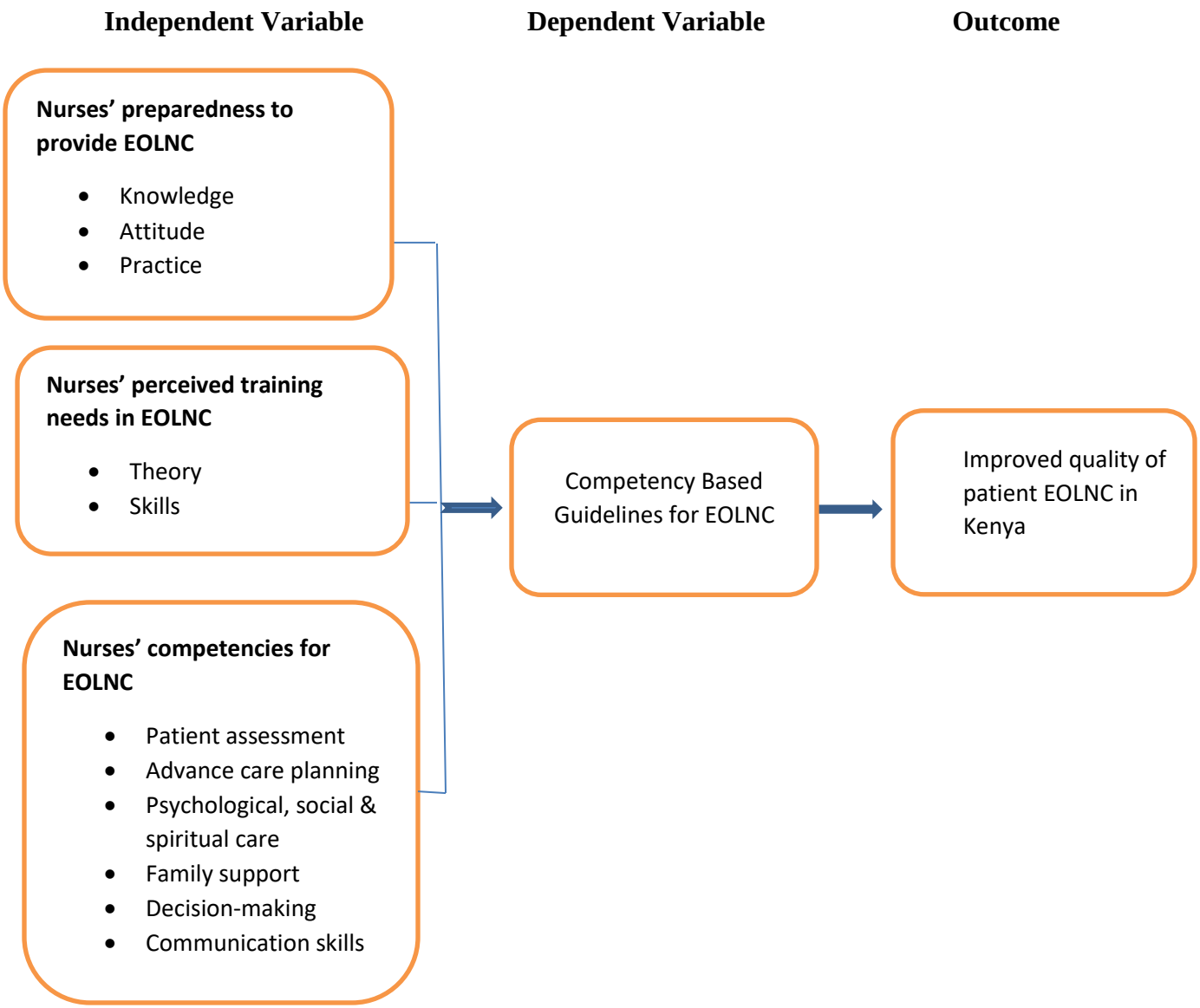

Figure 3.2: Conceptual framework illustrating the relationship between variables (Source, Author 2017)

3.7. Conclusion

To significantly increase the quality of care that individuals receive at the EOL, it is imperative to identify the barriers to good quality EOLNC. These barriers exist across the course of life threatening illness from diagnosis to hospital-based care. Literature highlighted lack of adequate knowledge, inappropriate attitudes by the nurses and inadequate practice skills as major barriers to EOLNC. Formal training of nurses in EOLNC, such as ELNEC, was noted to exist in both

developed and developing countries. However, this majorly emphasized the theoretical component as some the components of ELNEC are integrated in the Kenyan nursing curricula for basic nursing programs. Nevertheless, there is need for continuous professional development for nurses on EOLNC as they are the frontline caregivers for those nearing the EOL. To this end, there is need for identification and validation of clinical competencies requisite for provision of EOLNC in Kenya and which also may be utilized in clinical training. Finally, the study utilized the Human Becoming theory and Kolcaba's theory of comfort.

CHAPTER FOUR: METHODOLOGY

4.0. Introduction

The aim of this study was to identify and validate appropriate core and sub competencies for End of Life Nursing Care (EOLNC) for Kenyan nurses.. To achieve this, it was prudent to explore nurses' perception on their level of preparedness to provide EOLNC and to determine their perceived training needs. Due to much attention that this subject has received recently, literature exists on the same in the developed countries. Thus, a quantitative research design using multiple data collection methods was adopted. These included survey and a modified Delphi technique (mDT). This chapter therefore, outlines the methodological approach utilized in the study to respond to the research questions and so accomplish the aims and objectives of the study. It begins with a description of the study design including the sample and recruitment. The instrumentation, validity and reliability, data collection, data analysis, ethical considerations, and finally the chapter closes by highlighting the limitations. This chapter has largely been presented in two major categories, phase I and phase II. However, for themes that cut across the two phases, these have been merged.

4.1. Phases of the study

The study was done in two phases as shown in figure 3 In phase I, cross-sectional study design was used to establish nurses' perception on their level of preparedness to provide EOLNC and to determine their perceived EOLNC training needs. This was then followed by phase II which involved a two-round modified Delphi process to identify core and sub competencies for EOLNC. A detailed description of the activities in each phase is as described below.

Phase I:

Nurses' preparedness to provide EOLNC

Phase II:

Core competencies for EOLNC (using modified Delphi Technique (DT)

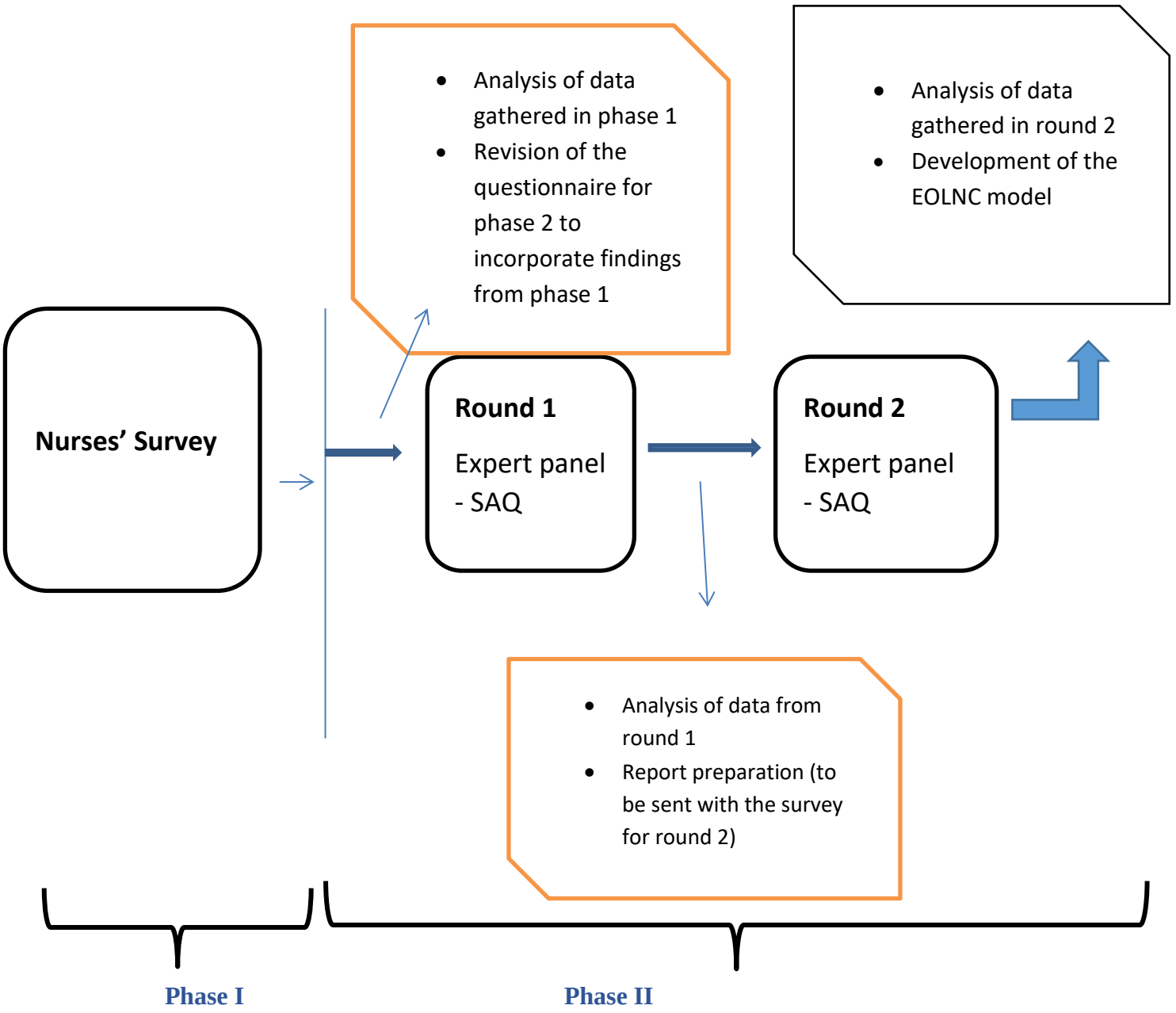

Figure 4.1: illustration of the Research Design

4.2. Methodology: Phase I

4.2.1. Research design

In phase one (I), cross-sectional study design was utilized to explore nurses' perception on their level of preparedness to provide EOLNC and to determine nurses' perceived training needs regarding EOLNC. The rationale for selection of this design was due to the fact that the researcher intended to collect data on nurses' perceived level of preparedness and perceived training needs. Hence data was collected at a specific point in time which is one of the characteristic of cross-sectional study design (Polit & Beck, 2010).

Unlike an experimental design, where there is an active intervention by the researcher to produce and measure change or to create differences, cross-sectional designs focus on studying and drawing inferences from existing differences between people, subjects, or phenomena. Additionally, in cross-section studies, groups identified for study may be selected purposely or using random sampling. Cross-section studies are capable of using data from a large number of subjects and, unlike observational studies, is not geographically bound. They can estimate prevalence of an outcome of interest because the sample is usually taken from the whole population.

The researcher sought to understand the prevailing characteristics of Kenyan nurses working in specialized units regarding their perception on level of preparedness to provide EOLNC and their training needs on the same at the time of the researcher's study. Therefore, cross-sectional design was found to be a good suitable research design that would facilitate the achievement of the aforementioned objectives.

4.2.2. Study Site

The study was conducted at Kenyatta National Hospital (KNH) which is approximately four kilometers from Nairobi central business district (CBD). Kenyatta National Hospital is an 1800 bed capacity facility with six thousand members of staff of whom 1600 are nurses. It was established in 1901 as a Native Hospital, with a two-ward, 40 bed capacity. In 1965, increase in demand for health care services necessitated the introduction of training for medical personnel and midwives in the hospital. Thus, in 1967, the University of Nairobi Medical School located at the hospital was established. Additionally, due to continued increase in demand for health care

services, in 1971, the construction of a ten-story Tower Block was started and completed in 1981. The Renal Unit started operation in 1984, while the Dental and the Orthopedics Units were relocated from Kabete in 1985 and 1993 respectively.

The hospital is the major training facility in Kenya for health care personnel in various disciplines both at undergraduate and post-graduate levels. KNH works closely with other institutions/organizations such as, University of Nairobi College of Health Sciences (CHS) and Kenya Medical Training College (KMTC). KNH offers specialized health care to patients and the services include but not limited to: cardiothoracic surgery, neurosurgery, orthopedic surgery, plastic surgery, reconstructive surgery, burns management; radiotherapy, chemotherapy, critical care services, renal services (including kidney transplantation), new born services, and violence recovery services.

The study was undertaken in eight Specialized Care Units (SCUs) at KNH. This included: Intensive Care Unit (ICU), High Dependence Unit (HDU), Burns Unit, Renal Unit, Oncology ward, Accident & Emergency Department, Palliative Care department and Oncology clinic. There were 381 nurses working in these units. KNH setting was chosen because it is the leading referral and teaching hospital in Kenya that is associated to a university. As such, it attends to a very high number of patients with life threatening illnesses who require EOLNC and the nurses working in KNH are experienced in providing care to patients in various units of specialization.

4.2.3. Study population

The study population included all nurses working in the SCUs at KNH. The hospital had 1600 nurses in total with 381 positioned in the SCUs as follows: ICU - 150; HDU – 14; BU - 30; RU - 30; oncology ward – 35; A & E – 90; oncology clinic - 22; and Palliative Care Unit - 10 (KNH Records, 2017). KNH was chosen because it has served as a teaching hospital and clinical experience setting for many health care providers including nurses. SCUs were chosen because of the fact that they provide focused care to patients with specific conditions and as such nurses in these units frequently care for patients at or nearing their end-of-life (those who present late and whose disease has progressed). Also, most nurses in Kenya undertake clinical placements at KNH during their training after which they are absorbed in other parts of the country where they replicate their knowledge, attitudes, and practice skills.

4.2.4. Sample size determination and sampling method

During this phase, data was collected to establish the current status of nurses' preparedness to provide EOLNC. This was necessary for identification of gaps and training needs on the same. Self-administered questionnaires (SAQ) were utilized to collect data. For data collection using SAQ, the study sample was first calculated and determined as described below.

The total number of nurses who qualified for the study was 381 as stated under study population. The Fischer's formula (Polit & Beck, 2010) was used for sample size determination as follows:

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

Where:

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

Z= the standard normal deviation at 95 % confidence level (=1.96)

P= the expected population correlation coefficient (population effect size)

(Since there is no documented population effect size, 50% (large effect size) was used to calculate the sample size)

q= 1- p

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

Substituting these figures in the above formula

$$= \frac{(1.96)^2 (0.50)(0.50)}{(0.05)^2}$$

$$= 384$$

As the target population was less than 10,000, the sample size was adjusted using the following formula by Yamane (1967):

$nf = n/ 1+ (n / N)$

Where nf = the desired sample size when population is less than 10,000
n = the desired sample size when population is more than 10,000
N= the estimate of the population size

Hence $nf = \frac{384}{1+ (384/ 381)}$

$= 384/ 2.01$

$=$ **191**

Thus, the calculated sample size was 191 nurses.

Proportionate sampling was utilized to determine the sample from each unit (Table 3). Further, the researcher used random sampling technique to identify the sample within the units. Systematic random sampling was found not to be suitable as the kth value was 1. Therefore, simple random sampling was utilized to get the participants from each unit. That is, equal numbers of "**Yes**" and "**No**" were written in small pieces of papers as per the sample required for that specific unit. These papers were placed in a small box and then mixed. The participants then picked a piece of paper and whoever picked a "**Yes**" was allowed to participate.

This was done at unit level immediately after receiving of the morning report from the night staff. This was done in order to capture a maximum number of nurses in the unit. The same was repeated on alternate days until the required sample size was achieved. Repeating on alternate days was preferred because majority of the staff had changed shift which minimized the possibility of a participant to be chosen twice. For inclusion in the study, one was required to be a nurse, working in either of the SCUs. Additionally, they were required to have registered and in possession of a current license practice from the NCK.

Table 4.1: The proportionate sample from each unit

S. No.	Units	Proportion of respondents	Total number of respondents per unit
1	Intensive Care Unit	150/381x191 = 75	75
2	High Dependence Unit	14/381x191= 7	7
3	Burns Unit	30/381x191 = 15	15
4	Renal Unit	30/381x191 = 15	15
5	Oncology ward/GFD	35/381x191 = 18	18
6	Accident & Emergency Department	90/381x191 = 45	45
7	Palliative Care Department	10/381x191 = 5	5
8	Oncology Clinic	22/381x191= 11	11
Total			**191**

4.2.5. Data collection tools

Survey was used to gather data. This was done through a self-administered questionnaire. The questionnaire was developed solely for this study. This was done following literature review of the major areas under investigation. Items identified in literature were inserted into the tool which was later submitted to the supervisors for review. Moreover, pre-testing was conducted which helped to refine the questionnaire further. It was constituted of both closed and open-ended questions. The questionnaire had four sections: demographic information; professional information; information on nurses' preparedness to practice in EOLC settings; and finally, information on nurses' perceived training needs. The questionnaire development was guided by the specific objectives of this study and each objective was informed by a research question. The questionnaire clearly outlined instructions for the sampled nurses (Appendix II). Further, it was written in English as all the sampled nurses were conversant with the English language since it is the language of instruction during training and the official language in Kenya.

4.2.6. Validity

In order to undertake validation of the questionnaires used in the two phases of the study, different approaches were used. Content validity was established by the researcher's supervisors and the sampled participants during pre-testing as they recognized the type of information being sought. The prime threat to internal validity for my research design was linked to selection of participants. To minimize the threat related to internal validity associated with my research design, random sampling method was used to get the sample. It is hoped that the chosen research design and careful planning enhanced the validity of the study.

4.2.7. Reliability

The questionnaires utilized in both phases had multiple Likert questions that formed several scales. Therefore, the researcher had to establish whether each scale in the questionnaires for both phases were reliable (had internal consistency). As such, a reliability analysis specifically Cronbach's alpha, was carried out on the following scales: a) nurses' knowledge on EOLNC scale comprising 15 items; b) nurses' attitudes on EOLNC scale comprising 14 items; c) nurses' practice skills comprising of 17 items; and d) nurses' training needs regarding EOLNC comprising 8 items.

Cronbach's alpha measures the correlation between the answers in a questionnaire through the analysis of the profile of the answers given by the participants, its values vary from 0 to 1. The closer to 1, the greater the reliability of the indicators. A generally accepted limit is 0.7 (Gottems et al., 2018). The Cronbach alpha reliability is classified as follows: very low ($\alpha \leq 0.30$); low ($0.30 < \alpha \leq 0.60$); moderate ($0.60 < \alpha \leq 0.75$); high ($0.75 < \alpha \leq 0.90$) and very high ($\alpha > 0.90$) (Maltby, Day, & Williams, Introduction to Statistics for Nurses, 2007). The following discussion elaborates the results of the reliability analysis in details as presented in table 4 below.

Table 4.2: Reliability Statistics for nurses' preparedness to provide EOLNC

Reliability Statistics			
	Components of nurses' preparedness	**Cronbach's Alpha**	**N of Items**
1	Knowledge	0.937	15
2	Attitude	0.849	14

3	Practice	Practice setting 0.740	6
		Care dilemmas 0.817	7
		Individual practice 0.878	3
		Barriers in practice 0.920	11
4	Training needs	0.385	9

To begin with, regarding nurses' knowledge, Cronbach's alpha revealed that the scale reached acceptable reliability, α=0.94 (Table 4.2). Most items appeared to be worthy of retention, resulting in a decrease in the alpha if deleted (Appendix VI). Therefore, all the items were retained. Additionally, results from a reliability analysis on the nurses' attitude on EOLNC scale comprising 14 items; Cronbach's alpha also revealed that the scale reached acceptable reliability, α=0.85 (Table 4.2) and as such, most items appeared to be worthy of retention, resulting in a decrease in the alpha if deleted (appendix VI). Similarly, none of the items was deleted.

Moreover, the internal consistency on the current practice on EOLNC scale comprising 6 items on the practice setting, 7 items on care dilemmas, 3 items on individual practice, and 11 items on barriers in practice was also established. Cronbach's alpha revealed the current practice scale to reach acceptable reliability, α=0.74, 0.82, 0.88, and 0.92 respectively (Table 4.2) and as such most items seemed worthy of retention, resulting in a decrease in the alpha if deleted (appendix VI). Hence, all the items in the mentioned scales were retained. Finally, a reliability analysis was carried out on the training needs scale comprising 9 items. Unlike the previous scales assessed, Cronbach's alpha for this scale showed that the scale did not reach acceptable reliability, α=0.39 (Table 4.2).

However, most items appeared to be worthy of retention, leading to a decrease in the alpha if deleted. An exception to this was item 8, which would increase the alpha to 0.92 if deleted (Appendix VI). Therefore, the assumption was that item 8 was not highly correlated with other items in the scale and it could be deleted from the questionnaire. The researcher made various attempts to correct the wording by replacing the term "grief/bereavement" with the terms "grief and bereavement care", "grief and bereavement support", and "breaking bad news". Despite these

efforts, the Cronbach's alpha did not change much. Therefore, considering the researcher's epistemological position (etic), this item was removed from the scale despite the fact that the researcher considered it relevant for nurses to provide good quality EOLNC.

4.2.8. Pretesting of the study tools

Nineteen questionnaires (which is 10% of the sample size) were pretested among nurses working in the acute room at KNH Emergency Department. This room functions as an acute/critical care unit in the emergency department and handles patients who eventually are admitted to the critical care unit. Nurses from this section were not included in the main study. After pretesting, the items in the questionnaire were reviewed accordingly. Major revisions were around sequencing the questions, therefore, the questions were rearranged so that questions addressing a similar area would follow each other. This however did not result to deletion or addition of items. Hence, the validity and reliability of the questionnaires as was established above was not altered.

4.2.9. Data collection procedure

Prior to commencement of the study, Institutional and National Council for Science and Technology (NACOSTI) ethical approval was obtained. Additionally, prior to completion of the questionnaire by the respondents, a written consent was gotten from each participant. Both quantitative and qualitative data was collected. The rationale for this was to allow for complementarity which according to Punch (2006) gives the researcher more confidence about the validity of the results.

Further, it was important to clarify where each data was gathered and also on the sort of combination to use (Punch, 2006). The self-administered questionnaires used in phase I as well as in phase II generated both quantitative and qualitative data. This ensured deeper exploration on nurses' preparedness to provide EOLNC in Kenya as well as training needs surrounding EOLNC. The data collection procedure is discussed in details below.

In order to ensure a high response rate, the researcher visited the hospital within a month before commencement of data collection in order to sensitize the nurses on the upcoming study. During the sensitization visit, the researcher clearly explained: the purpose and benefits of the study; voluntary participation; the selection criteria; and withdrawal from the study; offer to send/share

results with respondents; anonymity; confidentiality; and use of code rather than participant's name.

Additionally, discussions regarding collection of the filled questionnaires were conducted during the sensitization visit and different approaches were explored. It was agreed that a box be placed in each unit where the nurses can drop their completed questionnaire. The researcher and/or research assistants picked the filled questionnaires on alternate days. A week after the sensitization visit, the researcher and research assistants personally distributed a set of documents (cover letter, consent form and questionnaire) to all the participants who met the inclusion criteria. A total of 191 nurses were given the set of documents.

The documents were coded at the designated space on the questionnaire which enabled the researcher to track the questionnaires. For follow-up purposes the researcher called and reminded the participants to complete and submit the filled questionnaire. Filling the questionnaire took 20 - 25 minutes to complete. The completed questionnaire was then dropped in the designated box and was collected by the researcher or assistants on alternate days. The filled questionnaires were assessed for completeness and coded for data entry into the computer. All the data gathered was stored under lock and key. The data collection period took three weeks.

4.2.10. Data analysis and presentation

The major aim of data analysis was to utilize the information from the sample to draw conclusions about the population of interest. The findings from any research study can be presented and interpreted in more than one way. Interpreting or making sense of findings is an important phase of the research process (Maltby, Day and Williams, 2007). It is at this stage of the process that a researcher makes an attempt to apply his/her findings to clinical practice, or to the theory out of which the study emerged. According to Maltby and colleagues (2007), research is the link between theory and practice, and it is at the point of interpretation that these links have to be demonstrated.

Data from the questionnaires was checked for accuracy and outliers; then organized, coded, and converted into quantitative summary reports for analysis using the statistical package for Social Sciences (SPSS) version 24 database. Data gathered was analyzed using descriptive statistics and presented as means and standard deviation while categorical data was presented as frequencies and percentages. Results were presented using tables, pie charts and column graphs. Qualitative data

obtained from the open-ended questions in the questionnaires was categorized into emerging patterns which were later grouped into topics and coded into quantitative data. That is, each topic was assigned a code which preceded the code generated for individual items under each topic. These were then tallied and summed up to get the quantitative data

Inferential statistics were conducted for the respective objectives stated for the study as discussed below. To begin with, for objective 2 which sought to explore whether a relationship existed between work station and nurses' perceived level of preparedness to provide EOLNC, cross tabulation was performed. Similarly, cross tabulation was performed for objective 4 which assessed whether a relationship existed between work station and nurses' perceived EOLNC training needs. Finally, for objective 5 which investigated whether a statistically significant relationship existed between nurses' perceived level of preparedness to provide EOLNC and perceived EOLNC training needs, Pearson correlation test was conducted.

Maltby, Day & Williams (2007) stated that the mean is the average attitude of the participants toward the consistency and significance of the various items. The higher the score, the better the consensus is among experts on the significance of that item. A value of >3.5 means that the items is substantially significant, and a value of <3.5 means the item is not significant. Consistency occurs when the SD of an item is ≤ 1, indicating that the participants have reached a definite level of consensus. Convergence is reached when there is a consensus for half (50%) of all items in the study (Malby, Day & Williams, 2007). When this happens, it is not necessary to conduct another round of survey.

4.3. Methodology: Phase 2

4.3.1. Design

In phase two (II), a two-round modified Delphi Technique (mDT) method was utilized to validate the 8 ELNEC competencies and to identify EOLNC sub competencies through consensus among the experts. The Delphi method was initially developed in 1950's by Olaf, Norman and Nicholas who concentrated on the effect of technology on warfare (Keeney, Hasson & McKenna see Trevelyan & Nicola 2015). However, the technique has since been used in health care research (Atkinson et al., 2015; Castro et al., 2016; Collins et al., 2017; Frenk et al., 2014; Geng et al., 2018).

For instance, a study that sought to develop a curriculum for a continuing medical education programme utilized a modified Delphi process (Esmaily, et al., 2008). Additionally, Delphi technique was also used in nursing as reported in a study by Lee *et al* (2015) where they sought to identify competencies required by emergency nurses for effective provision of care to women following violence.

Delphi is a systematic technique that seeks to obtain expert input using a series of evolving questionnaires while allowing for anonymity and asynchronous participation(R Avella, 2016). The Delphi method is a widely accepted research technique(Atkinson et al., 2015; Collins & Yen, n.d.; Frenk et al., 2014), particularly in studies seeking to find agreement among experts who have divergent views and perspectives on a given issue(R Avella, 2016). Therefore, the Delphi process facilitates group problem-solving utilizing an iterative process of problem description and discussion, feedback, and revisions. An important feature of this method is the anonymity between experts. This study used a modified Delphi process to form a framework for EOL care clinical competencies for nurses.

The use of Delphi technique in nursing is well documented in literature.(Bostwick & Linden, 2016; Collins & Yen, n.d.; Lalloo, Demou, Kiran, Cloeren, et al., 2016; Toronto, 2016). A two-round modified Delphi Technique (mDT) method was used to identify and seek for consensus on EOL care competencies for nurses. This study modified the Delphi process by starting with a list of statements instead of open-ended questions as is characteristic of the traditional Delphi process.(RAvella, 2016) Furthermore, this study omitted the explicit summary of results in each round. Instead, the information from the participants was incorporated into the survey content.

Data was collected at two different points in time to seek for consensus on core and sub competencies for EOLNC for Kenyan nurses. For data collection in this phase, a questionnaire in form of a Likert scale was used to examine consensus regarding core and sub competencies to be incorporated in the clinical competency guidelines.

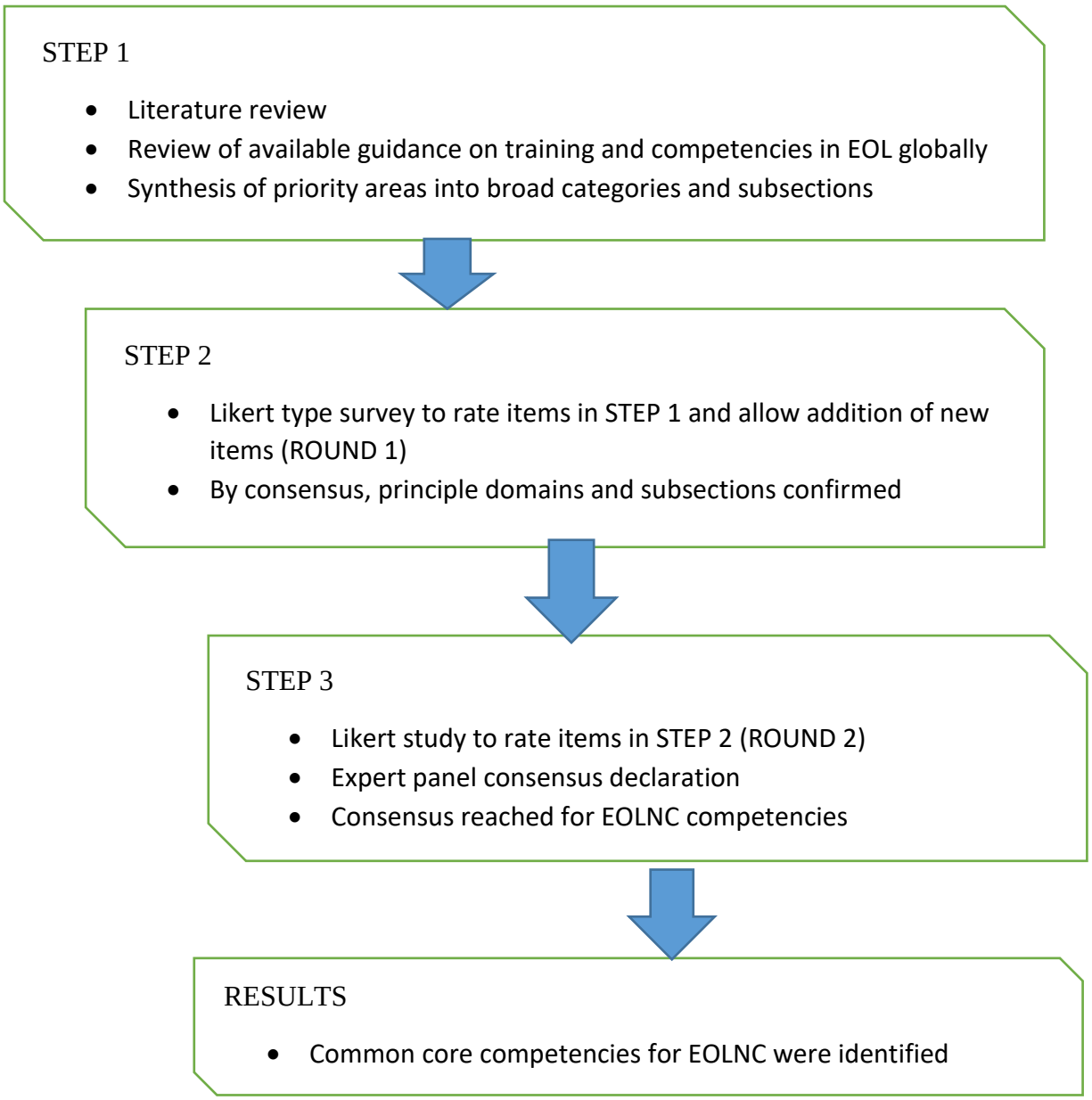

Figure 4.2: The modified Delphi process

The aim of the round 1 survey was to validate the core competencies as adopted from the ELNEC program (*ELNEC Introduction Slides.Ppt*, n.d.; Ferrell et al., 2015) and determine the sub competencies that should be included in each core competency in the framework. Core competencies needed to be validated because they emerged from the developed countries which have different characteristics from Kenya which is a developing country and as such there was

need to ascertain their importance within a developing country's setting. While sub competencies were considered to be specific nursing behaviors within each core competency. Participants were asked to state the extent to which they agreed on the importance of the core competencies using a 5-point Likert scale. Further, they were also asked to state the extent to which they agreed on the importance of the sub competencies on the same 5-point Likert scale. The goal of the Round 2 survey was to validate the revised core competencies and identified sub competencies included in each core competency. In Round 2, participants were asked to rate the importance of the sub competencies in each core competency, using the 5-point Likert scale as was used in Round 1. They were also asked to list any sub competencies they felt needed to be removed from or added to the list. This study also excluded the explicit summary of results in each round, incorporating the information from participants into the survey content instead. These modifications have successfully been used in a previous study (Joyner & Stevenson, 2017).

4.3.2. Expert Panel Composition and Size

It is recommended that the Delphi panel should be constituted of highly trained and proficient within the specialized area of knowledge related to the objective being investigated (Meskell *et al.,* 2014). Meskell and colleagues (2014) reasoned that between six and twelve members are sufficient for DT and according to Murphy et al (n.d.), if a mixture of experts with different specialties is used, between five and ten members are ideal. According to Murphy *et al* (n.d), one of the most important phases of DT is selecting suitable members for the Delphi panel as the validity of the results dependent on the competence and knowledge of panel members. Regarding the sampling of the panel members, there is no specific method prescribed.

In essence, an accurate instrument for identifying the number of individuals or the number of panels for inclusion in any individual study is nonexistent. Though there are some disagreements about the composition and panel size of DT, it has been recommended that the panel size may vary according to the topics covered. Additionally, the panel size ought to consider the nature of different viewpoints to be included and the time and money available (R Avella, 2016); it is further suggested that the use of a combination of individuals with multiple specialties and heterogeneous groups may be better than the homogeneous groups. However, controversy exists regarding the number of panel experts. One Delphi study considered fewer than 20 members in their expert panels (Arbabisarjou et al., 2016) while in yet another study more than 100 members were involved

(Joyner & Stevenson, 2017). Further, Delphi panel requires active participation by individuals who are knowledgeable and with the expertise of the study matter.

The Fehring criteria were adapted and used to select experts to be included in the study (Rn et al., 2015). The criteria has the following items: being involved in care and/or teaching with at least one certificate of clinical practice (specialization) in the area of interest of the study; having master's degree with thesis in the area of interest of the study; being a health professional; having clinical experience of at least one year; having PhD degree with dissertation in the area of interest of the study; having published articles on the theme in reference journals and having published relevant research in the area of interest. A participant is considered an expert if she/he has met at least one of the items described above.

Therefore, this study used the following criteria for selection of panel members: a) Have undergone training in palliative care nursing, b) Frequently provides palliative care as part of their role, and c) Have at least one-year experience in patient care in situations of managing patients with a life threatening illness, in the context of teaching and/or care. Registration by NCK was not considered an inclusion criterion because it is limited to nurses trained in palliative care at post-basic diploma level. As such, nurses trained in palliative care at higher levels which is primarily undertaken outside the country are left out.

4.3.2.1. Sample size determination and sampling method

For nurses in possession of a post basic diploma in palliative care nursing, a register exists within the NCK. The researcher requested for the list of nurses existing in the palliative care register from NCK including the county of residence. Thereafter, purposive sampling was used to identify nurses within the capital city (Nairobi) due to its unique characteristics. Specifically, it is a cosmopolitan city and information is easily available and accessible. Moreover, this is where the researcher was based enhancing accessibility to the experts; and also, this is where KNH is located, the facility where nurses who participated in the first phase work. This exposed both the nurses and the experts an environment that is more or less the same which was important for this study. A total of 68 nurses were registered by NCK and 15 out of these were located within Nairobi county. Therefore, all the 15 nurses were sampled. As for nurses trained at degree level and above in palliative care nursing, a register does not exist in NCK to facilitate their identification and utilization of

probability sampling techniques such as random sampling. Therefore, purposive sampling was used to identify the initial participant and snowballing was used for subsequent recruitment of experts from this group. Five experts were identified through snowballing. Therefore, a total of 20 experts participated.

4.3.3. Delphi procedure

4.3.3.1. Tool development

The round 1 questionnaire was designed by adapting the competencies within the ELNEC programme as the core competencies (Ferrell et al., 2015) and as such eight core competencies were considered. These were: 1) Palliative care nursing, 2) Pain management, 3) Symptom management, 4) Ethical issues, 5) Cultural and Spiritual considerations, 6) Communication, 7) Loss, Grief and Bereavement, and 8) Final Hours. These 8 core competencies were converted to a Likert scale to validate them within the Kenyan context. The developed questionnaire was administered in the first and second round. The selection of the ELNEC competencies was guided by the fact that some nurses in Kenya had undergone a training on ELNEC which resulted to palliative care being integrated into the basic nursing curricula in Kenya. As such, the researcher observed that in order to understand nurses' perception on their level of preparedness and their perceived training needs, it would be helpful to utilize content that they were already conversant with or at least heard about.

Sub-competencies were defined as subsets of knowledge, skills, and attitudes contained within each core competency. For identification of this, the following literature was used: 1) The ELNEC content (Ferrell et al., 2015) and 2) The NCK syllabi that has content in end of life care; specifically, the a) post-basic diploma in palliative care(*Palliative Care Syllabus June 2013.Doc*, n.d.), and b) Bachelor of Science in Nursing (*BScN Direct Entry 2014.Docx*, n.d.). These syllabi form the basis for the professional competencies approved by the NCK. All competencies prescribed in the NCK documents were linked to specific ELNEC competencies (N=8) and overlapping competencies were merged. The list of proposed sub competencies was converted to a Likert scale with 76 items linked to the 8 core competencies. The developed questionnaire was administered in both the first and the second round.

4.3.3.1.1. Round 1

The round 1 questionnaire consisted of three sections. The first section asked for demographic information. The second section asked the experts to rate the importance of each of the 8 core competencies using a 5-point Likert scale (5, strongly agree; 4, agree; 3, neutral; 2, disagree; 1, strongly disagree). Finally, the third section asked the experts to rate the extent to which they agreed with the 76 statements as the sub competencies using the same 5-point Likert scale, with 1 indicating *strongly disagree* and 5 indicating *strongly agree*. There were also two open-ended questions: a) list any competency(s) that is(are) missing, and b) list the competency(s) you want deleted. These questions were in each of the following sections:1) Core competencies, 2) Knowledge dimension, 3) Attitude dimension, and 4) Practice dimension. A pack including a cover letter, instructions, and round 1 questionnaire were delivered to the 20 experts. The panel was given a 2-week deadline to return the completed questionnaire, and a reminder was sent via text 1 week before the deadline. In addition, another reminder was sent to those who had still not responded after the lapse of two weeks. This follow-up strategy for non-respondents was also used in the subsequent round. Descriptive statistics including median and interquartile range (IQR) were used to analyze the first round data. The acceptable criteria of each item were median equal to or greater than 3.50 and interquartile range equal to or less than 1.50 (Table 5). while consensus was defined as 75% agreement for each competency. Since the results indicated that consensus was not reached for all the competencies listed, the study proceeded to round two (table 5).

4.3.3.1.2. Round 2

The qualitative data gathered from Round 1 was considered (see 4.3.6 for analysis) and the suggested revisions were made into the second questionnaire. The round two pack was delivered to experts who had participated in the first round, the documents included a cover letter, instructions and questionnaire for round two. The same 5-point Likert scale as that used in Round 1 was employed, with 1 indicating *strongly disagree* and 5 indicating *strongly agree*. The above follow-up strategy for non-respondents was employed. The experts were given a 2-week deadline to return the completed questionnaire. Similarly, descriptive statistics including median and interquartile range (IQR) were used to analyze the second round data. The same acceptable criteria as the first round were applied. All statements both in core competencies and sub competencies in

round 2 scored more than 75% an indication that consensus was reached. Therefore, the Delphi process stopped at the second round.

The duration between the first round and the second round was two weeks, this was to allow for analysis and preparation of the report from the data gathered. The rationale for a short duration between the two rounds was to ensure a high response rate (Trevelyan & Robinson, 2015). The researcher collected the filled questionnaires twice a week for a period of four weeks (one month). Data collection was anticipated to take two weeks but it took one month due to the participants' busy work schedule. The data collection period for the entire study was six months.

4.3.4. Validity and Reliability

In this study, there is evidence of content and face validity in that the development of the questionnaires was based on literature both local and international. Additionally, the open-ended questions allowed experts to generate additional competencies to the list provided. On the other hand, reliability was enhanced in two ways. To begin with, the participants did not need to meet face-to-face, avoiding group bias, and quasi-anonymity was ensured in this study, contributing to the equivalence of the research conditions. Further, the second round provided opportunity for experts to confirm and reconsider their responses from round 1.

4.3.5. Pre-testing

Two experts from the Delphi panel tested the questionnaire. The two experts, one from the academic category specialized in palliative care nursing and the other from the clinical category. These two experts represented a broad view of EOL care. They filled out the questionnaire and answered an extra survey for the content validity of the questionnaire. Since the researcher received a few minor grammatical remarks from the pre-test conducted, the researcher included the answers of the two experts as data for the main study later.

4.3.6. Data Analysis

The qualitative data from round one was categorized into major topics and coding was done. That is, the researcher had some preconceived topics that were generated based on existing knowledge. The suggested changes were then integrated into the questionnaire used in round one. While the

quantitative data from the two surveys were organized, coded, and converted into quantitative summary reports for analysis using the Statistical Package for Social Sciences (SPSS) version 24 database. Descriptive statistics of median (Md) and interquartile range (IQR) were used to calculate all items to obtain the overall group response and the spread of responses, respectively. For the purpose of data analysis to examine the percentage of overall agreement among the experts, variables were recoded to combine *agree* and *strongly agree* into a single category. The same recoding was done for the *strongly disagree* and *disagree.*

As literature does not provide any agreed standard on how to measure consensus, considering the size and the diversity of the experts, 75% was considered as a relatively 'strong' definition of consensus. To calculate the spread of response, the criteria of median and IQR recommended by Punpataracheevin (Prak & Wivatvanit, 2018) were used. Hence, the acceptable criteria of each item were median equal to or greater than 3.50 and interquartile range equal to or less than 1.50 (Table 5). This acceptable criterion was applied in both rounds. The researcher, considered the difference between the levels of agreement or disagreement as less important than the fact that the participants agreed or disagreed with the competencies. The number of rounds were determined by the achievement of the above stated criterion for each item.

Table 4.3: Criteria of Median and Interquartile Range (IQR) (adapted from Punpataracheevin 2008)

Range of median	**Meaning of the criteria**
4.50-5.00	The opinions of the experts agree that the competency of End-of-Life nursing care in Kenya is the most significant
3.50-4.49	The opinions of the experts agree that the competency of End-of-Life nursing care in Kenya is more significant
2.50-3.49	The opinions of the experts agree that the competency of End-of-Life nursing care in Kenya is moderately significant
1.50-2.49	The opinions of the experts agree that the competency of End-of-Life nursing care in Kenya is less significant
1.00-1.50	The opinions of the experts agree that the competency of End-of-Life nursing care in Kenya is least significant

Interquartile Range (IQR)	Meaning of IQR
Less than or equal to 1.50	The expert opinion of competencies of End-of-Life nursing care in Kenya has achieved consensus
More than 1.50	The expert opinion of competencies of End-of-Life nursing care in Kenya has not achieved consensus

4.4. Selection and training of research assistants

Two research assistants at the level of Bachelor of Science in Nursing were recruited and taught on the purpose of the research, the objectives, how to administer the research tools and data collection techniques. Additionally, they were also trained on how to check the tools for completeness as well as, coding and data entry into the computer. During the training, confidentiality was also emphasized and the research assistants were directed to avoid coercion of participants especially in cases of unwillingness to continue with the study. During the study period, the research assistants were introduced to relevant persons from time to time as it were deemed necessary. The research assistants in partnership with the investigator collected the filled questionnaires.

4.5. Ethical considerations

Approval to conduct the study was gotten from the Kenyatta National Hospital/ University of Nairobi Ethics and Research Committee (KNH/UON-ERC) and National Commission for Science, Technology and Innovations (NACOSTI). For phase I, permission to access the study population was obtained from the research office within KNH. A written consent was obtained from all the participants while verbal consent was gotten from the key informant. The respondents who met the inclusion criteria were notified that their participation was voluntary and that they were free to withdraw from the study at will. The questionnaires were coded and the respondents were not required to indicate their names or any other form of identification. For phase II, the experts were in different locations as such written consent was obtained from each expert and questionnaires were hand delivered to each expert. Information provided was treated with utmost confidentiality and the respondents were made aware of this.

4.6. Research assumptions

In regards to the research with this sample of nurses, the assumptions pertaining to the EOLNC knowledge of nurses prior to the study were that nurses were likely to possess adequate knowledge because: a) It is possible that a nurse would have a basic understanding of EOLNC among this population due to broadcasting (television programs, movies, or news stories); b) exposure during clinical placement at the time of their training; or c) through individual experiences. Additionally, other assumptions being made were that identification of EOLNC core competencies would help enhance evidence-based practice in the hospitals in Kenya. This would consequently impact on the quality of EOLNC for patients and families.

4.7. Study limitations

The relatively low sample size in some of the specialized care units poses a challenge in generalization. The collection of data at two different points in time in the second phase is likely to have led to subject attrition. Therefore, the results of this study are limited to nursing professionals who work in large, academic, inpatient settings commonly referred to as national acute care hospitals in Kenya.

Response rates varied among the specialized nursing units, and those who responded to the survey may have been more likely to be interested in EOL care. The self-report method considered in this study could result in reporting bias particularly because the survey instrument did not measure actual competencies in EOL care but, rather, it assessed the perceived competencies.

The cross-sectional research design used in this study could have had some limitations such as, but not limited to: results being static and time bound and therefore did not give an indication of a sequence of events or reveal historical or temporal contexts. As such, the design only provides a snapshot of analysis so there is always the possibility that a study could have differing results if another time-frame had been chosen.

CHAPTER FIVE: RESULTS

5.0 Introduction

This chapter presents results of analyzed data in line with the research objective. The study was conducted in two phases, therefore this chapter describes the results in phase one and phase two in details. The results from phase I are tabulated in tables 5.1 to 5.31 and illustrated in figures 5.1 to 5.9. Results from phase II are tabulated in tables 5.32 to 5.42 and illustrated in figures 5.10 to 5.12. The chapter ends by presenting results from inferential analysis conducted on the information gathered on different variables in the study.

5.1. Results: Phase I

5.1.1. Nurses' Survey – Descriptive statistics

This was done by administration of questionnaires to 191 nurses working in Specialized Care units (SCUs) at Kenyatta National Hospital (KNH). The information from questionnaires was organized, coded, analysed and converted into quantitative reports for analysis using SPSS version 24. The analysed data was organized under headings that reflect the research objectives.

5.1.1.1. Response Rate

In the study, 191 questionnaires were issued to the respondents, with 174 filled and returned indicating a response rate of 91.1% which is quite suitable to make a finale for the study (table 5.1). According to Mugenda (2011) and Babbie (2004), it is appropriate for a descriptive study to have a response rate of above 50 %. The information gathered is adequate and acceptable to analyze and publish, with 60 % deemed as good and 70 % as very good.

Table 5.1: Nurses' survey response rate

Response	Frequency	Percent
Returned	174	87
Unreturned	17	13
Total	**191**	**100**

5.1.1.2. Demographic characteristics of the participants (n = 174)

5.1.1.2.1. Gender of the respondents

Female comprised 52.4% (n=88) of the participants with males constituting 47.6% (n=80) as shown in figure 5.1 below. This shows that the female nurses were more than the male nurses though the margin of the differences was small (4.8%).

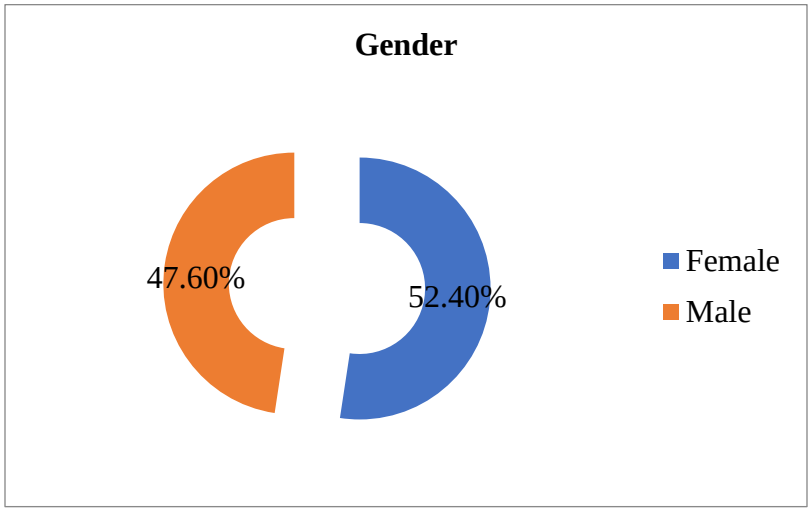

Figure 5.1: Gender

5.1.1.2.2. Age of the respondents

Table 5.2: Age of the respondents

Age	Frequency	Percentage
20_30	28	18.1
31_40	81	52.3
41_50	39	25.2
51_60	7	4.5
Total	**155**	**100.0**

From table 5.2 above, it can be seen that 52.3% (n=81) of the respondents were aged between 31-40 years while only 4.7% (n=7) were aged above 50 years. This implies that the study participants were mature nurses capable of responding to the study items.

Table 5.3: Age distribution of the respondents

Statistics	Age in completed years
Mean	38.81
Std. Deviation	7.56
Minimum	22
Maximum	56

Further, it can be seen in table 5.3 that the participants' ages ranged from 22 – 56 years. The average age of respondents in the sampling unit was 38.81 years, and the variation in the age in completed years for the respondents was 7.56. This shows that the respondents were advanced in age and therefore they were able to give objective responses to the items assessed.

5.1.1.2.3. Nursing/professional qualification

With regard to nursing qualifications, 66.9% (n=117) of the respondents were diploma holders (KRCHN) while 21.1% (n=37) were undergraduate (BScN) as reflected in the graph below (figure 5.2).

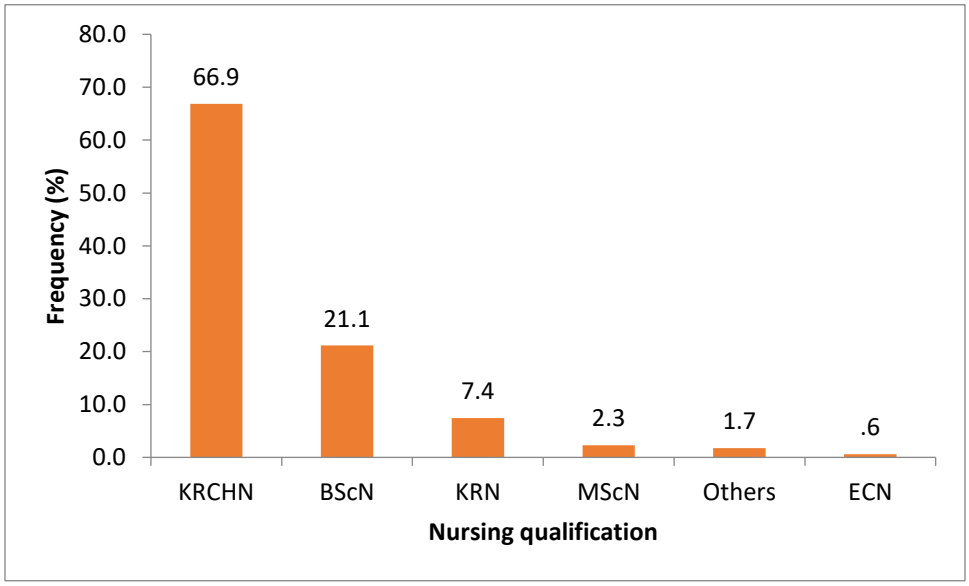

Figure 5.2: Nursing qualification frequencies

The qualifications above reflect the current trend in nursing education in Kenya where nursing has shifted from training certificate nurses to training diploma nurses and above.

5.1.1.2.4. Work station

Table 5.4: Workstations of the respondents

Work station	Frequency	Percentage
Intensive Care Unit	66	37.9
Accident &Emergency	45	25.9
Renal Unit	21	12.1
Burns Unit	17	9.8
Oncology ward	9	5.2
High Dependency Unit (HDU)	6	3.4
Oncology Clinic	6	3.4
Palliative Care Unit	4	2.3
Total	**174**	**100**

From table 5.4 above, it can be seen that 37.9% (n=66) of the respondents were working in the ICU. This could be explained by the fact that sampling was done proportionally to the total number of nurses in each of the SCUs. While the least number (2.3%) came from the PCU. This reflects the current scenario in Kenya where PC as an area of specialization is still at the infancy stage.

5.1.1.2.5. Duration worked in the unit

Table 5.5: Duration worked in the unit

Period worked in the unit	Frequency	Percentage
Less than 1 year	18	10.8
1.5_5.4	87	52.1
5.5_10.4	45	26.9
More than 10.5 years	17	10.2
Total	**167**	**100.0**

Regarding the duration that the respondents had worked in the current unit, 35.9%(n= 60) had worked in their respective units for between 1.5 to 5.4 years; and 10.2% (n=17) of the respondents had worked for more than 10.5 years (Table 5.5).

Table 5.6: Statistics on Duration worked in the unit

Statistics	Duration Worked in the Unit
Mean	4.924
Std. Deviation	3.773
Minimum	0.1
Maximum	15.0

The maximum number of years practiced in the respective work stations was 15.0 years while the minimum was 0.1 years; and an average of 4.9 years. The variation in the number of years that respondents had worked in their specific units was 3.8 (Table 5.6). It can be seen that a good number of the respondents had worked for less than 5 years in their current unit. This reflects the current trend in post-basic nursing education in Kenya which does not happen immediately post qualifying from a basic nursing programme.

5.1.1.2.6. Major role of the respondents

Table 5.7: Major role of the respondents (responses received n=173)

Major Role	Frequency	Percentage
Direct patient care	161	93.1
Administration	6	3.5
Nursing policy implementation	3	1.7
Health promotion/ Heath education	2	1.2
Teaching/ Clinical instruction	1	.6
Total	**173**	**100.0**

Major role for 93.1% (n=161) of the respondents was direct patient care; and 0.6% (n=1) participated in teaching/clinical instruction (Table 5.7). This finding implied that the respondents were conversant with the study items investigated and hence were a good sample unit to shade light on the current status pertaining to EOLNC.

5.1.1.2.7. Participants' experience of caring for the dying

Majority comprising of 92.9%(n=158) of the respondents indicated that they care for dying patients in their current practice while 7.1%(n=12) do not (Figure 5.3). This implies that the respondents were conversant with provision of care to the dying and therefore were able to respond to the items assessed.

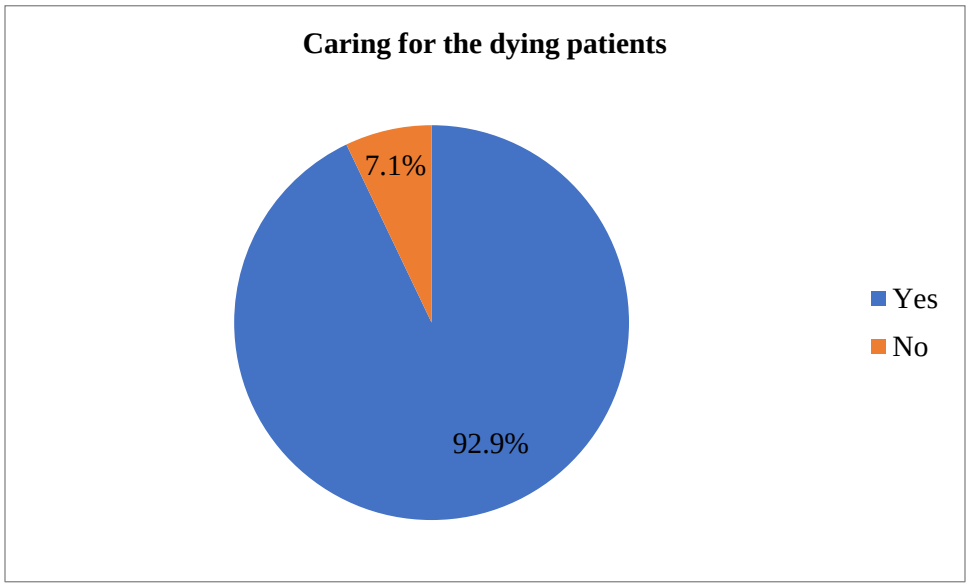

Figure 5.3: Experience of caring for dying patients

5.1.1.2.8. Years practiced nursing

Table 5.8: Years practiced nursing (responses received n=172)

Years practiced	Frequency	Percentage
Less than 5years	32	18.6
5.5-10	54	31.4
10.5-15	26	15.1
15.5-20	43	25.0
20.5-25	10	5.8
25.5-30	5	2.9
More than 30.5 years	2	1.2
Total	**172**	**100**

Regarding the years of practice in nursing: 31.4% (n=54) of the respondents had between 5.5 to 10 years; 25.0% (n=43) had between 15.5 to 20 years; 18.6% (n=32) had less than 5 years in nursing practice; 15.1% (n=26) had 10.5 to 15 years; 5.8% (n=10) had 20.5 to 25 years; 2.9% (n=5) had 25.5 to 30 years of experience; and a minority (1.2%; n=2) had more than 30.5 years of nursing experience (Table 5.8).

Table 5.9: Descriptive statistics for years practiced nursing

Statistics	Years Practiced Nursing
Mean	11.849
Std. Deviation	7.2046
Minimum	0.5
Maximum	33.0

The maximum number of years that the respondents had practiced nursing was 33.0 years and the minimum was 0.5 years and an average of 11.849 years (Table 5.9). The findings indicated that the respondents had more years of experience in general nursing but fewer years in their current work station. This reflects the journey of acquiring a post-basic training in an area of specialization

in Kenya. The training takes sometime following the basic qualification as one is required to have practiced as a nurse for at least two years following completion of the basic training before one can enroll for a post-basic training.

5.1.1.2.9. Professional courses undertake by participants

Table 5.10: Professional courses of the respondents (responses received n=153)

Professional Courses	Frequency	Percentage
Critical Care	87	56.9
Palliative care	18	11.8
Renal nursing	12	7.8
Accident and emergency	9	5.9
HIV and Aids	6	3.9
Oncology nursing	4	2.6
Pain management	4	2.6
Child Health	2	1.3
Stoma care	1	0.7
Diabetic care	1	0.7
Reproductive health	1	0.7
Others	8	5.2
Total	**153**	**100**

Regarding professional courses undertaken by the respondents to enhance their competencies, the following was noted: Critical care (56.9%; n=87), Palliative care (11.8%; n=18), Renal nursing (7.8%; n=12), Accident & Emergency (5.9%; n=9), and HIV & AIDS (3.9%; n=6) were the five top most courses undertaken. Other courses are as tabulated in table 5.10 below. Findings indicated that most had done a course related to critical care. This reflects the composition of the sample as majority were working in the critical care unit and hence they had undergone training a in critical care.

5.1.1.3. Nurses' perception on their level of preparedness to provide EOLNC

The study sought to establish nurses' perceived level of preparedness to provide EOLNC in Kenya. In order to investigate this, nurses' perception on their level of preparedness was examined under three dimensions: knowledge, attitudes, and practice. Results from this study are presented below.

5.1.1.3.1. Nurses' perception on their level of EOLNC Knowledge

Participants were asked to rate their perception regarding their level of knowledge using the 13-item Likert scale that was developed for this study. The scale asked the nurses about their perceived level of knowledge on EOL care topics. The perceived knowledge items were in Likert-type scale format with a 4-point scale with the following rating: 1=expert, 2=moderate, 3=some and 4=none. Nurses with higher scores on this subscale had lower perceived level of knowledge. The individual responses for each of the items of the level of knowledge scale were averaged.

Table 5.11: Nurses' level of EOLNC knowledge ("N" indicates responses received)

		Ratings [n (%)]					
	End-of-Life care topics	**Expert (1) n (%)**	**Moderate (2) n (%)**	**Some (3) n (%)**	**None (4) n (%)**	**N**	**Mean**
1.	Goals of EOLC.	5(2.9)	70(40.7)	71(41.3)	26(15.1)	172	2.5
2.	Pain management at EOL.	6(3.8)	60(37.7)	61(38.4)	32(20.1)	159	2.6
3.	Management of other symptoms (e.g., dyspnea, restlessness) at EOL	9(5.4)	41(24.4)	72(42.9)	46(27.4)	168	2.9
4.	Communication with patients/ families at EOL.	17(9.9)	66(38.6)	51(29.8)	37(21.6)	171	2.6
5.	Roles/ needs of family care-givers in EOL.	11(6.5)	64(37.6)	53(31.2)	42(24.7)	170	2.7
6.	Care of patients at the time of death.	14(8.2)	53(31)	65(38)	39(22.8)	171	2.8
7.	Care of the body after death.	17(10.1)	49(29.2)	64(38.1)	38(22.6)	168	2.7

8.	Ethical issues in EOL.	10(6.3)	62(39)	55(34.6)	32(20.1)	159	2.6
9.	The role of a nurse in a family that is grieving/ bereaved.	12(7.1)	58(34.3)	67(39.6)	32(18.9)	169	2.7
10.	Cultural factors that influence EOL care.	13(7.5)	65(37.6)	64(37)	32(18.5)	173	2.5
11.	Religious factors that influence EOL care.	10(5.8)	64(37)	71(41)	28(16.2)	173	2.5
12.	Referral to hospice/Palliative Care Unit.	15(8.7)	65(37.6)	63(36.4)	30(17.3)	173	2.6
13.	Home care for a dying patient.	20(11.6)	47(27.2)	74(42.8)	32(18.5)	173	2.7

***Scale 1= Expert; 2=Moderate; 3=Some; 4=None**

Respondents had the following opinions on their perception on preparedness to practice EOLNC as far as the level of knowledge on EOL nursing care was concerned. As indicated in table 5.11, the following were their responses to the items investigated. The results are presented based on the highest score in the Likert scale for each individual item: 40.7% (n=70) indicated their level of knowledge to be moderate regarding goals of EOLC; 38.4%(n=61) had moderate level of knowledge on pain management at EOL; 42.9% (n=72) had some level of knowledge on management of other symptoms (e.g., dyspnea, restlessness) at EOL; 38.6% (n=66) had moderate level of knowledge on communication with patients/ families at EOL; 37.6% (n=64) had moderate level of knowledge on the roles/ needs of family care-givers in EOL; and 38% (n=65) had some level of knowledge on care of patients at the time of death.

Additionally, 38.1% (n=64) of the respondents said that they had some level of knowledge on care of the body after death; 39% (n=62) had moderate level of knowledge on ethical issues in EOL; 39.6 % (n=67) had some level of knowledge on the role of a nurse in a family that is grieving/ bereaved; 37.6% (n=65) had some knowledge on cultural factors that influence EOL care; 41% (n=71) had some level of knowledge on religious factors the influence EOL care ; 37.6%(n=65)

had moderate level of knowledge on referral to hospice/Palliative Care Unit; and finally, 42.8% (n=74) had some level of knowledge on home care for a dying patient.

Table 5.12: Nurses' responses on their level of EOLNC knowledge ("N" indicates responses received)

	End-of-Life topics	High n (%)	Low n (%)	N	Mean
1.	Goals of EOLC.	75(43.6)	97(56.4)	172	2.5
2.	Pain management at EOL.	66(41.5)	93(58.5)	159	2.6
3.	Management of other symptoms (e.g., dyspnea, restlessness) at EOL	50(29.8)	118(70.3)	168	2.9
4.	Communication with patients/ families at EOL.	83(48.5)	88(51.4)	171	2.6
5.	Roles/ needs of family care-givers in EOL.	75(44.1)	95(55.9)	170	2.7
6.	Care of patients at the time of death.	67(39.2)	104(60.8)	171	2.8
7.	Care of the body after death.	66(39.3)	102(60.7)	168	2.7
8.	Ethics issues in EOL.	72(45.2)	87(54.7)	159	2.6
9.	The role of a nurse in a family that is grieving/ bereaved.	70(41.4)	99(58.5)	169	2.7
10.	Cultural factors that influence EOL care.	78(45.1)	96(55.5)	173	2.5
11.	Religious factors that influence EOL care.	74(42.8)	99(57.2)	173	2.5
12.	Referral to hospice/Palliative Care Unit.	80(46.3)	93(53.7)	173	2.6
13.	Home care for a dying patient.	67(38.8)	106(61.3)	173	2.7

***Scale 1= Expert; 2=Moderate; 3=Some; 4=None**

In order to determine the nurses' perception on their level of EOLNC knowledge, the number of responses that were reported as 'none' or 'some' were categorized as *low* while items that were reported to be 'moderate' or 'expert' were categorized as *high* level of knowledge. Also, individual responses for each item were averaged. Items for which the respondent left blank were eliminated. Therefore, the divisor for the mean was the number of items with valid responses.

Findings in table 5.112, indicated that more than half of the nurses scored more than 50% on each topic assessed an indication that the nurses perceived themselves to possess low level of EOLNC knowledge. Taking into consideration the mean value arrived at (mean=2.7), findings indicated that the nurses perceived themselves to have low level of EOLNC knowledge.

5.1.1.3.1.1. Extent of individual's EOLNC knowledgeability

Knowledgeability, which was assessed as a single item, results indicated that majority, comprising of 87.8% (n=144) of the respondents were not knowledgeable on EOLC while 12.2% (n=20) were knowledgeable (Table 5.13).

Table 5.13: Extent of EOLC knowledgeability (responses received n=164)

Extent of EOLNC Knowledgeability	Frequency	Percentage
Knowledgeable	20	12.2
Not Knowledgeable	144	87.8
Total	**164**	**100**

Findings indicated that majority of the respondents perceived themselves as not knowledgeable with a few of the respondents indicating that they were knowledgeable (Table 5.13). This reflects the current situation in Kenya where there is a gap regarding the amount of EOL care content in the basic nursing curricula.

5.1.1.3.2. Nurses' attitudes towards provision of EOLNC

5.1.1.3.2.1 Attitudes regarding the topic on personal effectiveness on provision of EOLNC

Table 5.14: Attitudes on the topic on personal effectiveness ("N" indicates responses received)

	Individual Effectiveness	Ratings [n (%)]			N	Mean
		Not at all effective n (%)	Somewhat effective n (%)	Effective n (%)		
1	Pain management	3(1.7)	93(53.8)	77(44.5)	173	2.4
2	Other symptoms management	7(4)	121(69.9)	45(26)	173	2.2

3	Communication with terminally ill patients	26(15.3)	101(59.4)	43(25.3)	170	2.1
4	Communication with family caregivers	26(15.1)	96(55.8)	50(29.1)	172	2.1
5	Instructions to family/caregiver on Managing the death event at home.	63(37.5)	89(53)	16(9.5)	168	1.7
6	Cultural issues in EOL care	68(39.5)	85(49.4)	19(11)	172	1.7
7	Overall EOL care for the terminally ill.	40(23.4)	97(56.7)	34(19.9)	171	2

When asked about their perception on their attitude towards provision of EOLNC, the respondents had the following opinions on their effectiveness as far as provision of EOLNC was concerned: 53.8% (n=93) cited that they were somewhat effective on pain management; 69.9% (n=121) considered their effectiveness on management of other symptoms as somewhat effective; 59.4% (n=101) indicated that on the item "communication with terminally ill patients" to be somewhat effective: 55.8% (n=96) felt that their "communication with family caregivers" was somewhat effective; 53% (n=89) rated themselves on instructions to family/caregiver on managing the death event at home as somewhat effective; and 49.4% (n=85) cited cultural issues in EOL care somewhat effective. When asked to rate their effectiveness on the on overall EOL care for the terminally ill 56.7%(n=97) cited their effectiveness as somewhat effective (Table 5.14). Taking into consideration the mean values arrived at using Likert scale with 7 items, respondents rated their attitudes as somewhat effective (mean = 2) an indication that the participants did not believe in themselves as far as provision of EOLNC was concerned.

5.1.1.3.2.2. Perception regarding institutional effectiveness on provision of EOLNC

Table 5.15: Attitudes on institutional effectiveness ("N" indicates responses received)

	Institutional Effectiveness	**Ratings [n (%)]**			**N**	**Mean**
		Not at all effective n (%)	**Somewhat effective n (%)**	**Effective n (%)**		

1	Pain management	3(1.7)	68(39.3)	102(59)	173	2.6
2	Other symptom management	5(2.9)	77(44.5)	91(52.6)	173	2.5
3	Communication with terminally ill patients	12(6.9)	99(57.2)	62(35.8)	173	2.3
4	Communication with family caregivers	16(9.3)	98(57)	57(33.1)	172	2.2
5	Support for family/caregiver in Managing the death event at home	48(28.4)	90(53.3)	30(17.8)	169	1.9
6	Cultural issues in EOL care	45(26.3)	88(51.5)	37(21.6)	171	1.9
7	Overall EOL care for the terminally ill	24(14)	101(59.1)	45(26.3)	171	2.1

The respondents had the following sentiments regarding institutional effectiveness on provision of EOLNC: 59% (n=102) found pain management to be effective; 52.6% (n=91) felt other symptom management was effective; 57.2% (n=99) cited communication with terminally ill patients as somewhat effective; 57% (n=98) deemed communication with family caregivers as somewhat effective; 53.3% (n=90) claimed that support for family/caregiver in managing the death event at home as somewhat effective; 51.5% (n=88) felt that the institution was somewhat effective in handling cultural issues in EOL care; and 59.1% (n=101) found that the effectiveness of the institution on overall EOL care for the terminally ill was somewhat effective (Table 5.15). Taking into consideration the mean values arrived at using Likert scale with 7 items, respondents rated their belief towards institutional effectiveness as somewhat effective (mean = 2) an indication that the participants did not believe that their institution was effective as far as provision of EOLNC was concerned.

5.1.1.3.2.4. Participants' believe regarding care of the dying

Believe regarding EOLC as shown in figure 5.4, is better now than 5 years ago was the opinion of 89.3% while 10.7% were of the opinion that EOLC is about the same as was 5 years ago.

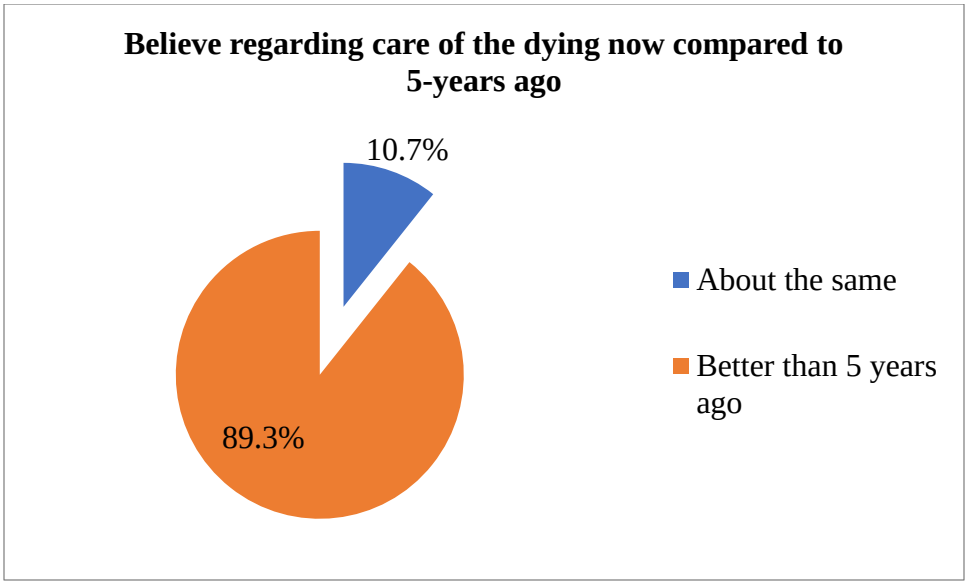

Figure 5.4: Belief regarding care of the dying now compared to 5-years ago

Despite the fact that the results highlighted major gaps as far as level of EOLNC knowledge and nurses' attitudes towards EOLNC was concerned, findings in figure 8 indicated that the nurses believed that there were some improvement regarding care of the dying. This could be attributed to the efforts that the NCK has put towards improvement of care for those with chronic illness by integrating PC content within the basic nursing programmes.

5.1.1.3.3. Nurses' perception of their practice skills

5.1.1.3.3.1. Participants' opinion on frequency of EOL care dilemmas

Table 5.16: Frequency of occurrence of EOL care dilemmas ("N" indicates responses received)

	Frequency of EOL care dilemmas occurring	Ratings [n (%)]			N	Mean
		Not Common n (%)	Somewhat Common n (%)	Common n (%)		
1	Preserving patient's choice and/or self-determination	81(47.9)	62(36.7)	26(15.4)	169	1.7

2	Use of advanced directives.	86(51.5)	52(31.1)	29(17.4)	167	1.7
3	Request for assisted suicide or euthanasia; Withholding/withdrawing therapeutically provided nutrition/hydration	125(73.5)	33(19.4)	12(7.1)	170	1.3
4	Terminating life sustaining therapies	123(71.5)	37(21.5)	12(7)	172	1.4
5	Legal issues at the end of life	110(64)	51(29.7)	11(6.4)	172	1.4
6	Panic of causing death by giving pain medication	96(55.8)	58(33.7)	18(10.5)	172	1.5
7	Uncertainty about the patient's prognosis	71(42)	74(43.8)	24(14.2)	169	1.7

Respondents were probed to give their opinion on the frequency of occurrence of EOL care dilemmas and gave the following responses (Table 5.16): 47.9% (n=81) rated that the dilemma on "preserving patient's choice/self-determination" was not common; 51.5% (n=86) indicated that dilemma surrounding "use of advanced directives" was not common; 73.5% (n=125) cited "request for assisted suicide, request for euthanasia, withholding/withdrawing medically provided nutrition/hydration" was not a common dilemma; 71.5% (n=123) noted that dilemma related to "discontinuing life sustaining therapies" was not common; 64% (n=110) found "legal issues at the end of life" not a common dilemma; 55.8% (n=96) rated "Fear of causing death by giving pain medication" was not common; and 43.8% (n=74) found "uncertainty about the patient's prognosis" somewhat common. Findings showed that the dilemmas investigated were not common in practice. This reflects the low level of knowledge pertaining to EOLNC which may have hindered the respondents from identifying the EOL care dilemmas.

5.1.1.3.3.2. Participants' experience regarding patient's request to end their life

Majority of the respondents, that is 77.9% (n=120) indicated that patients had not asked them for medication to end their life while a minority which comprised 22.1% (n=34) had received requests

from patients about medication to end his/her life (Figure 5.5). This implies that nurses are faced with some ethical-legal issues while providing EOLNC.

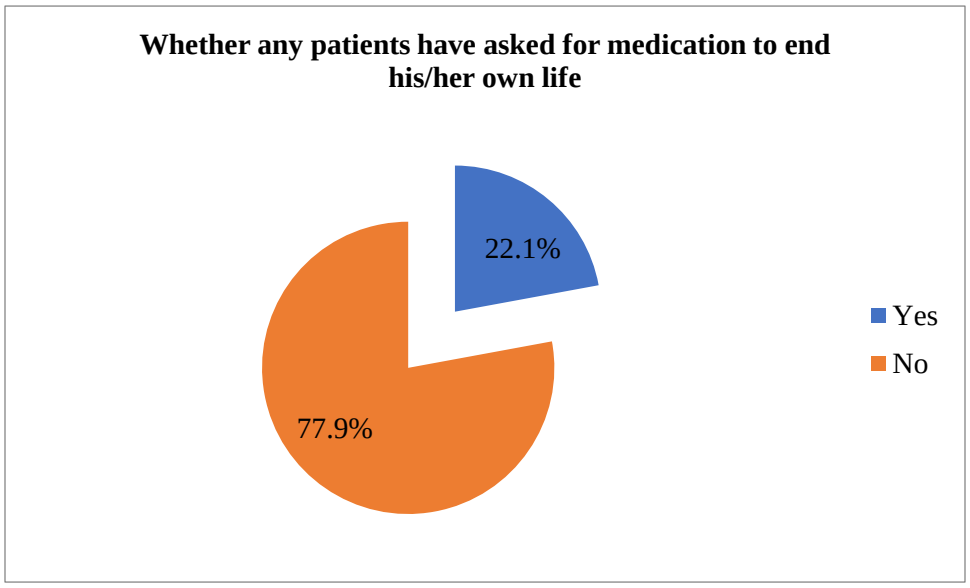

Figure 5.5: Response regarding patients request for medication to end his/her own life

5.1.1.3.3.4. Legalization of assisted suicide

Majority of the respondents that comprised 84.1% (n=143) were of the opinion that there should be no legalization of assisted suicide while 15.9%(n=27) were of the opinion that there should be legalization of assisted suicide (Figure 5.6). This implies that some of the nurses felt it would be good to consider legalization of assisted suicide.

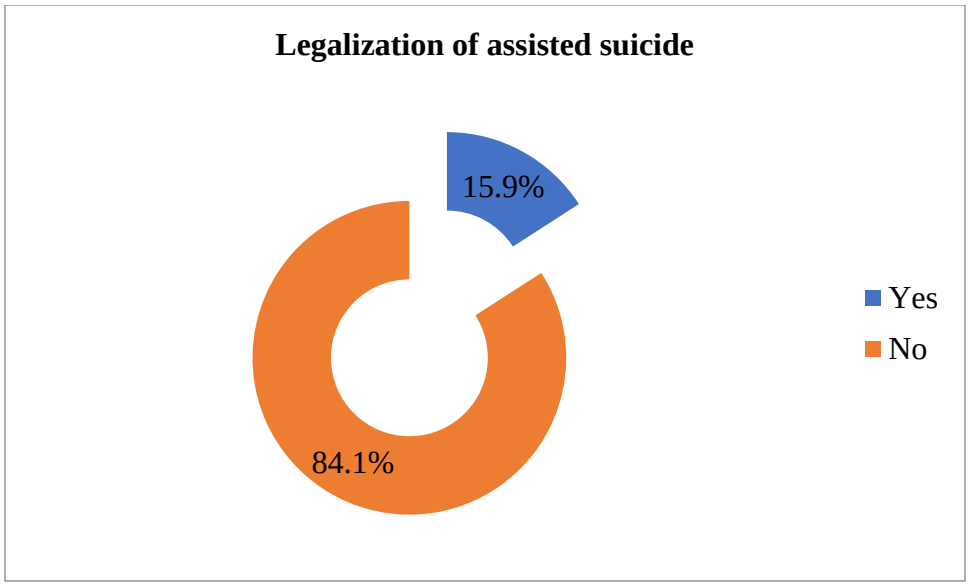

Figure 5.6: Opinion on legalization of assisted suicide

5.1.1.3.3.5. Legalization of euthanasia

Majority comprising of 74.6%(n=126) of the sample unit were not in favour of legalization of euthanasia whereas 25.4%(n=43) were in favour of legalization of euthanasia (Figure 5.7). This indicated that the nurses were divided regarding legalization of euthanasia.

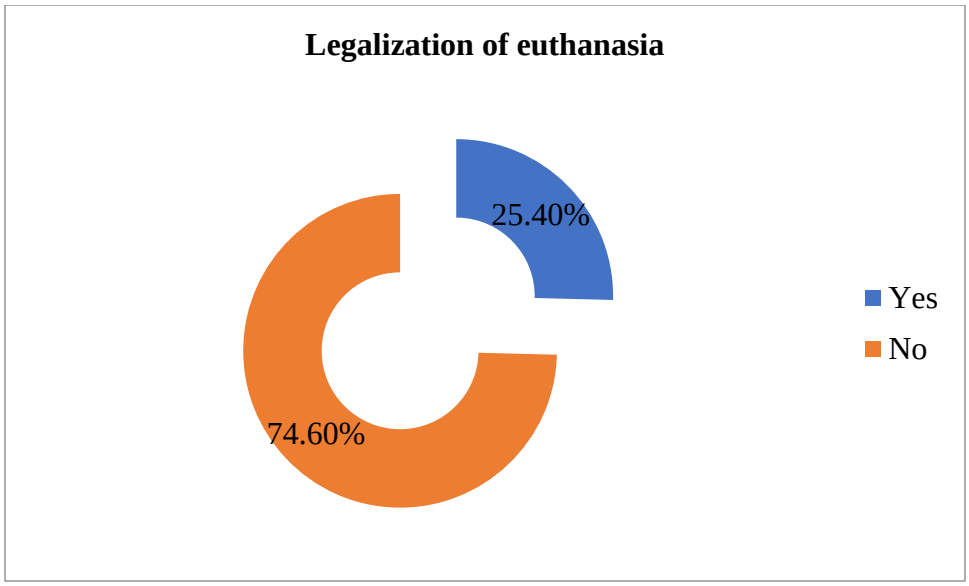

Figure 5.7: Opinion on legalization of euthanasia

5.1.1.3.3.6. Perceived barriers to providing good quality EOLNC

Table 5.17: Barriers to providing good quality EOLNC ("N" indicates responses received)

		Ratings (%)				
	Barriers to providing good quality EOLNC	**Not a barrier n (%)**	**Somewhat of a barrier n (%)**	**A barrier n (%)**	**N**	**Mean**
1	Lack of knowledge by HCPs	26(15.3)	67(39.4)	77(45.3)	170	2.3
2	Health care professional's' personal discomfort with death	29(17.1)	102(60)	38(22.4)	170	2
3	Avoidance of dying patients by HCPs	39(23.2)	79(47)	50(29.8)	168	2.1
4	HCPs fear of causing addiction by administering opioids for pain	31(18.3)	90(53.3)	48(28.4)	169	2.1
5	Patients' avoidance of death	45(26.3)	77(45)	49(28.7)	171	2

6	Family member's avoidance of death.	37(22.2)	75(44.9)	55(32.9)	167	2.1
7	Cultural factors influencing end-of-life care	30(17.9)	77(45.8)	61(36.3)	168	2.2
8	Patients'/families 'fear of addiction	47(27.8)	73(43.2)	49(29)	169	2
11	Legal restrictions placed on HCPs in prescribing opioids for pain	29(17.1)	75(44.1)	66(38.8)	170	2.2
12	Lack of continuity of EOLC across settings	26(15.4)	68(40.2)	75(44.4)	169	2.3

When respondents were probed to rate the extent of barrier the following items were to providing good EOL care, they gave the following responses: 45.3% (n=77) found "*Lack of knowledge by health care professionals*" as a severe barrier; 60% (n=102) felt "*Health care professional's personal discomfort with death*" somewhat a barrier; 47% (n=79) deemed "*avoidance of dying patients by health care professional's*" somewhat a barrier; 53.3% (n=90) cited "*health care professional fear of causing addiction by administering pain medications*" somewhat a barrier; and 45% (n=77) felt "*patients' avoidance of the topic on death*" somewhat a barrier.

Almost half of (44.9%; n=75) the sample unit claimed "*family member's avoidance of topic on death*" was somewhat a barrier; 45.8% (n=77) felt that "*cultural factors influencing end-of-life care*" somewhat a barrier; 43.2% (n=73) found "*patients'/families' fear of addiction*" somewhat a barrier; 44.1% (n=75) found "*legal restrictions placed on health care professionals in prescribing pain medication*" to be somewhat a barrier; and 44.4% (n=75) deemed "*lack of continuity of care across settings"* a severe barrier (Table 5.17). The mean from the ten items was 2.1 an indication that the items listed were barriers to provision of good quality EOLNC.

5.1.1.4. Nurses' perceived EOLNC training needs

The current study sought to identify nurses' perceived EOLNC training needs in Kenya. Results from this study are presented below.

Table 5.18: Adequacy of the basic nursing education program on EOLNC content ("N" indicates responses received)

	EOLNC content in the basic nursing education program	Ratings n (%)			N	Mean
		Not adequate	Somewhat adequate	Adequate		
1	Goals of PC	72(42.1)	69(40.4)	30(17.5)	171	1.8
2	Pain management at the EOL	68(40.7)	60(35.9)	39(23.4)	167	1.8
3	Other symptoms management	40(23.7)	72(42.6)	57(33.7)	169	2.1
4	Communication with patients/families at EOL	51(36.1)	81(47.9)	27(16)	169	1.8
5	Role of family caregiver in EOL	69(40.6)	69(40.6)	32(18.8)	170	1.8
6	Care of patients at time of death.	60(35.5)	72(42.6)	37(21.9)	169	1.9
7	Ethical issues in EOL care	81(47.9)	63(37.3)	25(14.8)	169	1.7
8	Overall content on EOL care	76(44.7)	67(39.4)	27(15.9)	170	1.7

Respondents when probed to provide their views on the adequacy of the basic nursing education program on EOL care had the following responses: 42.1% (n=72) indicated that the content on " *goals of palliative care"* was not adequate; 40.7% (n=68) were of the opinion that "*pain management at the end-of-life*" content was not adequate; 42.6% (n=72) indicated that content on "*other symptoms management (i.e. dyspnea restlessness)*" was somewhat adequate; and 47.9% (n=81) reported that content on communication with patients/families at EOL was somewhat adequate.

As shown in table 5.18, the sample unit was divided in their opinions on the adequacy of "*role/needs of family caregiver in end-of-life care*" content in the basic nursing program with 40.6% (n=69) rating the program as not adequate, whereas 40.6% (n=69) rated it somewhat adequate. 42.6% (n=72) deemed content on "the care of patients at time of death" somewhat adequate; 47.9% (n=81) found "*ethical issues in end-of-life care*" not adequate; and 44.7% (n=76) found "*overall content on end-of-life care*" not adequate. Taking into consideration the mean of 1.8 from the 8 items assessed, findings indicated that the basic nursing education program was not adequate in preparation of nurses for provision of EOLNC.

A chi square test for independence was conducted to evaluate whether there are correlations among participants' perception of overall content in EOL care versus the sub-dimensions' of EOL care content. Overall content in EOL care and sub-dimensions of EOL care content are not related (Pearson chi square test, p=0.000). Thus there was no association in the scoring of the EOL care content by the participants. The lack of association between overall content of EOL care and the sub-dimensions of EOL care content indicated that there is more that would contribute to the overall EOL care content other than the 8 items that were evaluated for this study. For instance, mode of delivery of the content.

5.1.1.4.1. Nurses' believe on importance of integration of EOLNC content to basic nursing program

Table 5.19: Participants' believe on importance of EOLC content to basic nursing program (responses received n=169)

Nurses' perception on importance of integration EOLC content to basic nursing education	Frequency	Percentage
Not important	13	7.7
Important	156	92.3
Total	**169**	**100.0**

Majority of the sample unit comprising of 92.3% (n=156) were of the opinion that it is important for EOLNC content to be included in basic nursing education program with 1.2%(n=2) noting that it was not important (Table 5.19). This finding reflects the gap observed in the hours allocated for EOL care content in the curricula for basic nursing education programmes in Kenya.

5.1.1.4.2. Participants' experience of caring for a dying patient while in school

Results suggest that majority of the respondents 87.5% (n=152) cared for a dying patient while in nursing school (student) whereas 12.5% (n=22) had a contrary opinion (Figure 5.8). Findings indicated that the nurses had provided care to a dying patient while in school supporting the importance of integrating EOLC content into the basic nursing education programmes.

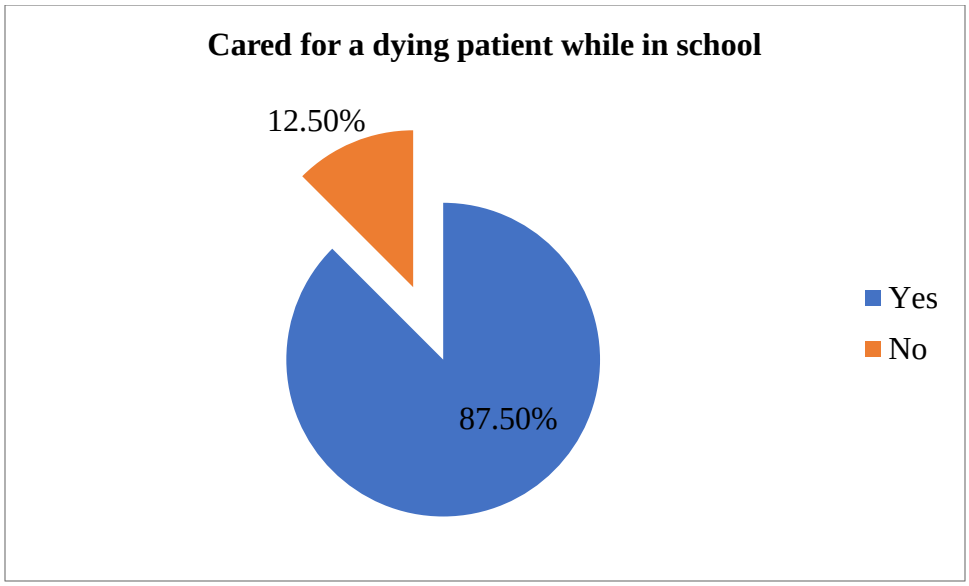

Figure 5.8: Cared for a dying patient while in school

5.1.1.4.3. Special skills required by nurses to provide good quality EOLC

Table 5.20: Special skills at EOL (responses received n=173)

Special skills at EOL	Frequency	Percentage
Counselling	62	35.8
General knowledge of EOLC	26	15.0
Palliative care training	24	13.9
Training on adequate pain management	13	7.5
Effective communications	11	6.4
Course in psychology	9	5.2
Symptom management	5	2.9
Care for a dying patient	5	2.9
Advanced cardiac life support	2	1.2
Listening	2	1.2
Empathy	2	1.2
Medical Legal issues	2	1.2
Ethical issues	2	1.2

Trauma	1	0.6
ETTAT	1	0.6
Advanced course on first aid & basic life support.	1	0.6
Early Quality CPR	1	0.6
Management of terminally ill.	1	0.6
Debriefing	1	0.6
Oncology nursing	1	0.6
Spiritual care	1	0.6
Total	173	100

The respondents indicated that the first four most preferred special skills required by nurses to provide good quality EOLC were: Counselling (33.9%; n=62), General knowledge on EOLC (14.2%; n=26), Palliative care training (13.1%; n=24), and Training on pain management (7.1%; n=13) (Table 5.20). Counselling skills were ranked highest which reflects the dynamic of EOLNC where there is need for effective communication within the multidisciplinary team.

5.1.1.5. Additional information on EOL nursing care

Table 5.21: Additional information from respondents (responses received n=37)

Any Additional Information	Frequency	Percentage
EOL will be important in tertiary and secondary health care institutions.	5	13.5
Debriefing training	4	10.8
To train relatives on EOLC and have proper homes for patients.	4	10.8
Medical legal laws to be explored fully.	3	8.1
Cultural beliefs (training).	3	8.1
Palliative care (training)	3	8.1
EOL should be in the nursing curriculum	3	8.1
Legalization of Euthanasia	3	8.1
Patient & other stakeholders' involvement	2	5.4

Prepare for acceptance of death	2	5.4
God takes life	1	2.7
Effective pain management	1	2.7
Primary Nursing (include EOL components)	1	2.7
Encourage writing a will	1	2.7
Increase sedation & painkillers like bhang	1	2.7
Total	**37**	**100**

The respondents were requested to write any additional information on EOLC, they had an array of additional information as shown in table 5.21. This information was coded and categorized then presented in the table below. The top most common opinions were: EOLC will be important in tertiary and secondary health care institutions (13.5%; n=5); to train relatives on EOLC and have proper homes for patients (10%; n=4); debriefing training (10%; n=4); medical legal laws to be explored fully, training on cultural issues, training on palliative care, EOL should be in the nursing curriculum and legalization of euthanasia (8.1%; n=3).

5.1.2 Nurses' Survey - Inferential Statistics

Inferential statistical analysis deduces properties of a population, for instance by testing hypotheses. Statistical inference is the process of utilizing data analysis to infer properties of an underlying probability distribution. Inferential statistics takes data from a sample and makes deductions about the larger population from which the sample was drawn. As such, we need to have confidence that our sample accurately reflects the population. This requirement affects the entire process of analysis. Hence, normality test was carried out to ascertain the aforementioned requirement.

5.1.2.1 Normality test

The above mentioned test was conducted to assess whether the sample was obtained from a normally distributed population. This is crucial because, violation of this assumption suggests that the study results are likely to give biased estimates of the parameters (Maltby, Day and Williams 2007). Kolmogorov-Smirnov and Shapiro-Wilk tests were used to test the normality of dependent

variables (nurses' perceived level of preparedness to practice and nurses' perceived training needs). As stated below, the null hypothesis in the Kolmogorov-Smirnov and Shapiro Wilk tests of normality is that the data for the variable is normally distributed while the alternative hypothesis is that data is not normally distributed.

The most favorable outcome for this test is to fail to reject the null hypothesis. The tests fail to reject the hypothesis of normality when the p-value is greater than or equal to 0.05. The decision rule is such that fail to reject H_0 if p value is >0.05 alpha level otherwise reject H_0 if p value is <0.05 alpha level. From the Shapiro-Wilk test conducted, the P- value for nurses' preparedness to practice EOLNC and nurses' perceived training needs was 0.584 and 0.482 respectively (Table 5.22). Therefore, we fail to reject the null hypothesis an indication that the data was normally distributed. Further, an autocorrelation test was conducted.

Table 5.22: Statistics for Normality tests

Tests of Normality						
	Kolmogorov-Smirnov[a]			**Shapiro-Wilk**		
	Statistic	**df**	**Sig.**	**Statistic**	**df**	**Sig.**
Nurses' perceived level of preparedness to practise	0.276	172	0.340*	0.828	172	0.584
Nurses' perceived training needs	0.243	172	0.216	0.871	172	0.482
a. Lilliefors Significance Correction						
*. This is a lower bound of the true significance						

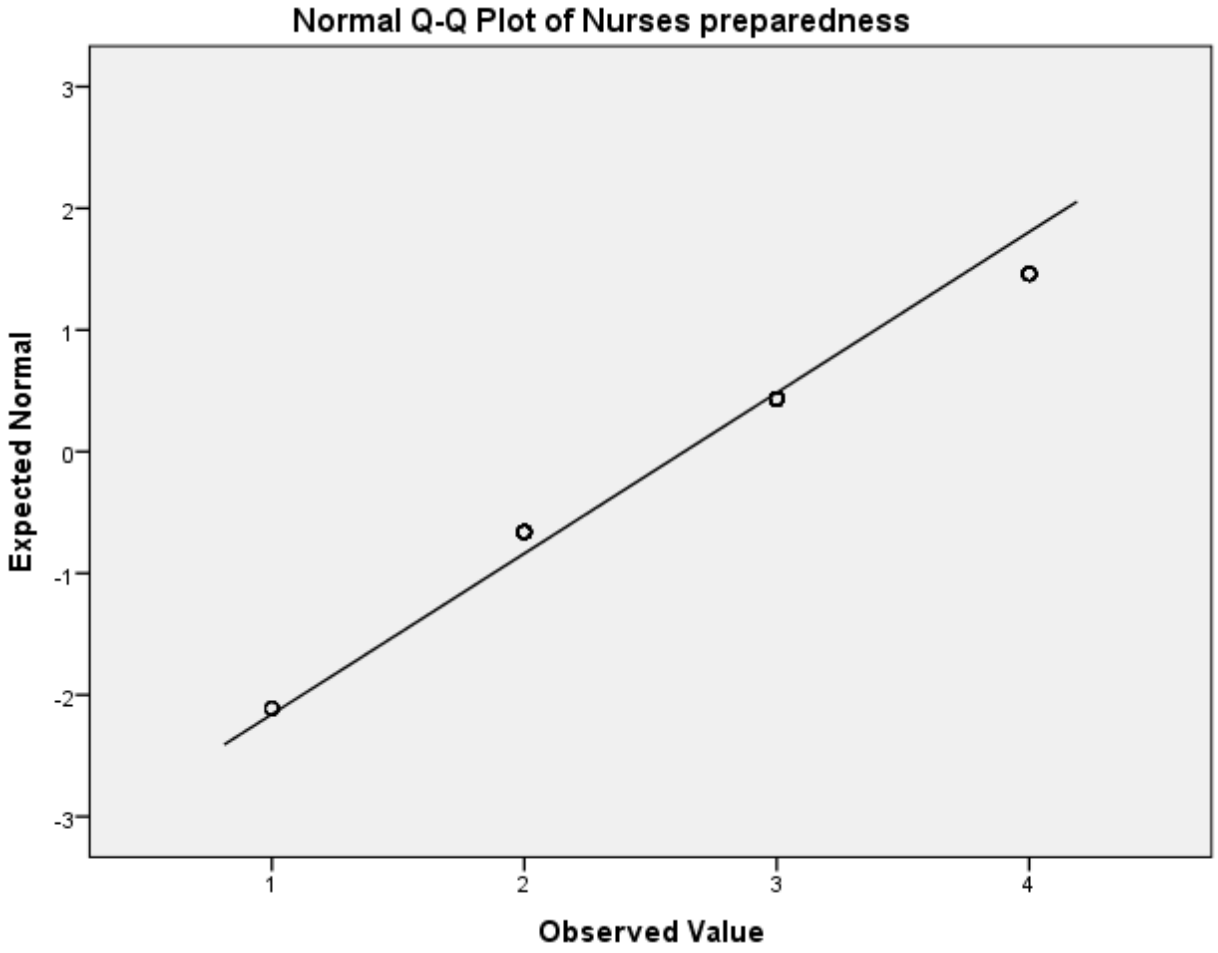

Figure 5.9: Q-Q plot of nurses' perceived level of preparedness to provide EOLNC

5.1.2.2 Test for Autocorrelation

The test for autocorrelation was examined utilizing the Durbin-Watson test which shows the degree of similarity between the values of the same variables. Presence of autocorrelation in data is an indication that the successful error terms are correlated and thus the regression model is "ailing" (Maltby, Day, & Williams, Introduction to Statistics for Nurses, 2007) and hence there is a possibility of multicollinearity. The results shown indicated that the Durbin-Watson's value is 1.628 (Table 5.23) which is within the acceptable range (1.5 to 2.5) and hence there was no

presence of autocorrelation in the data. In the absence of autocorrelation as shown in table 5.23, it therefore meant that the data was reliable for additional analysis.

Table 5.23: Statistics for Durbin-Watson test

Model Summary	
Model	Durbin-Watson
1	1.628
a. Predictors: (Constant), Work station	
b. Dependent Variable: nurses' perceived level of preparedness to provide EOLNC and nurses' perceived training needs in EOLNC	

5.1.2.3 Relationship between work station and nurses' perceived level of preparedness to provide EOLNC

5.1.2.3.1. Relationship between work station and perceived level of knowledge on EOLNC

To establish if there was a relationship between work station and nurses' perceived level of knowledge to provide EOLNC, cross tabulation was done.

Table 5.24: Cross-tabulation for work station and knowledge

Work station	**Knowledge**				**N**
	Expert (1) n (%)	**Moderate (2) n (%)**	**Some (3) n (%)**	**None (4) n (%)**	
Intensive Care Unit	3(4.5)	22(33.3)	30(45.5)	11(16.7)	66
High Dependency Unit	0(0)	1(16.7)	3(50)	2(33.3)	6
Renal Unit	1(4.8)	5(23.8)	9(42.9)	6(28.6)	21
Oncology Ward	1(11.1	4(44.4)	3(33.3)	1(11.1)	9
Accident & Emergency	1(2.2)	10(22)	34(75.6)	0(0)	45
Oncology Clinic	1(16.7)	2(22)	2(33.3)	1(16.7)	6
Palliative Care Dept.	1(25)	3(75)	0(0)	0(0)	4
Burns Unit	0(0)	4(23.5)	10(58.8)	3(17.6)	17

The results showed that respondents from three of the eight work stations perceived themselves to be possessing high level of EOLNC knowledge. These were palliative care department (100%; n=4); oncology ward (55.5%; n=5) and oncology clinic (50%; n=3). The other five departments had low scores on perception of the nurses on their level of EOLNC knowledge. Specifically, ICU (62.2%; n=41); HDU (83.3%; n=5); renal (71.5%; n=15); A&E (75.6%; n=34); and Burns unit (76.5%; n=13). (Table 5.24).

There was particularly no major difference regarding nurses' perception of their level on EOLNC knowledge. However, the respondents working in palliative care department possessed a higher level of EOLNC knowledge than their colleagues as all the nurses in this department rated their level of knowledge as high on all the items assessed.

5.1.2.3.2. Relationship between nurses' perceived attitudes and work station

Investigations regarding the respondents' attitudes towards EOLNC were reported in table 5.25 below.

Table 5.25: Cross-tabulation for work station and attitude

Work station	Attitude			
	Not at all effective n (%)	Somewhat effective n (%)	Effective n (%)	N
Intensive Care Unit	2(3)	50(75.8)	14(21.2)	66
High Dependency Unit	0(0)	3(50)	3(50)	6
Renal Unit	0(0)	14(66.7)	7(33.3)	21
Oncology Ward	0(0)	6(66.7)	3(33.3)	9
Accident & Emergency	1(2.3)	42(95.5)	1(2.3)	44
Oncology Clinic	0(0)	3(50)	3(50)	6
Palliative Care Dept.	0(0)	1(25)	3(75)	4
Burns Unit	0(0)	15(88.2)	2(11.8)	17

Results showed that more than half of the respondents (>60%) from six out of the eight work stations investigated agreed that their attitudes were somewhat effective as follows: A & E 95.5% (n=42), Burns unit 88.2% (n=15), ICU 75.8% (n=50), renal unit 66.7% (n=14), and finally oncology ward 66.7% (n=6). Only one work station that had a majority of the respondents (>60%) indicating that their EOLNC attitudes were very effective, the palliative care department (75%; n=3). Notably, two other work stations had 50% of the respondents indicating that their EOLNC attitudes were very effective. Namely, HDU (n=3) and oncology clinic (n=3) (Table 5.25). Therefore, majority of the respondents (75%) felt that their EOLNC attitudes were not appropriate as was indicated by the high scoring in the somewhat effective response.

Consequently, differences existed in the rating of EOLNC attitudes by the respondents. Three (37.5%) work stations of the eight investigated had more than 50% of the respondents indicating that their EOLNC attitudes were very effective. The difference that existed in the scoring of EOLNC as tabulated in table 5.25 could not be attributed to a particular work station.

5.1.2.3.3. Relationship between nurses' perceived practice skills and work station

Table 5.26: Cross-tabulation for work station and practice

Work station	Practice				N
	Strongly Disagree n (%)	Disagree n (%)	Agree n (%)	Strongly Agree n (%)	
Intensive Care Unit	2(3)	58(87.9)	6(9.1)	0(0)	66
High Dependency Unit	0(0)	6(100)	0(0)	0(0)	6
Renal Unit	1(4.8)	16(76.2)	4(19)	0(0)	21
Oncology Ward	0(0)	9(100)	0(0)	0(0)	9
Accident & Emergency	0(0)	42(93.3)	2(4.4)	1(2.2)	45
Oncology Clinic	0(0)	5(83.3)	1(16.7)	0(0)	6
Palliative Care Dept.	0(0)	2(50)	2(50)	0(0)	4
Burns Unit	0(0)	17(100)	0(0)	0(0)	17

Findings from table 5.26 below, indicated that the respondents had inadequate EOLNC practice skills. This is so because, only one work station (12.5%) out of the eight that were investigated had 50% (n=2) of the respondents agree with the items in the practice dimension. These were respondents from the palliative care department. Otherwise, more than 50% of the respondents from the eight work stations disagreed with the items examining the EOLNC practice skills.

Interestingly, all the respondents from three work stations (37.5%) disagreed with the EOLNC practice skills examined. Namely, HDU (N=6), oncology ward (N=9), and burns unit (N=17). Of the remaining five work stations, four (80%) had a majority of the respondents (>60%) disagreeing with the EOLNC practice skills' items investigated. Precisely, A & E (93.3%; n=42), ICU (90.9%; n=60), oncology clinic (83.3%; n=5), and finally, renal unit (81%; n=17). The PC department had 50% of the respondents disagree with the EOLNC practice skills' items that we assessed.

So, there was negligible difference that was noted with the scoring of the EOLNC practice skills by the respondents from different work stations. There was similar scoring by more than 50% of the respondents from all the work stations on the EOLNC items investigated. This was an indication that there was no particular relationship between work station and EOLNC practice skills.

Finally, the study sought to explore if a relationship existed between work station and nurses' perceived level of preparedness to provide EOLNC. Results showed that there were no remarkable differences between work station and nurses' perceived level of preparedness to provide EOLNC and as such, there was no relationship between the two. However, the differences in scoring between respondents from different work stations and nurses' perceived level of preparedness to provide EOLNC was not examined for statistical significance as this was not the objective for the current study.

5.1.2.4 Relationship between work station and nurses' perceived EOLNC training needs

To establish if there was a relationship between work station and nurses' perceived training needs for EOLNC, cross tabulation was done.

Table 5.27: Cross tabulation for work station and nurses' perceived training needs

Work station	Nurses perceived training needs (Adequacy of basic nursing program)			
	Not Adequate n (%)	Somewhat Adequate n (%)	Adequate n (%)	N
Intensive Care Unit	11(16.9)	41(63.1)	13(20)	65
High Dependency Unit	2(33.3)	3(50)	1(16.7)	6
Renal Unit	1(5)	13(65)	6(30)	20
Oncology Ward	2(22.2)	4(44.4)	3(33.3)	9
Accident & Emergency	31(72.1)	11(25.6)	1(2.3)	43
Oncology Clinic	0(0)	4(66.7)	2(33.3)	6
Palliative Care Dept.	3(75)	0(0)	1(25)	4
Burns Unit	8(47.1)	9(52.9)	0(0)	17

From the results, most respondents indicated that the basic nursing program adequately covered knowledge content on EOLNC. Precisely, all the respondents working in the oncology clinic indicated that the content was adequate (N=6). Adequacy of the EOLNC knowledge content in the basic nursing program was also supported by respondents working in renal unit (95%; n=19); ICU (83.1%; n=54); oncology ward (77.7%; n=7); HDU (66.7%; n=4); and burns unit (52.9%; n=9) (Table 5.27).

However, this was not the case for respondents who work in palliative care department as 75% (n=3) of them indicated that the EOLNC knowledge content in the basic nursing program was not adequately covered. The same was reported by respondents working in the accident and emergency department (72.1%; n=31). Hence, from table 28 below, the results revealed that majority of the participants agreed that the basic nursing program did not adequately cover content regarding EOLNC. This explains the results presented earlier which indicated that the respondents had inadequate knowledge on EOLNC.

In conclusion, findings indicated that there was no particular pattern of scoring by the respondents from the different work stations. Hence, work station was not indicated as a factor regarding training needs in EOLNC as most of the respondents irrespective of the work station indicated that the basic nursing program had inadequate coverage of knowledge on EOLNC. Nevertheless, the differences in scoring between respondents from different work stations and nurses' perceived EOLNC training needs was not examined for statistical significance as this was not the objective for the current study.

5.1.2.5 Relationship between nurses' perceived level of preparedness to provide EOLNC and perceived EOLNC training needs

Having established that the data generated was normally distributed and that a relationship existed between nurses' perceived training needs in EOLNC and nurses' perceived level of preparedness to provide EOLNC, a correlation test, specifically, Pearson correlation test which is a parametric test was done. The rationale for the parametric test was based on the fact that the data being tested for correlation was normally distributed which is a characteristic required while conducting parametric tests (Maltby, Day, & Williams, Introduction to Statistics for Nurses, 2007).

Correlation tests examine the strength of the linear relationship between two variables and the correlation coefficients range from -1.0 (a perfect negative correlation) to positive 1.0 (a perfect positive correlation). Maltby and colleagues (2007), indicated that the closer correlation coefficients get to -1.0 or 1.0, the stronger the correlation and vice versa. Ordinal or ratio data (or a combination) must be used. This study wanted to test the following hypothesis: a) Ho: There is no statistically significant relationship between nurses' perceived level of preparedness to provide EOLNC and nurses' perceived EOLNC training needs; and b) Ha: There is a statistically significant relationship between nurses' perceived level of preparedness to provide EOLNC and nurses' perceived EOLNC training needs. The statistical hypothesis test for this p-value is to reject ($p < 0.05$) or fail to reject ($p > 0.05$) the null hypothesis. A Pearson's correlation was run to determine the relationship between 174 nurses' perceived level of preparedness to provide EOLNC and nurses' perceived EOLNC training needs.

Table 5.28: Correlation statistics on nurses' perceived level of preparedness & nurses' training needs

Correlations			
		Nurses' perceived level of preparedness to provide	Nurses' perceived EOLNC training needs
Nurses' perceived level of preparedness to provide	Pearson Correlation	1	
	Sig. (2-tailed)		
	N	171	
Nurses' perceived EOLNC training needs	Pearson Correlation	.689**	1
	Sig. (2-tailed)	0.001	
	N	169	171
**. Correlation is significant at the 0.01 level (2-tailed).			
*. Correlation is significant at the 0.05 level (2-tailed).			

My results revealed that there was a statistically significant relationship (p=0.001) (Table 5.28). So, the null hypothesis was rejected as it was established that there was a statistically significant relationship between nurses' perceived level of preparedness to provide EOLNC and nurses' perceived EOLNC training needs. The direction of the relationship is strong positive (perceived training needs and nurses' perceived level of preparedness to practice are positively correlated), which meant that these variables increase together (r = 0.689). The existence of strong positive relationship between variables however does not necessarily mean that one causes the other. The likelihood of hidden or intervening variables should always be factored in.

To determine the relationship between nurses' perceived EOLNC training needs and nurses' perceived level of preparedness to provide EOLNC, a simple linear regression was performed based on the model below:

$$Y = \beta_0 + \beta_1 X_1 + e \quad \text{..... (i)}$$

Where: -

Y = nurses' perceived level of preparedness to provide EOLNC

β_0= Constant, showing nurses' perceived EOLNC training needs in the absence of the factors

B1-β2= Regression Coefficients

X_1= Nurses perceived EOLNC training needs

ε =Error Term

5.1.2.5.1 Coefficient of Determination

The above test explains how much variability of one factor can be caused by its relationship to another factor. It tells us the proportion of the variation in the dependent variable (Y) than can be explained by the variation in the independent variable (X). In the context of my study, nurses' perceived EOLNC training needs (Y) influenced nurses' perceived level of preparedness to provide EOLNC (X). Coefficient of determination is symbolized by R^2 since it is square of the coefficient of correlation symbolized by *R*.

R is the measure of the quality of prediction of the dependent variable. As can be seen in table 31 below, R is 0.378 which shows a moderately good level of prediction. The R Square, is the proportion of variance in the dependent variable that can be expounded by the independent variables. The value 0.143 showed that our independent variables explain 14.3% of the variability of our dependent variable (Table 5.29).

Table 5.29: Statistics on Coefficient of Determination

Model Summary - Statistics				
Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.378[a]	.143	.138	.70056
a. Predictors: (Constant), Nurses perceived training needs				

It is important to note that before performing the coefficient of determination, there must be a confirmation that a relationship exists between X and Y. For my study, this was documented earlier in the section on correlation which confirmed the existence of the relationship (Table 5.29). Further to the performance of the coefficient of determination and explaining the relationship between

variable X and Y, the overall significance of the model was tested. Therefore, ANOVA for regression was done to establish the overall significance of the model.

5.1.2.5.2 Overall Significance of the study Model

The F-test of the overall significance relates a model with no predictors to the model specified for the study. The *F*-ratio in the **ANOVA** table examines whether the overall regression model is a good fit for the data. Table 5.30 below indicates that the independent variables statistically significantly predict the dependent variable, F (1, 173) = 328.618, $p \leq 0.001$. This meant that the regression model was a good fit of the data.

Table 5.30: Statistics for overall significance of the study model

ANOVA[a]						
Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	14.045	1	14.045	28.618	.000[b]
	Residual	84.415	172	.491		
	Total	98.460	173			
a. Dependent Variable: Nurses' perceived level of preparedness						
b. Predictors: (Constant), Nurses' perceived training needs						

5.1.2.5.3 Regression Coefficients

Finally, after ascertaining that: a) there was a statistically significant relationship between nurses' perceived EOLNC training needs and nurses' perceived level of preparedness to provide EOLNC; b) the nature of the relationship was strong positive; and c) that the regression model was a good fit for the data, regression coefficient was performed.

Table 5.31: Statistics for Regression Coefficients

Coefficients[a]				
Model	Unstandardized Coefficients	Standardized Coefficients	t	Sig.

		B	Std. Error	Beta		
1	(Constant)	1.875	.151		12.411	.000
	Nurses' perceived training needs	.428	.080	.378	5.350	.000
a. Dependent Variable: Nurses' perceived level of preparedness						

The findings on the individual coefficients shown revealed that nurses' perceived EOLNC training needs significantly influenced nurses' perceived level of preparedness to provide EOLNC (5.350, PV≤0.001) at 5% level of significance. Nurses' perceived level of preparedness to provide EOLNC = 1.875 + 0.428 Nurses' perceived EOLNC training needs (Table 5.31).

5.1.3. Summary of Phase I results

The study sought to find out the current state of nurses' perceived level of preparedness to provide EOLNC. The survey questionnaire yielded 91.1% response rates. The study identified three dimensions within the nurses' perceived level of preparedness domain, comprising a total of 36 items interrelated to care of individuals who are at/or nearing their end of life, including knowledge (15 items), attitudes (14 items), and practice (16 items). The mean scores of all items varied across different dimensions, an indication that the participants had varied opinions concerning their preparedness to provide EOLNC. In the knowledge category, the mean scores for all items was 2.7 in a scale of 3. This was an indication that the participants perceived themselves to possess low level of knowledge on EOLNC.

Further, in the attitudes dimension, on the component regarding individual effectiveness, the participants indicated that they were somewhat effective in provision of EOLNC. These sentiments however changed regarding the effectiveness of the institution to provision of EOLNC as the same items were highly scored by the participants. This was an indication that the respondents possessed inappropriate attitude as they believed their institution was more effective in supporting provision of EOLNC than they believed in themselves towards provision of the same.

Additionally, in the practice dimension, it was fascinating to note that most of the dilemmas investigated in the study were not common in practice. However, this was not the case regarding barriers to provision of good quality EOLNC, as all the items examined were identified by the

participants to be barriers to provision of good quality EOLNC. Thus, participants had inadequate skills in the practice dimension. Finally, regarding the adequacy of the basic nursing education program in preparation of nurses to provide EOLNC, most of the items investigated were not adequately covered. Only one item on "*Other symptoms management (i.e. dyspnea, restlessness)*" was noted to be somewhat adequately covered in the basic nursing program.

5.2. Results: Phase II (modified Delphi Process - Round 1 and 2)

This phase was done by administration of questionnaires to 20 experts with formal training in palliative care (PC). The questionnaires were administered in two rounds. The aim of the round one survey was to: a) validate the 8 ELNEC competencies as core competencies that a nurse(s) should possess for provision of high quality EOL care; and b) to establish a framework of common competencies within the core competencies that describe the nurse's behavior. While round two aimed at validating the revised core and sub competencies. For both round 1 and 2 survey, participants were asked in a 5-point Likert scale to rate the extent to which they agreed with the list of core and sub competencies as the requisite EOL care clinical competencies for this group of nurses. All competencies were considered in line with what the experts regarded as vital attributes for the non-specialist palliative care nurse(s) in Kenya for provision of high quality EOL care.

Additionally, in round one, experts were asked two open-ended questions: a) list any competency(s) that is(are) missing, and b) list the competency(s) you want deleted. These questions were in each of the following sections:1) Core competencies, 2) Knowledge dimension, 3) Attitude dimension, and 4) Practice dimension. These open-ended questions were repeated in the second round survey. Responses received in round one were incorporated into the round 2 survey. However, there was no response received from the round two open-ended questions. The response rate for round 1 and 2 was 100% and 85% respectively. Details of the results from this two round modified Delphi process are as discussed in the subsequent sections.

5.2.1. Demographic characteristics of the participants (n= 20)

In this first round, demographic characteristics of the participants was observed to provide some background features of the experts. This however was not repeated in the second round since the same experts who participated in the first round were involved and no new additions. Details of the experts' characteristics are as discussed below.

5.2.1.1. Gender of panel respondents

The female represented 50% (n=10) of the sample while the male gender was equally 50% (n=10). There was equivalent representation of both female and male genders in the study as shown in figure 5.10. This implies that practice in an area of specialization seems to attract the male gender diluting the previous trend where nursing was dominated by the female gender.

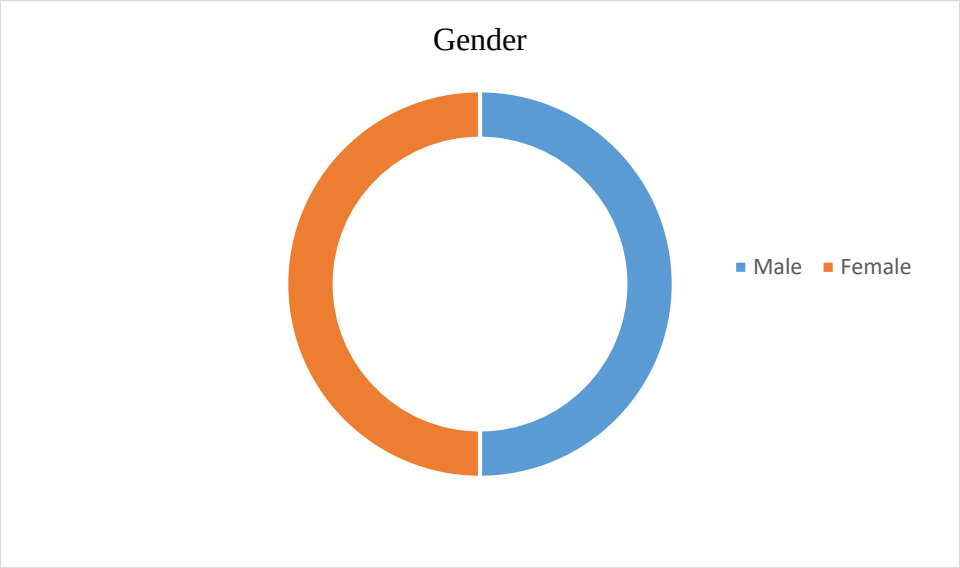

Figure 5.10: Gender of panel respondents

5.2.1.2. Age of the respondents

Results showed that most of the respondents were aged between 31-40 years old (40%; n=8), followed by those in the age bracket of 21-30 years (25%; n=5); then those in the age bracket of under 21 (20%; n=4); and the least age bracket was that of 41 to 50 years (15%; n=3) (Figure 5.11). Results indicated that most of the respondents were more than 30 years old and hence were able to respond to the research items under investigation.

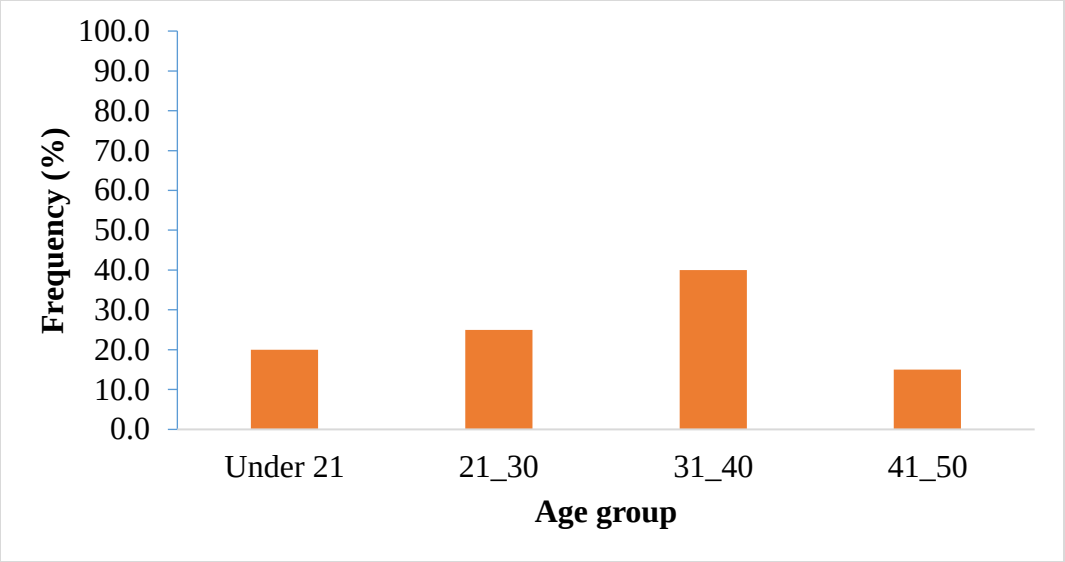

Figure 5.11: Age group of respondents

5.2.1.3. Level of education of the panel respondents

Table 5.32: Level of education of panel respondents

Level of education	Frequency	Percentage
Post-Basic Diploma	15	75.0
Bachelor's Degree	3	15.0
Master's Degree	2	10.0
Total	**20**	**100.0**

The most represented level of education in palliative care nursing amongst panelist was as follows: Post-Basic Diploma (75%; n= 15), Bachelor's degree (15%; n=3), and Master's degree (10%; n= 2) (Table 5.32). Nurses with a post-basic diploma were more than those in the other levels of education. This is a reflection of the current trend in nursing education in Kenya where most nurses are undertaking a post-basic diploma in an area of interest to enhance their competencies. These post-basic qualifications are recognized particularly by the government leading to a promotion immediately upon completion.

5.2.1.4. Respondents' area of practice

When asked to state their area of practice between the two areas of practice provided (figure 5.12), respondents were equally represented between clinical 50% (n=10) and academic 50% (n=10). This implies that the opinions provided pertaining to EOLNC competencies were well represented to reflect academic and clinical views.

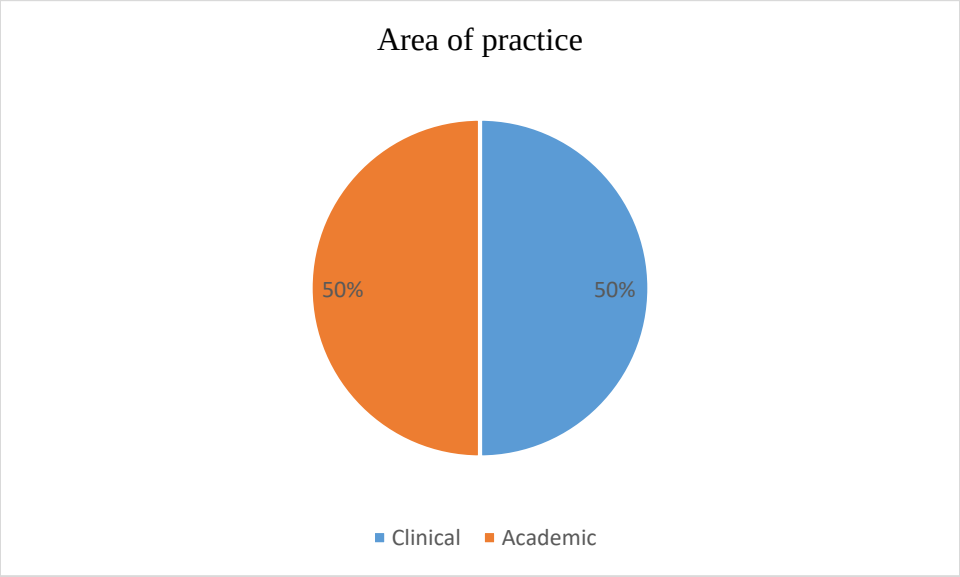

Figure 5.12: Area of practice of panel respondents

5.2.1.5. Nursing experience in current area of practice

Table 5.33: Years of current employment in respondent's area of practice

Years of current employment in area of practice	Frequency	Percentage
less than 1.4 years	1	5.0
1.4 – 5.4 years	6	30.0
5.5 – 10.4 years	9	45.5
More than 10.5 years	4	20.0
Total	**20**	**100.0**

Almost half of the respondents comprising 45% (n=9) of the sample had been in their area of practice for a period of between 5.5 to 10.4 years, followed closely by those with nursing experience of between 1.4 to 5.4 years (30%; n=6) then those with more than 10.5 years (20%; n=4); and a minority had less than 1.4years of experience (5%; n=1) (Table 5.33). The results above indicated that the respondents had some experience on EOL care and hence gave valuable contribution to area under study.

5.2.1.6. Participants' response to possession of an advance directive

When respondents were asked if they had an advance directive, none of the respondents had an advance directive. The lack of an advance directive by all respondents reflects the current position of advance directives in Kenya which has not yet received popularity.

5.2.2. Core Competencies for EOL nursing care

This study endeavored to validate the 8 ELNEC core competencies and to identify common EOLNC competencies within the core competencies for nurses in Kenya. The competencies were investigated under three dimensions; knowledge, attitudes, and practice. Quantitative data was analyzed using descriptive statistics, specifically, median and interquartile range while qualitative data was grouped into themes then coded for quantitative analysis.

5.2.2.1. Results: Round 1

Participants were first asked to state the extent to which they agreed with the importance of the 8 ELNEC competencies that constituted the core competencies.

Table 5.34: Results for participants' agreement of importance of core competencies (ELNEC) in Round 1 of a 2-round modified Delphi study.

Core Competencies (competencies)	Agree (%)	Disagree (%)	Median	IQR	Suggestions for review
Palliative Nursing Care	100	0	5	0	None
Pain Management	100	0	5	1	None
Symptom Management	100	0	5	0	None
Ethical issues	75	25	3.5	1.5	Add "Legal"
Cultural and Spiritual considerations	40	60	2.5	2	Add "Psychosocial"
Communication	100	0	5	1	None

Loss, Grief and Bereavement	100	0	5	0	None
Final Hours	40	60	2.5	1.9	Reword to "Death and Dying"

As indicated in Table 5.34 there was general agreement that nurses should be familiar with the 8 core competencies (at least 40% agreement of all core competencies). However, this percentage was below the percentage of overall agreement level which was 75% an indication that overall consensus was not reached. Throughout the analysis process, the experts' qualitative input in the questionnaires regarding added and/or comments on the competencies were collated and grouped narratively to identify new competencies. That is, ten experts suggested the addition of the term "legal" to the ethical competency to allow inclusion of competency surrounding legal aspects. Additionally, 16 experts suggested an addition of the word "psychosocial" to the "cultural and spiritual considerations" core competency to allow inclusion of competencies surrounding sexuality and informal caregivers. Lastly, 15 experts suggested that "final hours" is reworded to "Death and Dying".

5.2.2.2. Results: Core competencies Round 2

In the second round of the study, 20 questionnaires were administered, and 17 were filled and returned yielding a response rate of 85%. Comments from the two open-ended questions were collated and grouped narratively.

Table 5.35: Results for participants' agreement of importance of core competencies in Round 2 of a 2-round modified Delphi study.

Core Competencies (competencies)	Agree (%)	Disagree (%)	Median	IQR
Palliative Nursing Care	100	0	5	0
Pain Management	100	0	5	0
Symptom Management	100	0	5	1
Ethical-Legal issues	90	10	4	1
Psychosocial, Cultural and Spiritual considerations	96	4	4	1
Communication	100	0	5	0
Loss, Grief and Bereavement	100	0	5	0
Death and Dying	97	3	5	1

Compared with the first round, the experts in this round did not make any request for changes in the core competencies. The modifications were mostly introduced to clarify the competencies by rewording. Therefore, based on the results of the first survey, three core competencies (4, 5 and 8) were changed as per the suggestions from the experts.

Therefore, the core competencies following revision were 1) Palliative Care Nursing, 2) Pain Management, 3) Symptom Management, 4) Ethical-Legal issues, 5) Psychosocial, Cultural and Spiritual considerations, 6) Communication, 7) Loss, Grief and Bereavement, and 8) Death and Dying. The second survey aimed to validate the revised core competencies and the competencies within each (sub competencies) revised core competency. To that end, participants were asked the extent to which they agreed with the revised core competencies and sub competencies as the EOL care competencies that this group of nurses should possess. Following revision, there was at least 90% agreement on the core competencies as indicated in table 5.35. The rewording of the core competencies was more in line with the extended role that nurses in Kenya undertake as the link between the patient/family and the health care professionals.

5.2.3. Sub Competencies

5.2.3.1. Knowledge Dimension - Round 1

The sub competencies for each core domain are as shown in Table 5.36 below.

Table 5.36: Results for participants' agreement of importance of knowledge competencies for EOLNC in Round 1 of a 2-round modified Delphi study (N=34)

1.1	Palliative Care Nursing	Agree (%)	Disagree (%)	Median	Interquartile Range (IR)	Suggestions for addition to the list
1.1.1	Understand the key concepts in palliative nursing care	90	10	4	1	Role of multidisciplinary team
1.1.2	Explain the general principles of palliative nursing care	95	5	4	1	
1.1.3	Discuss approaches used in palliative care	77	23	3	1.7	
1.1.4	Describe support systems available and how to access appropriate support services	76	24	3.5	1.5	
1.1.5	Awareness of triggers and reactions to stressful/distressing situations	80	20	3.5	1	
1.1.6	Understand referral patterns and access to specialist palliative care	87	13	3.5	1	
1.1.7	Demonstrate an understanding of the approaches to assessment in palliative care tools which may be utilized in the holistic assessment process	78	22	3.5	1	
2.1	Pain Management					
2.1.1	Explain the importance of a holistic approach to pain assessment and management	90	10	4	1	Principles of pain management
2.1.2	Describe the principles of pain management for patients with advanced progressive disease	98	2	4	1	
2.1.3	Identify the common physical, spiritual, and psychosocial issues that impact on pain management	80	20	3.5	1	
2.1.4	Describe the pharmacological and non-pharmacological aspects of pain management	98	2	4	1	
2.1.5	Describe barriers to pain management	99	1	4	1	
3.1	Symptom Management					

3.1.1	Explain the importance of a holistic approach to symptom assessment and management	90	10	4	1	Complementary therapies
3.1.2	Describe the principles of palliative symptom management for patients with advanced progressive disease	80	20	3.5	1	
3.1.3	Identify the common physical, spiritual, and psychosocial issues that impact on symptom management	78	22	3.5	1	
3.1.4	Describe the causes and presentation of palliative care emergencies	70	30	3	1.9	
3.1.5	Demonstrate awareness and understanding of Advanced Care Planning, and the times at which it would be appropriate	73	28	3	1.6	
3.1.6	Understand common chronic illness, the expected natural course and trajectories, common treatments and complications	75	25	3.5	1.5	
4.1	Ethical-Legal issues					
4.1.1	Understand the relevant laws and policies or regulations	74	26	3	1.6	Ethical and legal management issues e.g., will writing, patient rights, euthanasia
4.1.2	Discuss ethical principles and their application to end-of-life nursing care	88	12	3.5	1	
4.1.3	Identify and discuss issues such as informed choice, mental capacity/incapacity legislation, consent, confidentiality and patient autonomy	70	30	3	1.9	
5.1	Psychosocial, Cultural and Spiritual considerations					
5.1.1	Understand how one's own personal beliefs and philosophy of life impact on the ways we act and interact with others	72	28	3	1.7	Concept of sexuality Effects of a terminal illness on sexuality Types of informal care givers Role of informal care givers in EOL care
5.1.2	Identify the spiritual and/or religious needs of patients/families/carers and describe how they may be addressed	77	33	3.5	1.5	
5.1.3	Demonstrate an understanding of cultural issues at EOL care	70	30	3	1.9	

5.1.4	Understand various aspects of spiritual care	70	30	2.8	1.9	
6.1	Communication					
6.1.1	Demonstrate an understanding of the components of open and sensitive communication	80	20	3.5	1	Breaking bad news to a patient/family
6.1.2	Understand the importance of using strategies that empower effective communication e.g. active listening, plain language, appropriate tone, empathy	87	13	3.5	1	
6.1.3	Explain the importance and impact of non-verbal and verbal communication within all aspects of care	90	10	4	1	
6.1.4	Explain the concepts of counselling	85	15	3.5	1	
7.1	Loss, Grief and Bereavement					
7.1.1	Understand that grief is a normal and appropriate response to loss which has physical, psychological, spiritual, emotional and social aspects that affect how it is experienced.	70	30	2.8	2	Referral mechanisms to appropriate support services
7.1.2	Understand the personal impact of loss, grief and bereavement.	80	20	3.5	1	
7.1.3	Understand the strategies to identify the losses that persons with cognitive and sensory impairment encounter and intervene appropriately	75	25	3.5	1.5	
8.1	Death and Dying					
8.1.1	Outline the practical issues surrounding the death of a patient, for example, death certification and registration	75	25	3.5	1.5	Role of a nurse during death and dying
8.1.2	Demonstrate knowledge of issues and policies relating to any legal, cultural, religious or health and safety requirements when caring for the patient’s body	70	30	2.8	2	

As with the core competencies, experts were in general agreement that nurses should possess all the 34 knowledge competencies within the 8 core competencies (at least76% agreement of all sub competencies). However, findings indicated that there were variations in the level of agreement with some competencies receiving a higher percentage rating by the experts. Findings showed that, the following four competencies had the highest level of agreement: a) Describe barriers to pain management (99% agreement); b) Describe the principles of pain management for patients with advanced progressive disease (98% agreement); c) Describe the pharmacological and non-pharmacological aspects of pain management (98% agreement); and d) Explain the general principles of palliative nursing care (95% agreement).

On the other hand, findings indicated that eight competencies had the least rating (76% agreement). However, five of these met the acceptable criteria as they had a median >3.5 and interquartile range (IR) <1.5. These were: a) Describe the causes and presentation of palliative care emergencies; b) Discuss approaches used in palliative care; c) Describe support systems available and how to access appropriate support services; d) Understand the strategies to identify the losses that persons with cognitive and sensory impairment encounter and intervene appropriately; and e) Outline the practical issues surrounding the death of a patient, for example, death certification and registration.

The other three however, did not meet the acceptable criteria as they had a median <3.5 and IR > 1.5. These were: a) Understand that grief is a normal and appropriate response to loss which has physical, psychological, spiritual, emotional and social aspects that affect how it is experienced; b) Understand how one's own personal beliefs and philosophy of life impact on the ways we act and interact with others; and c) Understand the relevant laws and policies or regulations. These results reflect the dynamic views that the experts had regarding requisite knowledge for EOL care provision for non-specialist nurses. It could also reflect the challenge of drawing a line between what a specialist PC nurse should possess and what a non-specialist PC nurse should possess.

Table 5.37: Sub competencies derived from participants' suggestions in Round 1 of a 2-round modified Delphi study

Core Competencies	Suggestions for sub competencies
Palliative Nursing Care	Demonstrate an understanding of the role of multidisciplinary team
	Be able to develop a patient-care plan using the nursing process and in a team-based manner
Pain Management	Demonstrate an understanding of the principles of pain management
	Be able to administer the appropriate pain therapies including opioids as prescribed
Symptom Management	Demonstrate an understanding of the complementary therapies
	Be able to identify palliative care emergencies and intervene appropriately
Ethical issues	Understand the ethical and legal management issues that impact on symptom management e.g., will writing, patient rights, euthanasia
	Apply ethical principles in provision of end of life care
Cultural and Spiritual considerations	Demonstrate an understanding of the concept of sexuality and how this is affected by the presence of a terminal illness
	Understand the types of informal care givers and their role in EOL care
	Be non-judgmental regarding patient sexuality while providing EOL care
	Be able to identify informal care giver's needs and intervene appropriately
Communication	Demonstrate an understanding of the process of breaking bad news to a patient/family
	Be sensitive and effective in your communication to patients and informal care givers
Loss, Grief and Bereavement	Demonstrate an understanding of the referral mechanisms to appropriate support services
Final Hours	Understand the role of a nurse during death and dying

Participants made various suggestions following the round one survey. These mainly were regarded addition to the list of competencies within the knowledge dimension as indicated in table 5.37.

5.2.3.1.1. Sub Competencies within the Knowledge Dimension - Round 2

Compared with the first round, the experts in this round did not make any request for changes. The modifications were mainly suggestion for competencies to be added into the list of the sub competencies for the knowledge dimension. A total of 8 sub competencies suggested for addition in round 1 were included in the round 2 questionnaire increasing the number of competencies from 34 to 43.

Table 5.38: Results for participants' agreement of importance of knowledge competencies for EOLNC in Round 2 of a 2-round modified Delphi study (N=43)

1.1	Palliative Care Nursing	Agree (%)	Disagree (%)	Median	Interquartile Range (IQR)
1.1.1	Understand the key concepts in palliative nursing care	90	10	4	1
1.1.2	Explain the general principles of palliative nursing care	95	5	5	1
1.1.3	Discuss approaches used in palliative care	90	10	4	1
1.1.4	Describe support systems available and how to access appropriate support services	90	10	5	0
1.1.5	Awareness of triggers and reactions to stressful/distressing situations	91	9	4	1
1.1.6	Understand referral patterns and access to specialist palliative care	90	10	4	1
1.1.7	Demonstrate an understanding of the approaches to assessment in palliative care tools which may be utilized in the holistic assessment process	92	8	4	1
1.1.8	*Demonstrate an understanding of the role of multidisciplinary team	98	2	5	0
2.1	Pain Management				
2.1.1	Explain the importance of a holistic approach to pain assessment and management	90	10	5	0
2.1.2	Describe the principles of pain management for patients with advanced progressive disease	98	2	5	1
2.1.3	Identify the common physical, spiritual, and psychosocial issues that impact on pain management	90	10	4	1
2.1.4	Describe the pharmacological and non-pharmacological aspects of pain management	98	2	5	0

2.1.5	Describe barriers to pain management	99	1	5	1
2.1.6	*Demonstrate an understanding of the principles of pain management	97	3	5	0
3.1	Symptom Management				
3.1.1	Explain the importance of a holistic approach to symptom assessment and management	90	10	5	0
3.1.2	Describe the principles of palliative symptom management for patients with advanced progressive disease	90	10	4	1
3.1.3	Identify the common physical, spiritual, and psychosocial issues that impact on symptom management	91	9	4	1
3.1.4	Describe the causes and presentation of palliative care emergencies	92	8	4	1
3.1.5	Demonstrate awareness and understanding of Advanced Care Planning, and the times at which it would be appropriate	90	10	4	1
3.1.6	Understand common chronic illness, the expected natural course and trajectories, common treatments and complications	97	3	5	0
3.1.7	*Demonstrate an understanding of the complementary therapies	93	7	4	1
4.1	Ethical-Legal issues				
4.1.1	Understand the relevant laws and policies or regulations	94	6	4	1
4.1.2	Discuss ethical principles and their application to end-of-life nursing care	96	4	5	0
4.1.3	Identify and discuss issues such as informed choice, mental capacity/incapacity legislation, consent, confidentiality and patient autonomy	90	10	5	1
4.1.4	*Understand the ethical and legal management issues that impact on symptom management e.g., will writing, patient rights, euthanasia	90	10	5	0
5.1	Psychosocial, Cultural and Spiritual considerations				
5.1.1	Understand how one's own personal beliefs and philosophy of life impact on the ways we act and interact with others	94	6	5	1
5.1.2	Identify the spiritual and/or religious needs of patients/families/carers and describe how they may be addressed	97	3	5	0
5.1.3	Demonstrate an understanding of cultural issues at EOL care	98	2	5	1
5.1.4	Understand various aspects of spiritual care	90	10	4	1

5.1.5	*Demonstrate an understanding of the concept of sexuality and how this is affected by the presence of a terminal illness	98	2	5	0
5.1.6	*Understand the types of informal care givers and their role in EOL care	97	3	5	1
6.1	Communication				
6.1.1	Demonstrate an understanding of the components of open and sensitive communication	95	5	5	0
6.1.2	Understand the importance of using strategies that empower effective communication e.g. active listening, plain language, appropriate tone, empathy	97	3	5	1
6.1.3	Explain the importance and impact of non-verbal and verbal communication within all aspects of care	95	4	5	0
6.1.4	Explain the concepts of counselling	96	4	5	1
6.1.5	*Demonstrate an understanding of the process of breaking bad news to a patient/family	98	2	5	0
7.1	Loss, Grief and Bereavement				
7.1.1	Understand that grief is a normal and appropriate response to loss which has physical, psychological, spiritual, emotional and social aspects that affect how it is experienced.	96	4	5	1
7.1.2	Understand the personal impact of loss, grief and bereavement.	98	2	5	0
7.1.3	Understand the strategies to identify the losses that persons with cognitive and sensory impairment encounter and intervene appropriately	95	5	4	1
7.1.4	*Demonstrate an understanding of the referral mechanisms to appropriate support services	93	7	4	1
8.1	Death and Dying				
8.1.1	Outline the practical issues surrounding the death of a patient, for example, death certification and registration	96	4	4	1
8.1.2	Demonstrate knowledge of issues and policies relating to any legal, cultural, religious or health and safety requirements when caring for the patient's body	97	3	5	0
8.1.3	*Understand the role of a nurse during death and dying	98	2	5	0

**Competencies suggested for inclusion in round 1*

As shown in table 5.38 all the 43 sub competencies in the knowledge dimension met the acceptable criteria. The experts believed the 43 sub competencies in the knowledge dimension represented the requisite competencies for EOLNC for non-specialist's palliative care nurses in Kenya. It is possible that the inclusion of the suggested competencies may have influenced participants' decision during the second round which led to a higher ranking for all the competencies.

5.2.3.2. Sub Competencies within the Attitude Dimension - Round 1

Experts were in general agreement that nurses should possess all the 16 attitude competencies listed within the 8 core competencies (at least76% agreement of all sub competencies). However, findings indicated that there were variations in the level of agreement with some competencies receiving a higher percentage rating by the experts.

Table 5.39: Results for participants' agreement of importance of attitude competencies for EOLNC in Round 1 of a 2-round modified Delphi study (N=16)

1.2	Palliative Care Nursing	Agree (%)	Disagree (%)	Median	Interquartile Range (IR)	Suggestions for addition to the list
1.2.1	Respect the roles, responsibilities and boundaries in multi-professional working	76	24	3	1.7	None
1.2.2	Value the opinions and views of others	77	23	3	1.7	
1.2.3	Value the collaborative approach to working with other services across various sectors	76	24	3.5	1.5	
1.2.4	Be respectful and empathetic to patients/clients with life-limiting conditions as you provide individualized care..	80	20	3.5	1	
1.2.5	Be supportive and caring to the patient and his/her family	87	13	3.5	1	
1.2.6	Be an advocate for patients/clients and ensure appropriate and timely palliative care interventions at EOL	78	22	3.5	1	
2.2	Pain Management					
2.2.1	Be respectful and sensitive to the patient's/family's subjective experience(s)	90	10	4	1	None
3.2	Symptom Management					
3.2.1	Treat everyone with whom you come into contact with dignity, respect, humanity and compassion	87	13	3.5	1	None
3.2.2	Value the ethical principles involved when planning care	90	10	4	1	
4.2	Ethical-Legal issues					
4.2.1	Be professional when the patient/family requests for further/modification of treatment .	80	20	3.5	1	None
5.2	Psychosocial, Cultural and Spiritual considerations					
5.2.1	Be objective and neutral to the patient and his/her family irrespective of the spiritual standpoint	76	24	3.5	1.5	Patient sexuality
5.2.2	Respect the opinions of the informal caregivers	80	20	3.5	1	

6.2	Communication					
6.2.1	Show respect for cultural and religious diversity when communicating with the family unit	85	15	3.5	1	None
6.2.2	Value the importance of establishing a rapport with the patient/carer based on openness, honesty and trust	90	10	4	1	
7.2	Loss, Grief and Bereavement					
7.2.1	Respect the individual nature of the grief response	80	20	3.5	1	None
8.2	Death and Dying					
8.2.1	Value the need for dignity and respect towards the patient and others at and around the time of death	95	5	4	1	None

As shown in table 5.39, findings showed that, the following four competencies had the highest level of agreement rating: a) Value the need for dignity and respect towards the patient and others at and around the time of death (95% agreement); b) Be respectful and sensitive to the patient's/family's subjective experience(s) (90% agreement); c) Value the ethical principles involved when planning care (90% agreement); and d) Value the importance of establishing a rapport with the patient/carer based on openness, honesty and trust (90% agreement).

On the other hand, findings indicated that four competencies had the least rating. However, two of these met the acceptable criteria as they had a median >3.5 and IR <1.5. These were: a) Value the collaborative approach to working with other services across various sectors (76% agreement); and b) Be objective and neutral to the patient and his/her family irrespective of the spiritual standpoint (76% agreement). The other two however, did not meet the acceptable criteria as they had a median <3.5 and IR > 1.5. These were: a) Respect the roles, responsibilities and boundaries in multi-professional working (76% agreement, median 3, IR 1.7); and b) Value the opinions and views of others (77% agreement, median 3, IR 1.7). These findings reflect the current status of EOLNC in Kenya that is marred with role conflict among the nurses with lack of clarity of where to draw the boundaries.

5.2.3.2.1. Sub-Competencies within the Attitude Dimension - Round 2

Following the incorporation of suggestions given in round 1, the number of sub competencies within the attitude dimension increased from 16 to 17. Experts rated the level of agreement with the listed sub competencies in the attitude dimension for EOLNC using a 5-point Likert scale.

Table 5.40: Results for participants' agreement of importance of attitude sub competencies for EOLNC in Round 2 of a 2-round modified Delphi study (N=17)

1.2	Palliative Care Nursing	Agree (%)	Disagree (%)	Median	Interquartile Range (IQR)
1.2.1	Respect the roles, responsibilities and boundaries in multi-professional working	96	4	5	0
1.2.2	Value the opinions and views of others	97	3	4	1
1.2.3	Value the collaborative approach to working with other services across various sectors	96	4	4	1
1.2.4	Be respectful and empathetic to patients/clients with life-limiting conditions as you provide individualized care..	98	2	5	1

1.2.5	Be supportive and caring to the patient and his/her family	97	3	5	0
1.2.6	Be an advocate for patients/clients and ensure appropriate and timely palliative care interventions at EOL	98	2	5	1
2.2	Pain Management				
2.2.1	Be respectful and sensitive to the patient's/family's subjective experience(s)	99	1	5	0
3.2	Symptom Management				
3.2.1	Treat everyone with whom you come into contact with dignity, respect, humanity and compassion	97	3	5	0
3.2.2	Value the ethical principles involved when planning care	96	4	5	1
4.2	Ethical-Legal issues				
4.2.1	Be professional when the patient/family requests for further/modification of treatment .	98	2	5	0
5.2	Psychosocial, Cultural and Spiritual considerations				
5.2.1	Be objective and neutral to the patient and his/her family irrespective of the spiritual standpoint	96	4	5	1
5.2.2	Respect the opinions of the informal caregivers	98	2	5	0
6.2	Communication				
6.2.1	Show respect for cultural and religious diversity when communicating with the family unit	95	5	5	1
6.2.2	Value the importance of establishing a rapport with the patient/carer based on openness, honesty and trust	99	1	5	0
6.2.3	*Be non-judgmental regarding patient sexuality while providing EOL care	98	2	5	0
7.2	Loss, Grief and Bereavement				
7.2.1	Respect the individual nature of the grief response	90	10	4	1
8.2	Death and Dying				
8.2.1	Value the need for dignity and respect towards the patient and others at and around the time of death	98	2	5	0

**Competencies suggested in round 1*

Table 5.40 summarizes the median, IQR and percentage of agreement for each sub competency in the attitude dimension. All the 17 sub competencies reached the acceptable criteria an indication that consensus was reached among the experts on the requisite sub competencies within the attitude dimension for non-specialist's palliative care nurses. The favorable rating regarding establishing rapport with patient (table 42), reflects the importance of a therapeutic relationship between the nurse and the patient to promote positive patient outcomes.

5.2.3.3. Sub Competencies within the Practice Dimension – Round 1

Experts were in general agreement that nurses should possess all the 26 practice competencies within the 8 core competencies (at least76% agreement of all subdomains). However, findings indicated that there were variations in the level of agreement with some competencies receiving a higher percentage rating by the experts (Table 5.41).

Table 5.41: Results for participants' agreement of importance of practice competencies for EOLNC in Round 1 of a 2-round modified Delphi study (N=26)

1.3	Palliative Care Nursing	Agree (%)	Disagree (%)	Median	Interquartile Range (IR)	Suggestions for addition to the list
1.3.1	Be able to apply research findings to improve end-of-life nursing care outcomes	80	20	3.5	1	Nursing process Provide care in a team-based manner
1.3.2	Effectively work in partnership with other specialist teams	87	13	3.5	1	
1.3.3	Be able to recognize when the person's care needs are complex and warrant referral to specialist palliative care	78	22	3.5	1	
2.3	Pain Management					
2.3.1	Utilize appropriate skills to assess, diagnose and manage pain	76	24	3	1.7	Administer appropriate pain therapies e.g., opioids
2.3.2	Be able to monitor outcomes of both pharmacological and non-pharmacological management plans	77	23	3	1.7	
2.3.3	Be able to utilize principles of pain management	76	24	3.5	1.5	
3.3	Symptom Management					
3.3.1	Be able to assess, diagnose and manage common symptoms at end of life associated with life-limiting conditions.	87	13	3.5	1	Palliative care emergencies and their interventions
3.3.2	Set realistic goals of care in partnership with patient/carer(s)	90	10	4	1	
3.3.3	Regularly review and evaluate care management plans and update appropriately	76	24	3.5	1.5	
3.3.4	Refer in an appropriate and timely manner to specialist palliative care team, or other disciplines as necessary	80	20	3.5	1	
4.3	Ethical-Legal issues					
4.3.1	Collaborate with others in the use of an ethical framework which guides decision making in the context of end of life care	90	10	4	1	Ethical principles in end of life care
4.3.2	Implement and monitor outcomes of ethical decisions	95	5	4	1	

4.3.3	Share and document information sensitively and while respecting confidentiality					
5.3	Psychosocial, Cultural and Spiritual considerations					
5.3.1	Be able to establish and respect people's wishes about their care and options/preferences	80	20	3.5	1	informal care giver's needs and interventions •
5.3.2	Be able to provide last offices in the context of the individuals' beliefs, culture and religious practice	76	24	3.5	1	
5.3.3	Identify the care needs of people from different cultural and religious backgrounds	78	22	3.5	1	
6.3	Communication					
6.3.1	Be flexible and modify personal communication style to facilitate communication with persons with a range of communication impairments..	96	4	4	1	Communication with informal care givers
6.3.2	Utilize counselling skills in the care of a patient/family	98	2	4	1	
6.3.3	Communicate with family/carers as appropriate, to determine anticipated care outcomes	95	5	3.5	1	
7.3	Loss, Grief and Bereavement					
7.3.1	Demonstrate self-awareness of personal experiences of loss, to prevent them from negatively impacting on patients/clients..	98	2	4	1	None
7.3.2	Be able to provide support in order to help the family to adapt to the bereavement and loss	80	20	3.5	1	
7.3.3	Be able to engage with a person who is experiencing loss in the context of professional scope of practice and/role	98	2	4	1	
7.3.4	Be able to identify those experiencing complicated grief and utilize resources to appropriately support them	76	24	3	1.7	
8.3	Death and Dying					
8.3.1	Care for the patient's body after death, respecting any wishes expressed by the family and any particular religious rites	78	22	3	1.8	None

8.3.2	Ensure appropriate identification/verification/certification of death, and care of the patient's body throughout duration of care	87	13	3.5	1	
8.3.3	Be able to anticipate, recognize and respond effectively to signs and symptoms of imminent death	90	10	4	1	

The following three competencies had the highest level of agreement: a) Be able to engage with a person who is experiencing loss in the context of professional scope of practice and/role (98% agreement); b) Demonstrate self-awareness of personal experiences of loss, to prevent them from negatively impacting on patients/clients (98% agreement); and c) Utilize counselling skills in the care of a patient/family (98% agreement). On the other hand, findings indicated that five sub competencies had the least rating. However, three of these met the acceptable criteria as they had a median >3.5 and IQR <1.5. These were: a) Be able to utilize principles of pain management (76% agreement); b) Regularly review and evaluate care management plans and update appropriately (76% agreement); c) Be able to provide last offices in the context of the individuals' beliefs, culture and religious practice (76% agreement).

The other two however, did not meet the acceptable criteria as they had a median <3.5 and IQR > 1.5. These were: a) Utilize appropriate skills to assess, diagnose and manage pain (76% agreement, median 3, IQR 1.7); and b) Be able to identify those experiencing complicated grief and utilize resources to appropriately support them (76% agreement, median 3, IQR 1.7). The favorable rating regarding self-awareness as far as loss is concerned reflects the human aspect of the nurse and provides for provision to refer challenging cases that may be influenced by the nurse's negative personal experience which may be detrimental to patient care outcomes.

5.2.3.3.1. Sub Competencies within the Practice Dimension – Round 2

Nurse experts (n=20) who participated in round one were invited to participate in round two and the response rate was 85% (n=17). In this second round, regarding the sub competencies in the practice dimension, the expert panel reached 90% or greater consensus for all the 32 sub competencies (Table 5.42). These included the 8 sub competencies suggested for addition in round one which had a total of 26 sub competencies.

Table 5.42: Results for participants' agreement of importance of practice competencies for EOLNC in Round 2 of a 2-round modified Delphi study (N=32)

1.3	Palliative Care Nursing	Agree (%)	Disagree (%)	Median	Interquartile Range (IR)
1.3.1	Be able to apply research findings to improve end-of-life nursing care outcomes	90	10	4	1
1.3.2	Effectively work in partnership with other specialist teams	96	4	5	
1.3.3	Be able to recognize when the person's care needs are complex and warrant referral to specialist palliative care	95	5	4	1
1.3.4	*Be able to develop a patient-care plan using the nursing process and in a team-based manner	98	2	5	0
2.3	Pain Management				
2.3.1	Utilize appropriate skills to assess, diagnose and manage pain	96	4	4	1
2.3.2	Be able to monitor outcomes of both pharmacological and non-pharmacological management plans	93	3	4	1
2.3.3	Be able to utilize principles of pain management	97	3	5	0
2.3.4	*Be able to administer the appropriate pain therapies including opioids as prescribed	100	0	5	0
3.3	Symptom Management				
3.3.1	Be able to assess, diagnose and manage common symptoms at end of life associated with life-limiting conditions.	98	2	5	0
3.3.2	Set realistic goals of care in partnership with patient/carer(s)	97	3	5	1
3.3.3	Regularly review and evaluate care management plans and update appropriately	98	2	5	1
3.3.4	Refer in an appropriate and timely manner to specialist palliative care team, or other disciplines as necessary	96	4	4	1
3.3.5	*Be able to identify palliative care emergencies and intervene appropriately	96	4	5	1
4.3	Ethical-Legal issues				
4.3.1	Collaborate with others in the use of an ethical framework which guides decision making in the context of end of life care	98	2	5	0
4.3.2	Implement and monitor outcomes of ethical decisions	98	2	5	1
4.3.3	Share and document information sensitively and while respecting confidentiality	100	0	5	0

4.3.4	*Apply ethical principles in provision of end of life care	96	4	5	1
5.3	Psychosocial, Cultural and Spiritual considerations				
5.3.1	Be able to establish and respect people's wishes about their care and options/preferences	94	6	5	1
5.3.2	Be able to provide last offices in the context of the individuals' beliefs, culture and religious practice	76	24	3.5	1
5.3.3	Identify the care needs of people from different cultural and religious backgrounds	93	7	4	1
5.3.4	*Be able to identify informal care giver's needs and intervene appropriately	98	2	5	0
6.3	Communication				
6.3.1	Be flexible and modify personal communication style to facilitate communication with persons with a range of communication impairments.	100	0	5	0
6.3.2	Utilize counselling skills in the care of a patient/family	98	2	5	0
6.3.3	Communicate with family/carers as appropriate, to determine anticipated care outcomes	97	3	5	1
6.3.4	*Be sensitive and effective in your communication to patients and informal care givers	96	4	4	1
7.3	Loss, Grief and Bereavement				
7.3.1	Demonstrate self-awareness of personal experiences of loss, to prevent them from negatively impacting on patients/clients..	98	2	5	0
7.3.2	Be able to provide support in order to help the family to adapt to the bereavement and loss	95	5	4	1
7.3.3	Be able to engage with a person who is experiencing loss in the context of professional scope of practice and/role	98	2	5	0
7.3.4	Be able to identify those experiencing complicated grief and utilize resources to appropriately support them	90	10	4	1
8.3	Death and Dying				
8.3.1	Care for the patient's body after death, respecting any wishes expressed by the family and any particular religious rites	90	10	4	1
8.3.2	Ensure appropriate identification/verification/certification of death,	95	5	5	0

	and care of the patient's body throughout duration of care				
8.3.3	Be able to anticipate, recognize and respond effectively to signs and symptoms of imminent death	97	3	5	0

**Competencies suggested in Round 1*

Further, as shown in table 5.42 all the sub competencies reached the acceptable criteria as far as the median (>3.50) and IQR (<1.50) were concerned. The favorable response reflected in table … as far as administration of pain medication is concerned (item 2.3.4), reflects the importance of pain management at EOL. This is in line with one of the principles of EOL care that highlights the importance of reducing suffering to achieve a good death. Additionally, the aspect of administration of prescribed analgesics by the nurse highlights one of the limitations facing nurses in Kenya where prescriptive rights are limited/lacking for them.

5.2.4. Summary of Phase 2 results

All the core and sub competencies met the set acceptable criteria as they had a median equal to or greater than 3.50, interquartile range equal to or less than 1.50 and >75% agreement. The results showed that a total of 8 core competencies and 92 sub competencies met the acceptable criterion in the second round indicating that consensus was reached. Therefore, the Delphi process stopped at the second round. Overall, the data from both the first and the second survey were in alignment. The first round aided to validate the EOL core competencies and to define the sub competencies within each core competency that nurses should possess. While the second round served to validate the revised core and sub competencies.

5.3. Conclusion

The first phase of the study ascertained that nurses had inadequate level of EOLNC knowledge, had deficiencies in their attitudes, and lastly, their practice skills were wanting. Further, it was reported that the EOL care content within the basic nursing curricula was inadequate. Finally, in phase one, it was observed that nurses were inadequately prepared for provision of EOL nursing care. The first and the second survey in the phase two of the study, indicated that consensus was reached for all the 8 core competencies and the 92 sub competencies. The combined results of the

two surveys were used to create a guideline for the required EOL nursing care clinical competencies for nurses for provision of high quality EOL care. Details of the clinical competency guidelines developed are in the subsequent chapter (6).

CHAPTER SIX: DISCUSSION, CONCLUSION AND RECOMMENDATIONS

6.0 Introduction

Globally, life expectancy was noted to have increased from 61.7 years to 71.8 years (Wang et al., 2016), however, the total deaths also were noted to increase to more than 200,000 per year (*Ken_en.Pdf*, n.d.). Thus, this indicated that there is a need to provide safe and high-quality end-of-life (EOL) care. All patients have a right to be cared for respectfully and with compassion while maintaining their comfort, dignity, and privacy. (*Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care*, n.d.).

End-of-life (EOL) is every health care provider's responsibility. A patient in distress whether physical, psychosocial or spiritual requires timely interventions from competent care providers. The avoidance of suffering is of paramount importance. This is the first known study that explored on Kenyan nurses' end-of-life nursing care (EOLNC) competencies. The most important findings of this study were: a) nurses were inadequately prepared to provide EOLNC; b) the basic nursing education program is deficient with EOLNC content; and c) consensus on common EOLNC core competencies was reached. Thus, this chapter outlines a discussion on key findings from this study. Additionally, limitations of this study are brought to light and conclusions from the discussion are drawn. Finally, implications of the results are also highlighted.

6.1. Discussion on Nurses' survey

6.1.1. Demographics

Findings indicated that female respondents were more (52.4%) than their counterparts the male (47.6%). Dominance of the female gender in the nursing profession is a phenomenon that has been confirmed in several studies. For instance, in the study by Coffey et al (2016) on nurses' knowledge on advance directives, majority of the participants were female; and the same was noted in one other study by Lalloo et al (2016) on occupational health nurses' competencies.

Interestingly, in a study by Hendricks-Ferguson et al (2015) on entry level nurses' experiences with palliative and EOL communication; and another by Bostwick and Linden (2016) on criteria for evaluating nursing students; all the participants were female. The dominance of the female gender in the nursing profession could majorly be attributed to the caring component that encompasses the biggest role that a nurse plays. The caring role is attributed to the female gender

as they naturally engage in the nursing of children. Other characteristics of the respondents in this study are as discussed in the subsequent paragraphs.

To begin with, the most common age profile (52.3%; n=81) of the Kenyan samples was 31-40 years. This finding differed with most studies conducted among nurses as literature indicated that they were older. For instance, in the study by Lee et al (2015) whose aim was identification of clinical competencies for emergency nurses for provision of effective care for women who have been violated, the study participants were aged between 41 to 50 years.

While in yet another study on health literacy for nurses, the average age of the participants was 55 years (Toronto, 2016). Hence, comparatively, Kenyan nurses were younger. This could be attributed to the fact that in Kenya, one can commence the nursing training immediately after completion of high school allowing the nurse to commence the journey in the nursing profession much earlier.

Also, findings from this study showed that more than half of the participants (66.9%; n=117) reported to possess a diploma as the highest level of training. This observation was contrary to that reported in literature which indicated a bachelor's degree as the highest level of training (Coffey et al., 2016). Notably, one other study on nurses' health literacy, all the participants possessed a PhD as the highest level of training (Toronto, 2016). Results on the diploma as the highest level of training by the Kenyan sample could be related to the fact that for a long time nursing in Kenya had only been offered at the lower level. It is not until recently, that nurses with higher level of training are gaining recognition and acceptance.

Additionally, findings from this study indicated that more than a quarter of the nurses (35.9%; n=60) had less than 10years post-registration experience and experience in the current workstation. This finding differed with other studies whose participants had more than 10years post-registration experience (Bostwick & Linden, 2016; Coffey et al., 2016; Hendricks-Ferguson et al., 2015; Lee et al., 2015; Toronto, 2016). This could be explained by the findings that were reported earlier which indicated that Kenyan nurses were relatively younger and thus had fewer years of experience.

Furthermore, this study noted that more than quarter of the participants (37.9%; n=66) worked in the intensive care unit (ICU). In Kenya, current training for nurses in the ICU and other acute care

settings, highlights the importance of cure and less training on how nurses would handle patients who are not responding to curative treatment (White et al., 2014). This study therefore, identified common core competencies for nurses to enable them to provide high quality EOL care and developed EOLNC competency based guidelines. This is particularly important for nurses in the ICU because this unit admits critically ill patients and therefore record a high number of patients who die within the unit (Montagnini et al., 2012).

Likewise, as was observed in the current study, direct patient care was reported to be the major role undertaken by majority of the nurses (93.1%; n=161). This concurs with the observations recorded by Albers and colleagues (n.d.) in their study on individualized EOLC with a team-based approach. Therefore, with a majority of the sample being participants providing direct patient care, it can be concluded that the position represented in this study regarding nurses' ability to provide EOLC reflects what happens at the acute care hospitals in Kenya. Further, this finding could be attributed to the purposive sampling technique that was utilized to identify the sample unit.

To conclude on the demographics, the current study sought to understand professional courses undertaken by the sample. Findings indicated that slightly more than half of the respondents (56.9%; n=87) had undertaken a course on critical care nursing followed by palliative care (11.8%; n=18). Various studies have highlighted the importance of continuous professional development by the nurses in promoting positive patient outcomes (Montagnini et al., 2012; Montoya, 2017; Sinha et al., 2015; Wenqin Li & Suvinee Wivatvanit, 2016; White et al., 2014). Bearing in mind that more than half of the sample in this study worked in the ICU, this can explain the high rating of critical care nursing as the course undertaken by a majority of the sample. The demographics observed in this study are reflective of the Kenyan context in that the area of specialized care that has received a lot of attention and support is the critical care area. This is so because institutions even sponsor their staff to undertake this course in order to improve care provided in the critical care settings. Finally, considering the limited long-term facilities in Kenya, it is possible that most patients requiring EOLNC are admitted in the acute care hospitals and as such, nurses in these hospitals do actually provide EOLNC.

6.1.2. Nurses' preparedness to provide EOLNC

The study sought to understand nurses' perceived level of preparedness to provide EOLNC. The survey questionnaire yielded 80% response rates. The study identified three dimensions within the

nurses' preparedness domain, comprising a total of 36 items related to care of individuals who are at/or nearing their end of life (EOL), namely knowledge (15 items), attitudes (14 items), and practice (16 items). The mean scores of all items varied across different dimensions an indication that the nurses were at different levels of preparedness.

Barriers to quality EOLC exist across the trajectory of life threatening illness from diagnosis to long-term and hospital-based care. One major barrier that was highlighted was nurses' lack of knowledge on EOLNC particularly regarding pain management (Dubois & Reed, 2014). Nurses indicated that cognitive changes in patients often made it difficult to assess the level of pain the patient was experiencing. These sentiments were also highlighted in a different systematic review study whose findings supported the fact that nurses have inadequate knowledge on EOLNC (Pulsford, Jackson, O'Brien, Yates, & Duxbury, 2011).

The above observation was also supported by findings from this study which noted that majority of the nurses from six out of the eight units sampled possessed low level of EOLNC knowledge. This observation was in line with what was documented by Boyd and colleagues (2010) in their study on advance care planning that indicated nurses had inadequate knowledge on advance care planning a component in EOL care. Inadequate knowledge on EOL care was not only noted in the nursing profession only, but was also documented for other health care professionals such as doctors (Lazenby et al., 2017) and pharmacists (Egelund et al., 2019). The low level of knowledge highlighted by participants in this study may be attributed to the gap identified in the Kenyan basic nursing programme curricula which has limited content pertaining to EOLNC. Finally, findings indicated that participants from the oncology and palliative care department had slightly higher perception on their level of knowledge. This is can be explained by the fact that these nurses are likely to have undertaken a post-basic training in either oncology or palliative care thus recording a favorable response.

In the attitudes dimension, findings from the current study indicated that most of the respondents perceived themselves to be somewhat effective in provision of EOLNC. These sentiments however changed regarding the effectiveness of the institution to provision of EOLNC as the same items were scored slightly higher by the participants. This was an indication that the participants believed their institution was providing better EOL care than they believed in themselves. The presence of support system in most hospitals in Kenya especially regarding spiritual care where most hospitals

have a spiritual leader attached to them and as such they are easily accessible by nurses when a family loses their loved one. There is also a similar observation as far as a counsellor/psychologists is concerned. The availability and accessibility of the spiritual leader and/or a counsellor/psychologist could have led the participants to perceive their institution as being more effective in provision of EOLNC.

Low self-confidence by the nurses towards EOL care is well documented in literature. For instance, in a study on nurses' perceived self-confidence in provision of EOL care, Coffey et al (2016) observed that nurses did not consider themselves to be effective in provision of EOL care. Additionally, low perception by nurses regarding their self-perceived EOL care competencies was also noted in one other study by Montagnini and colleagues (2012).

Interestingly, the same study noted that the nurses scored their confidence much lower than their counterparts in the medical field. Lack of confidence by nurses towards provision of EOL care could be linked to the fact that the nursing profession has for decades been considered an aide to the doctor and thus all the nurse was expected to do was to carry out orders. This position may have affected the perception that nurses have towards themselves. Finally, issues regarding EOL are majorly a personal experience and as such, one is likely to behave depending on their perception of EOL and also their level of self-awareness. These aspects are likely to have led to the low perception reported in this study by the nurses as far as their effectiveness in provision of EOLNC was concerned.

Moreover, in the practice dimension, majority of the participants (92.9%; n=158) confirmed that they take care of dying patients during their practice and recorded that their practice skills were inadequate. Most of them indicated that the dilemmas identified were not common in their practice (M=1.5). This finding is likely to reflect the inadequate knowledge towards EOLNC which may have hindered the respondents from identifying the barriers in the first place due to lack of insight. Additionally, regarding barriers to provision of good quality EOLNC, findings suggested that all the items listed were barriers to some extent.

Nonetheless, item 2 on *"Lack of knowledge by health care professionals*" and item 12 on "*Lack of continuity of care across settings*" were rated by most participants as severe barrier to provision of good quality EOLNC. This therefore posed a challenge to provide good quality EOLNC as patients who are nearing/at their EOL exhibit various symptoms (Stenzel et al., 2015) and as such

there is need for multidisciplinary approach to care for them and a good plan for continuity of care ought to be formulated. Thus, the need for continuity of care.

The benefits of continuity of care in all settings at EOL care are well documented in literature. For instance, Wilmont (2015) recorded patients' experiences as "comforting" while approaching death. This was achieved through honest discussions with patients and family members which in turn eased their discomfort. Moreover, in yet another study, the importance of meeting patients' and families' needs as death approached made the discomfort bearable (Rodgers et al., 2016).

6.1.3. Gaps in Existing nursing educational program

Regarding the adequacy of basic nursing education program in preparation of nurses to provide EOLNC, findings from this study affirmed the fact that most items in the knowledge dimension were inadequately covered in the basic nursing program. The inadequacy of EOL care content in the basic nursing program, was documented by Montagnini and colleagues (2012) in their study on what nurses perceived to be EOL care competencies. Additionally, the gap that exists in the basic nursing program as far as EOLNC content is concerned was also recorded in a different study by Glover et al, (2017).

In this study, among the items scored for adequacy of EOL care content in the basic nursing education program only one item (3) of the nine items had a mean score > 2 as the rest were below 2; the item on "*Other symptoms management (i.e. dyspnea, restlessness) at EOL"*. The favorable scoring for this topic could be attributed to the fact that most topics may have been covered in the basic nursing program under the general management of patients.

Interestingly, the deficit in EOL care content in the basic training curricula was not only limited to nurses. Sinha et al (2015) noted that the medical curriculum did not adequately emphasize EOL care and the role of support services e.g., hospice, and interprofessional collaboration. Findings from this study highlighted the need and importance of interprofessional education as a vehicle to provision of safe and high-quality EOLC.

Many factors may be attributed to the existing gap as far as EOLNC knowledge in basic nursing program is concerned. For instance, the beliefs of teaching staff arising from EOL experiences which are unique to each individual can change the attitude and meaning of what students are actually taught (Condon, Grimsley, Kelley, & Nissen, 2013). Dillard and Siktberg (see Condon *et al*, 2013) observed

that teaching staff may be uninformed of what students learn through faculty expressions, priorities and interaction with them but students are very cognizant of this; and these gestures from the faculty craft a more lasting impact on the students than what is actually taught.

Moreover, the current study noted that a small number of the respondents possessed a high level of knowledge on EOLNC. The high level of knowledge demonstrated by these few respondents highlighted the aspect of experiential learning as it can be implied that the knowledge that the nurses demonstrated to possess may have been acquired during practice (Abate et al., 2019). As such, there is need for critical mass in EOLNC to foster mentorship as it is evident that learning also happens during practice.

Conversely, there is need for a structured education program regarding EOL and the care involved (Sinha et al., 2015) . This is so because, people suffering from life-threatening illnesses have numerous technological advances obtainable to them to elongate and support their life. These technological advances change from time to time and hence the need for nurses to remain abreast (Goel, et al., 2014).

Finally, findings from this study showed that majority of the sample (92.3%; n=156) emphasized the importance for the EOLC content to be enhanced in the basic nursing education program. This is because students take care of dying patients during their study period as was confirmed in the current study by majority of the respondents (87.5%). Moreover, nurses are the frontline caregivers for those nearing the EOL (Hendricks-Ferguson, Sawin, Montgomery, Phillips-Salimi, & Haase, 2015). As such, patients and/or their families expect to obtain expert EOLC characterized by good symptom management, physical care, and integrated care (Virdun et al., 2017) all of which will require a nurse who is well versed with EOL care knowledge

6.2. Discussion on EOL nursing care competencies

6.2.1. Panel Demographics

Regarding the panel demographic characteristics, my results indicated that there was equal representation of both female and male genders. This differed from results in most studies which had a big representation of the female gender (Lalloo, Demou, Kiran, Gaffney, et al., 2016; Lee et al., 2015); and in other scenarios of a Delphi studies all experts were female (Bostwick & Linden, 2016; Toronto, 2016). The difference in gender representation in my study could be attributed to

the fact that the experts involved had acquired more competencies beside general nursing which may have propelled more male nurses to advance to areas of interest and move away from general nursing.

Most (55%) of the experts were above 30 years an observation that was similar to other studies (Bostwick & Linden, 2016; Lalloo, Demou, Kiran, Gaffney, et al., 2016). This could be explained by the fact that to undergo nursing training to acquire more competencies one is required to have acquired a basic nursing level and thereafter undergo another training in area of interest. Additionally, majority of the experts had a post basic diploma which is undertaken after two years of formal employment as a registered nurse. That is, one is required to have undertaken a diploma in nursing which is three and a half years; after which on is required to have practice as a registered nurse for two years prior to admission for a post basic diploma.

There was equal distribution in area of practice with half of the experts working in the clinical area and the other half in the academics. The use of a heterogeneous group of experts has been documented in previous Delphi studies (Joyner & Stevenson, 2017; R Avella, 2016). Additionally, Frenk and colleagues (2014) in their study on developing global health competency model majority of the participants were from academics and the other group were practitioners. A heterogeneous composition of the expert group was also noted in other studies (Hughes et al., 2016; Lee et al., 2015).

Though most of the experts were aged above 31 years, 65% of them had been in their area of practice for more than five years. Panel membership as was reported by R Avella (2016) is a task that is not left to the researcher to decide. Instead various parameters such as academic qualifications, years of practice, interest, time etc. are utilized. In my study, snowballing was utilized to constitute the panel members.

Interestingly, my study results indicated that none of the experts had an advance directive. This observation may reflect the fact that nurses lack knowledge regarding EOLNC as an advance directive is one of the components in EOLNC. The lack of knowledge on advance directives was noted in a study by Coffey and colleagues (2016). This observation from my study could be attributed to the fact that there is no legislation on Ads and thus little attention is given to this aspect. Moreover, Kenya as a country has many religions and thus the view towards Ads maybe diverse complicating its popularity further.

6.2.2. Competencies for EOL nursing care

Following the review of the initial 8 ELNEC competencies as suggested in round 1, the two round survey validated the 8 ELNEC competencies as core EOL nursing care clinical competencies. As a result, the following were considered the core competencies: a) Palliative Care Nursing, 2) Pain Management, 3) Symptom Management, 4) Ethical-Legal issues, 5) Psychosocial, Cultural and Spiritual considerations, 6) Communication, 7) Loss, Grief and Bereavement, and finally, 8) Death and Dying. The relevance of the 8 ELNEC core competencies that was reported in this study, is consistent with what Mollay et al (2011) documented following an ELNEC training that was conducted in Kenya in 2008 where participants indicated that the 8 ELNEC competencies were relevant to the Kenyan setting.

However, regarding the sub competencies in each core competency, participants suggested a number of additional sub competencies for each core competency. This was as follows: to begin with, in the Palliative Care Nursing core competency, two additions were proposed. These were, demonstrate an understanding of the role of the multidisciplinary team; and be able to develop a patient-care plan using the nursing process (NP) and in a team-based manner. The desire for these sub competencies is likely to have originated from the principles of palliative care that advocates for a holistic approach to care provision and thus the need for interprofessional collaboration (Coulter et al., 2015; Ho et al., 2016; Kobewka et al., 2017). The inclusion of the nursing process as a sub competency is key in provision of nursing care.

The nursing process was proposed by Yura and Walsh in 1967 as a decision making approach that promotes critical thinking (Stonehouse, 2017) and it comprises of a cyclical process of five stages (Semachew, 2018). The importance of the nursing process reported in this study is consistent with findings of a study that was conducted in Kenya which indicated that implementation of the nursing process led to improved quality of nursing care in hospitals (Wagoro & Rakuom, 2015). The proposal by the experts to add a competency in nursing process could have arisen due to the fact that the experts are nurses and as such understand the benefits of utilizing the nursing process in management of patients with life threatening illness(s).

In the Pain Management core competency, the following were suggested as additional sub competencies: a) demonstrating an understanding of the principles of pain management; and b) being able to administer the appropriate analgesics including opioids. Pain management at EOL is

critical to reduce suffering which is associated with a 'bad death' (Burles et al., 2016). The proposal from the experts to include a competency on administration of analgesics as opposed to prescription is likely to have emanated from the fact that in Kenya, nurses at whichever level, have limited prescriptive rights. However, they are required to administer treatment, monitor and evaluate the patient during the treatment period and as such the need for knowledge in pain management (Sedillo et al., 2015).

Demonstrating an understanding of the complementary therapies; and being able to identify palliative care emergencies and intervene appropriately were additions to the Symptom Management core competency. Patients at EOL are likely to present with multiple symptoms some of which can be reversed leading to improved quality of life (Armstrong et al., 2019). The desire to have these sub competencies added is likely to have originated from the role the nurse plays during care provision at EOL, that of promoting comfort in all facets of a patient life.(Abate et al., 2019; Hu et al., 2019)

Identifying the ethical and legal management issues that impact on symptom management such as will writing and patient rights; and application of ethical principles in provision of EOL care were added to the Ethical-Legal issues core competency. The proposal for inclusion of these sub competencies is likely to have been triggered by the need to embrace advance directives in care planning (Brännström & Jaarsma, 2015) which may have ethical-legal implications(Bülbül et al., 2015; Cipolletta & Oprandi, 2014) particularly in Kenya where the law is silent on advance directives.

Demonstrating an understanding of the effects of a terminal illness to sexuality; Understanding the types of informal care givers and the role they play in EOL care; Being non-judgmental regarding patient sexuality while providing EOL care; and Being able to identify informal care giver's needs were potential additions to the Cultural and Spiritual core competency. This may have been triggered by the fact that the presence of a life threatening illness impacts heavily on both the patient and the family, and as such there is need to support the patient and the family care givers in all aspects of their lives (Bijnsdorp et al., 2019; Grant, 2017; Hu et al., 2019)

Further, demonstrating an understanding of breaking bad news to a patient/family; and being sensitive while communicating to patients/informal care givers were suggested for inclusion into Communication core competency. Experts may have suggested the inclusion of these sub

competencies due to the need to foster collaborative relationships during care provision and the importance of effective communication in the whole trajectory of care.(Coyle et al., 2015; Nouvet et al., 2016; Ó Coimín et al., 2019; Price et al., 2017)

Moreover, in the Loss, Grief and Bereavement core competency, demonstrating an understanding of the referral mechanisms was added. The proposal to include this sub competency could have emanated from the understanding that the nurses under investigation were non-specialist palliative care nurses and as such may be limited in handling complicated grief which is quite common following death (Kentish-Barnes et al., 2016). Hence, it is important for this group of nurses to understand referral mechanisms not only for complicated grief, but any other aspects that patients maybe experiencing distress in order to refer appropriately.

In the eighth and last core competency, understanding the role of a nurse during death and dying was added to the Death and Dying core competency. Experts could have suggested the inclusion of this sub competency due to the fear that nurses have expressed regarding death and dying (Barrere & Durkin, 2014; Lewis, 2013) and understanding their role would enable them to be adequately involved. Adequate involvement by nurses in EOL care is key for provision of high quality EOL care as it is noted that they interact with patients the most during their hospital stay (Barrere & Durkin, 2014; Lewis, 2013).

It is therefore indispensable that hospital nurses play a key role in provision of high quality EOL care and as such they require to be well versed with EOL clinical competencies if this objective is to be achieved. This study aimed to develop guidelines for EOL nursing care clinical competencies with a focus on nurses working in acute setting. The combined results of the 2 surveys were used to create a guideline for requisite clinical competencies (table 45) for non-specialist palliative care nurses for provision of high quality EOL care.

Clinical competency guidelines facilitate the transfer of research evidence into practice (McDonald et al., 2019; Norris et al., 2019; Tetreault et al., 2019). This is so because the guidelines describe the required behavior by the professional which contributes to improved care when the guidelines are effectively implemented. The positive impact of clinical competency guidelines in care provision is documented in literature (McDonald et al., 2019; Tetreault et al., 2019). There exist different approaches to development of clinical guidelines. Systematic reviews are the gold-standard approach for synthesizing research evidence (Petkovic et al., 2020) and should thus be

the foundation of guidelines, but the substantial time and resources required to produce them potentially limit their contribution and uptake into clinical guidelines.(Norris et al., 2019)

However, it is reported that there is potential for a wider range of evidence to be included in the guideline development process at both national and local levels.(Petkovic et al., 2020; Steels & van Staa, 2019; Verschueren et al., 2019) This study considered experts within the country for identification and validation of the EOL care competencies. Mainly, the developed competencies were from the perspective of palliative care nurse experts within the country. Thus, this excluded opinions from other members in the collaborative team.

Namely, families who have been through the EOL experience and were recipients of EOL nursing care services. Inclusion of the bereaved families into the development of clinical competency guidelines would facilitate gathering of opinions which will in turn be used to refine the identified EOL nursing care competencies and as a result improve EOL nursing care.(Aiyelaagbe et al., 2017) In this regard, the identified list of competencies is not extensive.

6.3. Theoretical Framework

This study was based on two theories: Rosemarie Parse's theory of human becoming and Kolcaba's theory of comfort; this section therefore provides a discussion on the relevance of the theory to the outcome of this study. Nurses are the health care professionals who spent much of the time with the patients (Hendricks-Ferguson et al., 2015). This emphasizes some characteristics of nursing practice which requires nurses to be humanly present and be personally involved in patient care. This reflects a component of the nurse and professor Rosemarie Parse's theory of human becoming. Parse's theory posits that the goal of the nursing practice is to improve health without considering any problems to be solved, but rather it is the subjective understanding of health that is to be improved, not necessarily the health condition itself.

This is a critical understanding for nursing as it emphasizes the need for planning with the patient and their families on goal of care. Therefore, for this to be effectively done, nurses will be required to possess a set of competencies that enable them to perform optimally. This study identified the requisite competencies for provision of high quality EOL care. The competencies identified are in alignment with the elements of health and well-being as indicated by Parse's human becoming

theory. This is especially so regarding the humanly presence of the nurse in care provision as well as valuing the subjective experience of quality of life.

Further, care provision to the dying is a challenge to many nurses (Verhofstede et al., 2015) especially pertaining to emotional engagement. However, the human becoming theory supports the importance of clinical experience for nurses in caring for the dying. The subjective journey of the patient and the nurse increases the nurses' awareness and insight. This is critical in nursing as the education component only will not teach the subjective understanding of health as this needs to be experienced.

According to Kolcaba's theory of comfort, nurses identify comfort needs of patients and/or family members and they design and coordinate interventions to address these needs (Coelho et al., 2016). Therefore, Kolcaba posits that patients get strengthened as their needs for three types of comfort (relief, ease, or transcendence renewal) are met in four contexts of human experience (physical, psychosocial, environmental, and social) (Betül Tosun et al., 2015). This is in line with the primary goal for high quality EOL care which is to promote comfort and dignity to patients and their families (Ferrell et al., 2015; Malloy et al., 2011).

This is important especially for patients with advanced disease who still experience discomfort (Brännström & Jaarsma, 2015; Cipolletta & Oprandi, 2014). This could be explained by the fact that these patients often have comfort needs that extend beyond physical symptoms management. As such, it is imperative that nurses possess competencies that go beyond the management of physical discomfort to include other aspects of patients' life.

The competencies identified in this study are in line with Parse's theory of Human Becoming which emphasizes the physical presence of the nurse during care provision; and Kolcaba's theory of comfort that emphasizes the importance of nursing interventions that promote comfort in all four facets. That is physical comfort which refer to bodily sensations (such as pain); psycho spiritual comfort which relates to internal self-awareness (such as sexuality); socio-cultural comfort which relates to interpersonal relationships (such as relationship with health team); and environmental comfort which relates to external surroundings (such as the safety of the environment, lighting, noise) (Betül Tosun et al., 2015; Gayoso et al., 2018) .

6.4. Conclusion

Findings from the first phase of this study noted that nurses had deficiencies in the level of EOL nursing care knowledge, attitudes and practice. The existing basic nursing curricula was noted to have gaps pertaining to content on end of life as majority of the nurses indicated that the program was inadequate in preparation of nurses for provision of end of life nursing care. Further, the study observed that there was no major difference regarding nurses' preparedness to provide EOLNC and their workstation. However, the respondents working in palliative care department were noted to possess a higher level of EOLNC knowledge than their colleagues. A similar observation was recorded as far as training needs were concerned. There was no workstation that was noted to be more or less prepared than the other. Hence, there was no relationship between training needs and workstation.

The second phase of the study indicated that consensus was reached among the experts regarding the EOL nursing care core and sub competencies requisite for provision of high quality EOL nursing care. Both surveys were found to be critical as they determined what EOL care competencies nurses should possess. The requisite competencies, as identified in this study, to provide care for individuals at EOL and their families could be used to guide future policy making. However, further validation of these competencies is required, both as an educational resource and as a strategy for actual practice.

6.5. Recommendations

This study established that the nurses had inadequate knowledge, attitude and practice skills. Hence, there is need to develop protocols relating to EOLNC and ensuring continuous monitoring and assessment of procedures and structures for providing EOLNC. This is vital, for determining their effectiveness, monitor performance over time and establish key areas for enhancement.

This study established that a gap exists in the basic nursing programme as far as EOLNC content is concerned. Therefore, there is need for evaluation of the EOL care content that has been integrated into the nursing curricula to guide decision-making on the best approaches to utilize to facilitate learning. Further, integration of clinical experience for nursing students to provide care to dying patients will boost the students' learning.

This study provides a starting point for understanding EOL care clinical competencies for nurses in Kenya. The competencies identified in this study need further examination in practice and in actual educational settings.

The opinions of nurses who provide end-of-life care as part of their role, bereaved families, and nursing students also need to be included to refine the nurses' end-of-life care competencies. These views could be gathered through for instance a phenomenological study.

Further studies with larger sample sizes representative of more geographical locations may lead to a more applicable clinical competency guideline for end-of-life care for nurses.

Finally, a large-scale survey to examine the appropriateness of the identified competencies during clinical application; as well as the relationship among these competencies, ongoing evaluation of competence, and the actual performance of nurses.

6.6. Implications

6.6.1. Practice

Lack of appropriate training for nurses on facilitating quality EOL care, renders them incapable of providing high quality EOLNC. Therefore, courses on EOLNC in Kenya ought to be stressed on by hospitals during on-the-job education and training. Additionally, interdisciplinary teams may well be constituted within the hospitals to offer focused EOLNC for persons who are nearing/at EOL. Furthermore, in Kenya, EOLNC as a specialty is still in its initial stages. On the road to improvement of quality of care provided to patients at or nearing their EOL, applicable knowledge and skills need to be reinforced among nurses in the specialized units, whereas capable persons should be trained as EOL clinical nurse experts. The guidelines developed in this study could help practitioners to develop continuous professional development programs for nurses to update their competencies. Additionally, it could form the basis for competency assessment within the clinical setting.

The modified Delphi survey method used in this study may be used to identify and validate nurses' competencies. Developing guidelines for nurses' competencies in this manner will result in better alignment with current health care needs and health services trends. The method may be adapted as necessary for the particular nursing specialty or panel of experts. All core and sub competencies

listed achieved consensus as either being at the most significant level or more significant level, and therefore, could be key indicators for end-of-life nursing care standards of practice.

6.6.2. Education

The results of this study are specific to the researcher's institution, however they were in agreement with what is documented in the literature. Therefore, this provides a platform for integration of EOL nursing care content in clinical settings. Further, focused education utilizing the identified competencies is recommended. On the other hand, prior to implementation of an EOL care education programme, it is important to conduct a baseline needs assessment to identify unique needs for each unit according to patient acuity level. Delivery of these competencies to registered nurses should embrace effective pedagogical methods using active learning strategies, e.g., simulation and roleplaying.

In addition to learning knowledge and practice skills, attitudes also are learned. They take time to inculcate in novices since the affective learning domain is challenging to measure. More so because, students' attitudes and values have significant impact on the results of what is learnt, especially associated with behavioral changes. For that reason, it is crucial that the attitude domain remains connected to other learning domains; failure to which outcomes of education efforts will reduce drastically.

Evaluation of these competencies in nursing education programs is key to prospective EOLNC education efforts geared towards improving patient/client outcomes. Development and utilization of instruments that highlight the importance of interprofessional collaboration may help nurses to comprehend the roles and perceptions of other members in the multidisciplinary team in provision of EOL care. As a result, decision-making at EOL will be logical as well as synchronized.

Finally, nurse educators could also use the framework to develop clinical experience tool for nursing students to be integrated in their clinical experience. Teaching students end-of-life care during the course of their clinical experience is an effective way to improve knowledge, attitudes and skills about end-of-life nursing care.

6.6.3. Policy

The 92 EOLNC competencies on which consensus was gained can serve as a guideline for the design of EOLNC programs in Kenya. The EOLNC common competencies highlighted in this

study will enable health care facilities with formulation of standard as well as practice procedures that tackle the required EOLNC skills, knowledge, and attitudes competencies for professional practice among registered nurses. A formal policy framework needs to be developed shading light on the national methodology to EOL care comprising but not limited to procedures for advance care planning; regulation of medical treatment; referral for expert palliative care advice and services; and finally, alignment with systems for recognizing and responding to clinical deterioration. Lastly, the results of this study can be incorporated into a focused discussion led by the Nursing Council of Kenya to develop national standards of EOL practice for nurses in Kenya.

Table 6.1: End-of-Life Nursing Care Competency Guidelines (EOLNC-CG) for nurses in Kenya

Core Competencies	Sub Competencies*	
Palliative Nursing Care	1.1	Knowledge
	1.1.1	Understand the key concepts in palliative nursing care
	1.1.2	Explain the general principles of palliative nursing care
	1.1.3	Discuss approaches used in palliative care
	1.1.4	Demonstrate an understanding of the role of multidisciplinary team
	1.1.5	Describe support systems available and how to access appropriate support services
	1.1.6	Awareness of triggers and reactions to stressful/distressing situations
	1.1.7	Understand referral patterns and access to specialist palliative care
	1.1.8	Demonstrate an understanding of the approaches to assessment in palliative care tools which may be utilized in the holistic assessment process
	1.2	Attitudes
	1.2.1	Respect the roles, responsibilities and boundaries in multi-professional working
	1.2.2	Value the opinions and views of others
	1.2.3	Value the collaborative approach to working with other services across various sectors
	1.2.4	Be respectful and empathetic to patients/clients with life-limiting conditions as you provide individualized care..
	1.2.5	Be supportive and caring to the patient and his/her family
	1.2.6	Be an advocate for patients/clients and ensure appropriate and timely palliative care interventions at EOL
	1.3	Skills
	1.3.1	Be able to apply research findings to improve end-of-life nursing care outcomes
	1.3.2	Effectively work in partnership with other specialist teams
	1.3.4	Be able to develop a patient-care plan using the nursing process and in a team-based manner
	1.3.5	Be able to recognize when the person's care needs are complex and warrant referral to specialist palliative care
Pain Management	2.1	Knowledge
	2.1.1	Explain the importance of a holistic approach to pain assessment and management
	2.1.2	Describe the principles of pain management for patients with advanced progressive disease
	2.1.3	Identify the common physical, spiritual, and psychosocial issues that impact on pain management
	2.1.4	Describe the pharmacological and non-pharmacological aspects of pain management
	2.1.5	Describe barriers to pain management

	2.1.6	Demonstrate an understanding of the principles of pain management
	2.2	Attitudes
	2.2.1	Be respectful and sensitive to the patient's/family's subjective experience(s)
	2.3	Skills
	2.3.1	Utilize appropriate skills to assess, diagnose and manage pain
	2.3.2	Be able to administer the appropriate pain therapies including opioids as prescribed
	2.3.3	Be able to monitor outcomes of both pharmacological and non-pharmacological management plans
	2.3.4	Be able to utilize principles of pain management
Symptom Management	3.1	Knowledge
	3.1.1	Explain the importance of a holistic approach to symptom assessment and management
	3.1.2	Describe the principles of palliative symptom management for patients with advanced progressive disease
	3.1.3	Identify the common physical, spiritual, and psychosocial issues that impact on symptom management
	3.1.4	Describe the causes and presentation of palliative care emergencies
	3.1.5	Demonstrate awareness and understanding of Advanced Care Planning, and the times at which it would be appropriate
	3.1.6	Understand common chronic illness, the expected natural course and trajectories, common treatments and complications
	3.1.7	Demonstrate an understanding of the complementary therapies
	3.2	Attitudes
	3.2.1	Treat everyone with whom you come into contact with dignity, respect, humanity and compassion
	3.2.3	Value the ethical principles involved when planning care
	3.3	Skills
	3.3.1	Be able to assess, diagnose and manage common symptoms at end of life associated with life-limiting conditions.
	3.3.2	Set realistic goals of care in partnership with patient/carer(s)
	3.3.3	Be able to identify palliative care emergencies and intervene appropriately
	3.3.4	Regularly review and evaluate care management plans and update appropriately
	3.3.5	Refer in an appropriate and timely manner to specialist palliative care team, or other disciplines as necessary
Ethical and Legal issues	4.1	Knowledge
	4.1.1	Understand the relevant laws and policies or regulations
	4.1.2	Discuss ethical principles and their application to end-of-life nursing care
	4.1.3	Identify and discuss issues such as informed choice, mental capacity/incapacity legislation, consent, confidentiality and patient autonomy

	4.1.4	Understand the ethical and legal management issues that impact on symptom management e.g., will writing, patient rights, euthanasia
	4.2	Attitudes
	4.2.1	Be professional when the patient/family requests for further/modification of treatment .
	4.3	Skills
	4.3.1	Collaborate with others in the use of an ethical framework which guides decision making in the context of end of life care
	4.3.2	Apply ethical principles in provision of end of life care
	4.3.3	Implement and monitor outcomes of ethical decisions
	4.3.4	Share and document information sensitively and while respecting confidentiality
Psychosocial, Cultural and Spiritual considerations	5.1	Knowledge
	5.1.1	Understand how one's own personal beliefs and philosophy of life impact on the ways we act and interact with others
	5.1.2	Identify the spiritual and/or religious needs of patients/families/carers and describe how they may be addressed
	5.1.3	Demonstrate an understanding of cultural issues at EOL care
	5.1.4	Understand various aspects of spiritual care
	5.1.5	Demonstrate an understanding of the concept of sexuality and how this is affected by the presence of a terminal illness
	5.1.6	Understand the types of informal care givers and their role in EOL care
	5.2	Attitudes
	5.2.1	Be objective and neutral to the patient and his/her family irrespective of the spiritual stance
	5.2.2	Be non-judgmental regarding patient sexuality while providing EOL care
	5.2.3	Respect the opinions of the informal caregivers
	5.3	Skills
	5.3.1	Be able to establish and respect people's wishes about their care and options/preferences
	5.3.2	Be able to provide last offices in the context of the individuals' beliefs, culture and religious practice
	5.3.3	Identify the care needs of people from different cultural and religious backgrounds
	5.3.4	Be able to identify informal care giver's needs and intervene appropriately
Communication	6.1	Knowledge
	6.1.1	Demonstrate an understanding of the components of open and sensitive communication
	6.1.2	Understand the importance of using strategies that empower effective communication e.g. active listening, plain language, appropriate tone, empathy
	6.1.3	Explain the importance and impact of non-verbal and verbal communication within all aspects of care

	6.1.4	Demonstrate an understanding of the process of breaking bad news to a patient/family
	6.1.5	Explain the concepts of counselling
	6.2	Attitudes
	6.2.1	Show respect for cultural and religious diversity when communicating with the family unit
	6.2.2	Value the importance of establishing a rapport with the patient/carer based on openness, honesty and trust
	6.3	Skills
	6.3.1	Be sensitive and effective in your communication to patients and informal care givers
	6.3.2	Be flexible and modify personal communication style to facilitate communication with persons with a range of communication impairments..
	6.3.3	Utilize counselling skills in the care of a patient/family
	6.3.4	Communicate with family/carers as appropriate, to determine anticipated care outcomes
Loss, Grief and Bereavement	7.1	Knowledge
	7.1.1	Understand that grief is a normal and appropriate response to loss which has physical, psychological, spiritual, emotional and social aspects that affect how it is experienced.
	7.1.2	Understand the personal impact of loss, grief and bereavement.
	7.1.3	Understand the strategies to identify the losses that persons with cognitive and sensory impairment encounter and intervene appropriately
	7.1.4	Demonstrate an understanding of the referral mechanisms to appropriate support services
	7.2	Attitudes
	7.2.1	Respect the individual nature of the grief response
	7.3	Skills
	7.3.1	Demonstrate self-awareness of personal experiences of loss, to prevent them from negatively impacting on patients/clients..
	7.3.2	Be able to provide support in order to help the family to adapt to the bereavement and loss
	7.3.3	Be able to engage with a person who is experiencing loss in the context of professional scope of practice and/role
	7.3.4	Be able to identify those experiencing complicated grief and utilize resources to appropriately support them
Death and Dying	8.1	Knowledge
	8.1.1	Outline the practical issues surrounding the death of a patient, for example, death certification and registration
	8.1.2	Demonstrate knowledge of issues and policies relating to any legal, cultural, religious or health and safety requirements when caring for the patient’s body
	8.1.3	Understand the role of a nurse during death and dying

	8.2	Attitudes
	8.2.1	Value the need for dignity and respect towards the patient and others at and around the time of death
	8.3	Skills
	8.3.1	Care for the patient's body after death, respecting any wishes expressed by the family and any particular religious rites
	8.3.2	Ensure appropriate identification/verification/certification of death, and care of the patient's body throughout duration of care
	8.3.3	Be able to anticipate, recognize and respond effectively to signs and symptoms of imminent death

**The list is not exhaustive….*

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APPENDIX I: NURSES' SURVEY CONSENT FORM

Dear Participant,

My name is **Gladys Warindi Machira**. I am a student at The University of Nairobi undertaking a degree in Doctor of Philosophy. I am conducting a study on **to assess nurses' preparedness to provide end-of-life nursing care** as a requirement for my studies. The importance of this study is that it will identify gaps in end-of-life nursing care (EOLNC).

In order to obtain the required information, a questionnaire will be used. I am kindly requesting you to participate in the study by filling in the questionnaire. Participation is voluntary and there is no penalty for declining to participate. You are free to withdraw from the study at any stage without fear of victimization. There are no risks involved. The information you provide will be treated with total confidentiality and you are not required to write your name or any other identification number on the questionnaire.

Findings from this study will inform decision-making on requisite competencies for EOLNC and as such benefit the nurses in that their EOLNC ability will be improved. This in turn will lead to improved quality of EOL care leading to '*good death*' for patients. Moreover, findings from this study will also inform policy on EOL care as well as nursing education and practice in EOL nursing care as competency guidelines will be developed. In the end, after the utilization of the findings there will be improved care for all patients at or nearing their EOL in Kenya. If you would wish to ask any questions about your rights as a participant or anything else about the research that is not clear, please contact me on **0733340039.**

I hope that you will complete and return the questionnaire to me. It should take approximately 20-30 minutes of your time.

Thank you for your time.

Respondent's consent:

I have read and understood the above details about the research. I voluntarily agree to participate in the study.

Respondent's sign …….. Date: ……..

Investigator's sign ……... Date: ……..

APPENDIX I1: QUESTIONNAIRE FOR NURSES

QN NO: …… **DATE: ……..**

Research to assess nurses' preparedness to provide end-of-life nursing care in an acute hospital

Instructions

1. Information obtained with this questionnaire is for study purposes only. Your responses will be held in total confidence.

2. Do not write your name.

3. The questionnaire has four sections and you are being requested to complete all the sections.

4. Place the filled questionnaire in the box provided.

Section A: Demographic characteristics:

Write/choose or respond by ticking the most appropriate responses

1. Please indicate your Gender: (**Tick appropriately**)
    1) Female
    2) Male
2. Indicate your age in completed years ……

3. Indicate your highest level of nursing qualifications: (**Tick appropriately**)
    1) ECN
    2) KRN`
    3) KRN/M
    4) KRCHN
    5) BScN
    6) MScN (specify area of specialization) …….
    7) Other ……

4. Please indicate your work station: (**Tick appropriately**)
    1) Intensive Care Unit/ Critical Care Unit
    2) High Dependency Unit
    3) Renal Unit / Nephrology Unit
    4) Burns Unit
    5) Cardiac Unit/ Cardiac Centre
    6) Palliative Care Unit
    7) Other (Please specify) ……

5. Please indicate the duration you have worked in the unit above? …….. years

6. Please indicate your **MAJOR ROLE** in the unit: (**Tick appropriately**)
    1) Direct patient care
    2) Administration
    3) Teaching / Clinical instruction
    5) Research
    6) Health promotion / Health education
    7) Nursing Policy implementation

4) Infection control 8) Other ……...

7. Indicate the number of years you have you practiced nursing? …… years

8. List courses you have undertaken to improve your work performance.

.....

.....

Section B: Nurses' preparedness to practice EOLNC

Knowledge
Instructions:

Please tell us what you feel your level of knowledge is on each of the following topics related to care of patients nearing or are at the end of their life.

1 = Expert; 2 = Moderate; 3 = Some; 4 = None

S. No.	Items (Topics)	1	2	3	4
1.	Goals of EOLC.				
2.	Pain management at EOL.				
3.	Management of other symptoms (e.g., dyspnea, restlessness) at EOL				
4.	Communication with patients/families at EOL.				
5.	Roles/needs of family care- givers in EOL.				
6.	Care of patients at the time of death.				
7.	Care of the body after death.				
8.	Ethical issues in EOL.				
9.	The role of a nurse in a family that is grieving/bereaved.				
10.	Cultural factors that influence EOL care.				
11.	Religious factors that influence EOL care.				
12.	Referral to hospice/Palliative Care Unit				
13.	Home care for a dying patient				

14. Overall, how knowledgeable are you regarding EOLC? (**Tick appropriately**)
……Not knowledgeable ……Somewhat knowledgeable

……Very knowledgeable

Attitude

15. Overall, how would you rate your effectiveness in the following areas? (**Tick appropriately**)

S. No.	Statements	Not at all effective	Somewhat effective	Very effective
A	Pain management			
B	Other symptom management			
C	Communication with terminally ill patients			
D	Communication with family caregivers			
E	Managing the death event at home			
F	Cultural issues in EOL care			
G	Overall EOL care for the terminally ill			

16. Overall, how would you rate the effectiveness of your institution is in the following areas? (**Tick appropriately**)

S. No.	Statements	Not at all effective	Somewhat effective	Very effective
A	Pain management			
B	Other symptom management			
C	Communication with terminally ill patients			
D	Communication with family caregivers			
E	Managing the death event at home			
F	Cultural issues in EOL care			
G	Overall EOL care for the terminally ill			

Practice

17. Please indicate how effective the following aspects of EOL care are in your setting? (**Tick appropriately**)

S. No.	Statements	Not at all effective	Somewhat effective	Very effective
A	Pain assessment			
B	Pain management			

C	Other symptom management			
D	Psychological support for dying patients			
E	Attention to spiritual needs			
F	Grief/bereavement support			

18. Please indicate how often the following EOL care dilemmas occur in your setting (**Tick appropriately**)

S. No.	Statements	Not common	Somewhat common	Very common
A	Preserving patient choice/self- determination			
B	Use of advance directives			
C	Requests for assisted suicide Requests for euthanasia Withholding/withdrawing medically provided nutrition/hydration			
D	Discontinuing life sustaining therapies			
E	Legal issues at the end of life			
F	Fear of causing death by giving pain medication			
G	Uncertainty about the patient's prognosis			

19. What is your believe regarding care of the dying today compared to 5 years ago? (**Tick appropriately**)

_____ worse than 5 years ago _____ about the same _____ better than 5 years ago

23. Overall, how would you rate the effectiveness of the following in caring for a dying patient in your setting? (**Tick appropriately**)

S. No.	Statements	Not effective	Somewhat effective	Very effective
A	Yourself			
B	Your nursing colleagues			
C	The physicians in your setting			

24. Please indicate how much of a barrier the following factors are to providing good EOL care in your setting? (**Tick appropriately**)

S. No.	Statements	Not a barrier	Somewhat of a barrier	Severe barrier
A	Lack of knowledge by health care professionals			
B	Health care professionals' personal discomfort with death			
C	Avoidance of dying patients by health care professionals			
D	Health care professionals fear of causing addiction by administering pain medications			
E	Patients' avoidance of death			
F	Family members' avoidance of death			
G	Cultural factors influencing end-of-life care			
H	Patients'/families' fear of addiction			
K	Legal restrictions placed on health care professionals in prescribing pain medications			
L	Lack of continuity of care across settings			

25. a) In your current role, do you care for dying patients? _____ Yes _____ No

b) If yes to the above question, has any patient asked for your help in getting a medication to use with the aim ending his/her own life?
Yes …… No ……..

26. Would you agree on the legalization of assisted suicide? …… Yes …….. No

27. Would you agree on the legalization of euthanasia? …….. Yes …… No

Education

28. Please indicate your thoughts on the adequacy of your basic nursing education program in preparing you in the following aspects of EOL care? (**Tick appropriately**)

S. No.	Statements	Not adequate	Somewhat adequate	Very adequate
A	Understanding the goals of palliative care			
B	Pain management at the end-of-life			
C	Other symptom management (i.e. dyspnea, restlessness)			

D	Communication with patients/families at end-of-life			
E	Role/needs of family caregivers in end-of-life care			
F	The care of patients at time of death			
G	Ethical issues in end-of-life care			
I	Overall content on end-of-life care			

29. While in nursing school, did you care for a dying patient? Yes No

30. Overall, how important do you believe EOL care content is to basic nursing education?
___ not important ___ somewhat important ___ very important

31. What special skills do you think a nurse requires in order to care for patients at EOL appropriately?
……..
……...
……

32. Please feel free to provide any other additional information on end-of-life care.
……
……

THANKYOU FOR YOUR TIME

APPENDIX III: DELPHI QUESTIONNAIRE ROUND 1

Section A: Consent

Title of Research Study: Development of evidence-based competency guidelines for end-of-life nursing care utilizing the Delphi process

Purpose:

Nurses frequently lack the competence necessary to assess and manage patients at/or nearing their end of life as well as their families. The purpose of this research study is to identify and validate end-of-life nursing care competencies which will inform the development of competency guidelines for end-of-life nursing care.

Principal Investigator: Gladys Machira B.Sc., MSc, PhD (c)

As one of the experts in palliative care who either come into contact with those nearing or are at their final hours or are teaching palliative care, you are being asked to participate in this Delphi Study. Delphi study is a systematic polling of the opinions of an expert panel knowledgeable on a given topic through iterative surveys in an attempt to reach group consensus on a given topic. The goal of this Delphi Study is the development of evidence-based competency guidelines for end-of-life nursing care.

In order to obtain the required information, a questionnaire will be used. I am kindly requesting you to participate in the study by filling in the questionnaire. Participation is voluntary and there is no penalty for declining to participate. You are free to withdraw from the study at any stage without fear of victimization. The information you provide will be treated with total confidentiality and you are not required to write your name or any other identification number on the questionnaire. If you would wish to ask any questions about your rights as a participant or anything else about the research that is not clear, please contact me on **0733340039.**

I hope that you will complete and return the questionnaire to me. It should take approximately 20-30 minutes of your time.

Thank you for your time.

Respondent's consent:

I have read and understood the above details about the research. I voluntarily agree to participate in the study.

Respondent's sign …….. Date: ……..

Investigator's sign ……... Date: ……..

Section B: Demographic information

Instructions: Please respond to the following questions in the spaces provided (circle/tick the most appropriate option)

1. What is your gender? a) Male b) Female
2. What is your age range?
   Under 21
   21-30
   31-40
   41-50
   51-60
   Over 60
3. What is your highest level of education?
   a) Diploma b) Bachelor's Degree
   b) Master's degree d) Doctoral degree
   e) Other
4. Which is your area of practice?
   a) Clinical b) Academic
5. Which option best describes your years of current employment in the above area of practice?
   Less than 1 year
   1-3 years
   Less than 5 years
   5 years
   Less than 10 years
   More than 10 years
6. Do you personally have an advance directive?
   a) Yes b) No

Section C: Core competencies for end-of-life nursing care (EOLNC)

Please RANK each subsection in terms of their importance as competencies for end-of-life nursing care (**Tick your response**).

5=Strongly Agree; 4=Agree; 3=Neutral; 2=Disagree; 1=Strongly Disagree

		1	**2**	**3**	**4**	**5**
A	Palliative nursing care					
B	Pain management					
C	Symptom management					
D	Ethical issues					
E	Cultural and Spiritual considerations					
F	Communication in end-of-life nursing care					
G	Loss, Grief and Bereavement					
H	Final Hours					

a) List any competency(s) that is (are) missing or require revision

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b) List the competency(s) you want deleted

Section D: Sub competencies for end-of-life nursing care (EOLNC)

Please RANK each subsection in terms of their importance as competencies for end-of-life nursing care (**Tick your response**)

5=Strongly Agree; 4=Agree; 3=Neutral; 2=Disagree; 1=Strongly Disagree

1. **Knowledge Dimension**

1.1	Palliative Care Nursing	1	2	3	4	5
1.1.1	Understand the key concepts in palliative nursing care					
1.1.2	Explain the general principles of palliative nursing care					
1.1.3	Discuss approaches used in palliative care					
1.1.4	Describe support systems available and how to access appropriate support services					
1.1.5	Awareness of triggers and reactions to stressful/distressing situations					
1.1.6	Understand referral patterns and access to specialist palliative care					
1.1.7	Demonstrate an understanding of the approaches to assessment in palliative care tools which may be utilized in the holistic assessment process					
2.1	Pain Management	1	2	3	4	5
2.1.1	Explain the importance of a holistic approach to pain assessment and management					
2.1.2	Describe the principles of pain management for patients with advanced progressive disease					
2.1.3	Identify the common physical, spiritual, and psychosocial issues that impact on pain management					
2.1.4	Describe the pharmacological and non-pharmacological aspects of pain management					
2.1.5	Describe barriers to pain management					
3.1	Symptom Management	1	2	3	4	5
3.1.1	Explain the importance of a holistic approach to symptom assessment and management					
3.1.2	Describe the principles of palliative symptom management for patients with advanced progressive disease					

3.1.3	Identify the common physical, spiritual, and psychosocial issues that impact on symptom management					
3.1.4	Describe the causes and presentation of palliative care emergencies					
3.1.5	Demonstrate awareness and understanding of Advanced Care Planning, and the times at which it would be appropriate					
3.1.6	Understand common chronic illness, the expected natural course and trajectories, common treatments and complications					
4.1	Ethical issues	1	2	3	4	5
4.1.1	Understand the relevant laws and policies or regulations					
4.1.2	Discuss ethical principles and their application to end-of-life nursing care					
4.1.3	Identify and discuss issues such as informed choice, mental capacity/incapacity legislation, consent, confidentiality and patient autonomy					
5.1	Cultural and Spiritual considerations	1	2	3	4	5
5.1.1	Understand how one's own personal beliefs and philosophy of life impact on the ways we act and interact with others					
5.1.2	Identify the spiritual and/or religious needs of patients/families/carers and describe how they may be addressed					
5.1.3	Demonstrate an understanding of cultural issues at EOL care					
5.1.4	Understand various aspects of spiritual care					
6.1	Communication	1	2	3	4	5
6.1.1	Demonstrate an understanding of the components of open and sensitive communication					
6.1.2	Understand the importance of using strategies that empower effective communication e.g. active listening, plain language, appropriate tone, empathy					
6.1.3	Explain the importance and impact of non-verbal and verbal communication within all aspects of care					
6.1.4	Explain the concepts of counselling					
7.1	Loss, Grief and Bereavement	1	2	3	4	5

7.1.1	Understand that grief is a normal and appropriate response to loss which has physical, psychological, spiritual, emotional and social aspects that affect how it is experienced.					
7.1.2	Understand the personal impact of loss, grief and bereavement.					
7.1.3	Understand the strategies to identify the losses that persons with cognitive and sensory impairment encounter and intervene appropriately					
8.1	Final Hours	1	2	3	4	5
8.1.1	Outline the practical issues surrounding the death of a patient, for example, death certification and registration					
8.1.2	Demonstrate knowledge of issues and policies relating to any legal, cultural, religious or health and safety requirements when caring for the patient's body					

2. Attitude Dimension

1.2	Palliative Care Nursing	1	2	3	4	5
1.2.1	Respect the roles, responsibilities and boundaries in multi-professional working					
1.2.2	Value the opinions and views of others					
1.2.3	Value the collaborative approach to working with other services across various sectors					
1.2.4	Be respectful and empathetic to patients/clients with life-limiting conditions as you provide individualized care..					
1.2.5	Be supportive and caring to the patient and his/her family					
1.2.6	Be an advocate for patients/clients and ensure appropriate and timely palliative care interventions at EOL					
2.2	Pain Management	1	2	3	4	5
2.2.1	Be respectful and sensitive to the patient's/family's subjective experience(s)					
3.2	Symptom Management	1	2	3	4	5
3.2.1	Treat everyone with whom you come into contact with dignity, respect, humanity and compassion					

3.2.2	Value the ethical principles involved when planning care					
4.2	Ethical issues	1	2	3	4	5
4.2.1	Be professional when the patient/family requests for further/modification of treatment .					
5.2	Cultural and Spiritual considerations	1	2	3	4	5
5.2.1	Be objective and neutral to the patient and his/her family irrespective of the spiritual standpoint					
5.2.2	Respect the opinions of the informal caregivers					
6.2	Communication	1	2	3	4	5
6.2.1	Show respect for cultural and religious diversity when communicating with the family unit					
6.2.2	Value the importance of establishing a rapport with the patient/carer based on openness, honesty and trust					
7.2	Loss, Grief and Bereavement	1	2	3	4	5
7.2.1	Respect the individual nature of the grief response					
8.2	Final Hours	1	2	3	4	5
8.2.1	Value the need for dignity and respect towards the patient and others at and around the time of death					

3. Practice Dimension

1.3	Palliative Care Nursing	1	2	3	4	5
1.3.1	Be able to apply research findings to improve end-of-life nursing care outcomes					
1.3.2	Effectively work in partnership with other specialist teams					
1.3.3	Be able to recognize when the person's care needs are complex and warrant referral to specialist palliative care					
2.3	Pain Management	1	2	3	4	5
2.3.1	Utilize appropriate skills to assess, diagnose and manage pain					
2.3.2	Be able to monitor outcomes of both pharmacological and non-pharmacological management plans					
2.3.3	Be able to utilize principles of pain management					
3.3	Symptom Management	1	2	3	4	5

3.3.1	Be able to assess, diagnose and manage common symptoms at end of life associated with life-limiting conditions.					
3.3.2	Set realistic goals of care in partnership with patient/carer(s)					
3.3.3	Regularly review and evaluate care management plans and update appropriately					
3.3.4	Refer in an appropriate and timely manner to specialist palliative care team, or other disciplines as necessary					
4.3	Ethical issues	1	2	3	4	5
4.3.1	Collaborate with others in the use of an ethical framework which guides decision making in the context of end of life care					
4.3.2	Implement and monitor outcomes of ethical decisions					
4.3.3	Share and document information sensitively and while respecting confidentiality					
5.3	Cultural and Spiritual considerations	1	2	3	4	5
5.3.1	Be able to establish and respect people's wishes about their care and options/preferences					
5.3.2	Be able to provide last offices in the context of the individuals' beliefs, culture and religious practice					
5.3.3	Identify the care needs of people from different cultural and religious backgrounds					
6.3	Communication	1	2	3	4	5
6.3.1	Be flexible and modify personal communication style to facilitate communication with persons with a range of communication impairments.					
6.3.2	Utilize counselling skills in the care of a patient/family					
6.3.3	Communicate with family/carers as appropriate, to determine anticipated care outcomes					
7.3	Loss, Grief and Bereavement	1	2	3	4	5
7.3.1	Demonstrate self-awareness of personal experiences of loss, to prevent them from negatively impacting on patients/clients..					
7.3.2	Be able to provide support in order to help the family to adapt to the bereavement and loss					
7.3.3	Be able to engage with a person who is experiencing loss in the context of professional scope of practice and/role					
7.3.4	Be able to identify those experiencing complicated grief and utilize resources to appropriately support them					

8.3	Final Hours	1	2	3	4	5
8.3.1	Care for the patient's body after death, respecting any wishes expressed by the family and any particular religious rites					
8.3.2	Ensure appropriate identification/verification/certification of death, and care of the patient's body throughout duration of care					
8.3.3	Be able to anticipate, recognize and respond effectively to signs and symptoms of imminent death					

a) List any competency(s) that is (are) missing or require revision **(please indicate section & number)**

---

b) List the competency(s) you want deleted **(please indicate section & number)**

THANK YOU FOR YOUR TIME

APPENDIX IV: DELPHI QUESTIONNAIRE ROUND 2

Dear Delphi Study panel member,

Thank you for agreeing to participate in the second round of the Delphi Study in order to identify and validate competencies needed by nurses to provide high quality end-of-life nursing care to a person who is at or nearing their end of life as well as their families.

This study aims to develop competency guidelines for end-of-life nursing care for use by nurses in practice for continuous professional development as well as in nursing education.

I hope that you will complete and return the questionnaire to me within 2 weeks. It should take approximately 20-30 minutes of your time to complete it.

Thank you for your time.

Sincerely,

Gladys Machira

Section A: Core competencies for end-of-life nursing care (EOLNC)

Please RANK each subsection in terms of their importance as competencies for end-of-life nursing care (**Tick your response**).

The asterisk (*) indicate sections that were revised following suggestions from round 1.

5=Strongly Agree; 4=Agree; 3=Neutral; 2=Disagree; 1=Strongly Disagree

		1	**2**	**3**	**4**	**5**
A	Palliative nursing care					
B	Pain management					
C	Symptom management					
D	*Ethical-Legal issues					
E	*Psychosocial, Cultural and Spiritual considerations					
F	Communication in end-of-life nursing care					
G	Loss, Grief and Bereavement					
H	*Death & Dying					

c) List any competency(s) that is (are) missing or require revision

---

---

d) List the competency(s) you want deleted

Section B: Sub competencies for end-of-life nursing care (EOLNC)

Please RANK each subsection in terms of their importance as competencies for end-of-life nursing care (**Tick your response**)

The asterisk (*) indicate competencies that were added following suggestions from round 1.

5=Strongly Agree; 4=Agree; 3=Neutral; 2=Disagree; 1=Strongly Disagree

2. Knowledge Dimension

1.1	Palliative Care Nursing	1	2	3	4	5
1.1.1	Understand the key concepts in palliative nursing care					
1.1.2	Explain the general principles of palliative nursing care					
1.1.3	Discuss approaches used in palliative care					
1.1.4	Describe support systems available and how to access appropriate support services					
1.1.5	Awareness of triggers and reactions to stressful/distressing situations					
1.1.6	Understand referral patterns and access to specialist palliative care					
1.1.7	Demonstrate an understanding of the approaches to assessment in palliative care tools which may be utilized in the holistic assessment process					
1.1.8	*Demonstrate an understanding of the role of multidisciplinary team					
2.1	Pain Management	1	2	3	4	5
2.1.1	Explain the importance of a holistic approach to pain assessment and management					
2.1.2	Describe the principles of pain management for patients with advanced progressive disease					
2.1.3	Identify the common physical, spiritual, and psychosocial issues that impact on pain management					
2.1.4	Describe the pharmacological and non-pharmacological aspects of pain management					
2.1.5	Describe barriers to pain management					
2.1.6	*Demonstrate an understanding of the principles of pain management					
3.1	Symptom Management	1	2	3	4	5
3.1.1	Explain the importance of a holistic approach to symptom assessment and management					

3.1.2	Describe the principles of palliative symptom management for patients with advanced progressive disease					
3.1.3	Identify the common physical, spiritual, and psychosocial issues that impact on symptom management					
3.1.4	Describe the causes and presentation of palliative care emergencies					
3.1.5	Demonstrate awareness and understanding of Advanced Care Planning, and the times at which it would be appropriate					
3.1.6	Understand common chronic illness, the expected natural course and trajectories, common treatments and complications					
3.1.7	*Demonstrate an understanding of the complementary therapies					
4.1	Ethical-Legal issues	1	2	3	4	5
4.1.1	Understand the relevant laws and policies or regulations					
4.1.2	Discuss ethical principles and their application to end-of-life nursing care					
4.1.3	Identify and discuss issues such as informed choice, mental capacity/incapacity legislation, consent, confidentiality and patient autonomy					
4.1.4	*Understand the ethical and legal management issues that impact on symptom management e.g., will writing, patient rights, euthanasia					
5.1	Psychosocial, Cultural and Spiritual considerations	1	2	3	4	5
5.1.1	Understand how one's own personal beliefs and philosophy of life impact on the ways we act and interact with others					
5.1.2	Identify the spiritual and/or religious needs of patients/families/carers and describe how they may be addressed					
5.1.3	Demonstrate an understanding of cultural issues at EOL care					
5.1.4	Understand various aspects of spiritual care					
5.1.5	*Demonstrate an understanding of the concept of sexuality and how this is affected by the presence of a terminal illness					
5.1.6	*Understand the types of informal care givers and their role in EOL care					
6.1	Communication	1	2	3	4	5

6.1.1	Demonstrate an understanding of the components of open and sensitive communication					
6.1.2	Understand the importance of using strategies that empower effective communication e.g. active listening, plain language, appropriate tone, empathy					
6.1.3	Explain the importance and impact of non-verbal and verbal communication within all aspects of care					
6.1.4	Explain the concepts of counselling					
6.1.5	*Demonstrate an understanding of the process of breaking bad news to a patient/family					
7.1	Loss, Grief and Bereavement	1	2	3	4	5
7.1.1	Understand that grief is a normal and appropriate response to loss which has physical, psychological, spiritual, emotional and social aspects that affect how it is experienced.					
7.1.2	Understand the personal impact of loss, grief and bereavement.					
7.1.3	Understand the strategies to identify the losses that persons with cognitive and sensory impairment encounter and intervene appropriately					
7.1.4	*Demonstrate an understanding of the referral mechanisms to appropriate support services					
8.1	Death and Dying	1	2	3	4	5
8.1.1	Outline the practical issues surrounding the death of a patient, for example, death certification and registration					
8.1.2	Demonstrate knowledge of issues and policies relating to any legal, cultural, religious or health and safety requirements when caring for the patient's body					
8.1.3	*Understand the role of a nurse during death and dying					

2. Attitude Dimension

1.2	Palliative Care Nursing	1	2	3	4	5
1.2.1	Respect the roles, responsibilities and boundaries in multi-professional working					
1.2.2	Value the opinions and views of others					
1.2.3	Value the collaborative approach to working with other services across various sectors					

1.2.4	Be respectful and empathetic to patients/clients with life-limiting conditions as you provide individualized care..					
1.2.5	Be supportive and caring to the patient and his/her family					
1.2.6	Be an advocate for patients/clients and ensure appropriate and timely palliative care interventions at EOL					
2.2	Pain Management	1	2	3	4	5
2.2.1	Be respectful and sensitive to the patient's/family's subjective experience(s)					
3.2	Symptom Management	1	2	3	4	5
3.2.1	Treat everyone with whom you come into contact with dignity, respect, humanity and compassion					
3.2.2	Value the ethical principles involved when planning care					
4.2	Ethical-Legal issues	1	2	3	4	5
4.2.1	Be professional when the patient/family requests for further/modification of treatment .					
5.2	Psychosocial, Cultural and Spiritual considerations	1	2	3	4	5
5.2.1	Be objective and neutral to the patient and his/her family irrespective of the spiritual standpoint					
5.2.2	Respect the opinions of the informal caregivers					
6.2	Communication	1	2	3	4	5
6.2.1	Show respect for cultural and religious diversity when communicating with the family unit					
6.2.2	Value the importance of establishing a rapport with the patient/carer based on openness, honesty and trust					
6.2.3	*Be non-judgmental regarding patient sexuality while providing EOL care					
7.2	Loss, Grief and Bereavement	1	2	3	4	5
7.2.1	Respect the individual nature of the grief response					
8.2	Death and Dying	1	2	3	4	5
8.2.1	Value the need for dignity and respect towards the patient and others at and around the time of death					

3. Practice Dimension

1.3	Palliative Care Nursing	1	2	3	4	5

1.3.1	Be able to apply research findings to improve end-of-life nursing care outcomes					
1.3.2	Effectively work in partnership with other specialist teams					
1.3.3	Be able to recognize when the person's care needs are complex and warrant referral to specialist palliative care					
1.3.4	*Be able to develop a patient-care plan using the nursing process and in a team-based manner					
2.3	Pain Management	1	2	3	4	5
2.3.1	Utilize appropriate skills to assess, diagnose and manage pain					
2.3.2	Be able to monitor outcomes of both pharmacological and non-pharmacological management plans					
2.3.3	Be able to utilize principles of pain management					
2.3.4	*Be able to administer the appropriate pain therapies including opioids as prescribed					
3.3	Symptom Management	1	2	3	4	5
3.3.1	Be able to assess, diagnose and manage common symptoms at end of life associated with life-limiting conditions.					
3.3.2	Set realistic goals of care in partnership with patient/carer(s)					
3.3.3	Regularly review and evaluate care management plans and update appropriately					
3.3.4	Refer in an appropriate and timely manner to specialist palliative care team, or other disciplines as necessary					
3.3.5	*Be able to identify palliative care emergencies and intervene appropriately					
4.3	Ethical-Legal issues	1	2	3	4	5
4.3.1	Collaborate with others in the use of an ethical framework which guides decision making in the context of end of life care					
4.3.2	Implement and monitor outcomes of ethical decisions					
4.3.3	Share and document information sensitively and while respecting confidentiality					
4.3.4	*Apply ethical principles in provision of end of life care					
5.3	Psychosocial, Cultural and Spiritual considerations	1	2	3	4	5
5.3.1	Be able to establish and respect people's wishes about their care and options/preferences					

5.3.2	Be able to provide last offices in the context of the individuals' beliefs, culture and religious practice					
5.3.3	Identify the care needs of people from different cultural and religious backgrounds					
5.3.4	*Be able to identify informal care giver's needs and intervene appropriately					
6.3	Communication	1	2	3	4	5
6.3.1	Be flexible and modify personal communication style to facilitate communication with persons with a range of communication impairments.					
6.3.2	Utilize counselling skills in the care of a patient/family					
6.3.3	Communicate with family/carers as appropriate, to determine anticipated care outcomes					
6.3.4	*Be sensitive and effective in your communication to patients and informal care givers					
7.3	Loss, Grief and Bereavement	1	2	3	4	5
7.3.1	Demonstrate self-awareness of personal experiences of loss, to prevent them from negatively impacting on patients/clients..					
7.3.2	Be able to provide support in order to help the family to adapt to the bereavement and loss					
7.3.3	Be able to engage with a person who is experiencing loss in the context of professional scope of practice and/role					
7.3.4	Be able to identify those experiencing complicated grief and utilize resources to appropriately support them					
8.3	Death and Dying	1	2	3	4	5
8.3.1	Care for the patient's body after death, respecting any wishes expressed by the family and any particular religious rites					
8.3.2	Ensure appropriate identification/verification/certification of death, and care of the patient's body throughout duration of care					
8.3.3	Be able to anticipate, recognize and respond effectively to signs and symptoms of imminent death					

c) List any competency(s) that is (are) missing or require revision **(please indicate section & number)**

---

d) List the competency(s) you want deleted **(please indicate section & number)**

THANK YOU FOR YOUR TIME

APPENDIX V: STATISTICS FOR CRONBACH'S ALPHA - SURVEY

Reliability test for knowledge items

Case Processing Summary

		N	%
Cases	Valid	14	70.0
	Excluded[a]	6	30.0
	Total	20	100.0

a. Listwise deletion based on all variables in the procedure.

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
Goals of EoL care	40.07	95.764	.737	.	.931
Pain management at EoL	40.00	97.077	.679	.	.933
Management of other symptoms (e.g., dyspnea, restlessness) at EoL	39.79	100.797	.390	.	.939
Communication with patients/families at EoL	40.00	95.385	.631	.	.934
The roles/needs of family caregivers in EoL	39.86	98.901	.427	.	.939
Care of patients at the time of death	40.21	92.489	.913	.	.927
Care of the body after death	39.86	97.824	.486	.	.938
Ethical issues in EoL	40.43	89.341	.847	.	.928
The role of a nurse in a family that is grieving/bereaved	39.79	95.874	.809	.	.930
Cultural factors that influence EoL care	40.21	90.335	.801	.	.929
Religious factors that influence EOL care.	39.79	95.874	.627	.	.934
Refferal to hospice/Palliative Care Unit	39.93	92.841	.736	.	.931
	40.07	87.148	.875	.	.927
Home care for a dying patient	40.14	89.978	.773	.	.930

Reliability test for Attitude

Case Processing Summary

		N	%
Cases	Valid	19	95.0
	Excluded[a]	1	5.0
	Total	20	100.0

a. Listwise deletion based on all variables in the procedure.

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
Pain management	28.00	23.222	.217	.	.852
Other symptom management	28.05	21.942	.544	.	.838
Communication with terminally ill patients	28.26	21.871	.377	.	.846
Communication with family caregivers	28.11	20.988	.530	.	.836
Managing the death event at home	28.47	21.819	.508	.	.839
Cultural issues in EoL care	28.63	22.357	.319	.	.849
Overall EoL care for the terminally ill	28.42	21.813	.437	.	.842
Pain management	27.79	22.064	.440	.	.842
Other symptom management	27.79	22.064	.350	.	.847
Communication with terminally ill patients	27.95	20.942	.577	.	.834
Communication with family caregivers	28.00	20.333	.606	.	.831
Managing the death event at home	28.32	20.561	.493	.	.840
Cultural issues in EoL care	28.21	19.287	.713	.	.823
Overall EoL care for the terminally ill	28.11	19.322	.737	.	.821

Training needs

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
Understanding goals of palliative care	14.75	76.197	.427	.817	.345
Pain management at EoL	14.75	75.882	.400	.789	.343
Other symptom management (e.g., dyspnea, restlessness)	14.50	76.789	.354	.713	.352
Communication with patients/families at EoL	14.85	75.924	.503	.808	.341
Role/needs of family caregivers in EoL care	14.95	76.050	.482	.839	.343
The care of patients at time of deth	14.75	76.303	.490	.881	.345
Ethical issues in EoL	14.85	73.608	.736	.750	.316
Grief/bereavement	13.50	17.316	.236	.538	.921
Overall content on EoL care	14.70	76.221	.383	.854	.347

APPENDIX VI: RESEARCH APPROVAL

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

KENYATTA NATIONAL HOSPITAL APPROVED 06 NOV 2017 KNH/UoN ERC P.O. Box 20723-00202

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

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

Ref: KNH-ERC/A/335

6th November, 2017

Gladys Warindi Machira
PhD Candida
School of Nursing Sciences
College of Health Sciences
University of Nairobi

Dear Gladys,

REVISED RESEARCH PROPOSAL --DEVELOPING AN EVIDENCE-BASED COMPETENCY MODEL FOR END-OF-LIFE NURSING CARE UTILIZING THE DELPHI PROCESS (P522/09/2017)

This is to inform you that the KNH- UoN Ethics & Research Committee (KNH- UoN ERC) has reviewed and approved your above proposal. The approval period is from 6th November 2017 –5th November 2018.

This approval is subject to compliance with the following requirements:

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

Protect to discover

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

Yours sincerely,

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

c.c. The Principal, College of Health Sciences, UoN
The Director, CS, KNH
The Assistant Director, Health Information, KNH
The Chairperson, KNH-UoN ERC
The Director, School of Nursing Sciences, UoN
Supervisors: Dr. Irene Mageto (School of Nursing Sciences, UoN), Dr. James Mwaura (School of Nursing Sciences, UoN)

APPENDIX VII: STUDY REGISTRATION CERTIFICATE FROM KNH

KNH/R&P/FORM/01

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

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

Study Registration Certificate

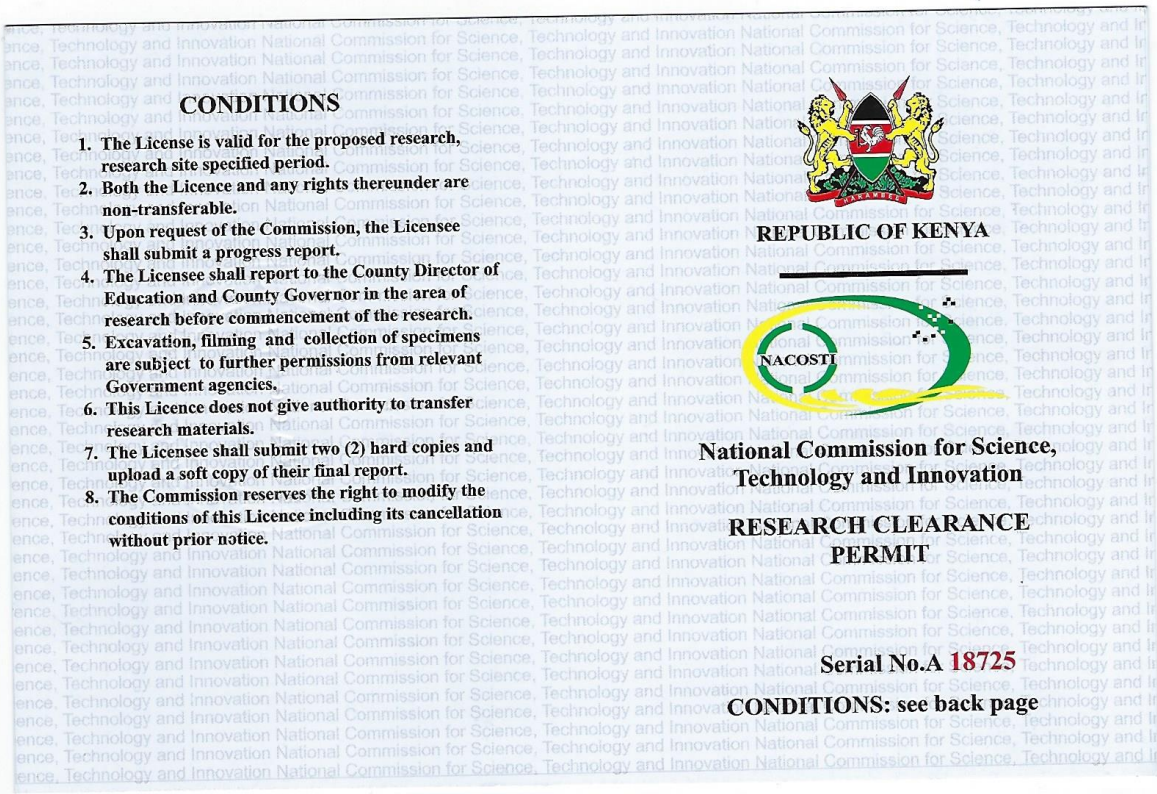
1. Name of the Principal Investigator/Researcher
   GLADYS WAMBUI MACHIRA
2. Email address: glawamac@gmail.com Tel No. 0733340039
3. Contact person (if different from PI) N/A
4. Email address: n/a Tel No. NA
5. Study Title
   Developing an evidence-based competency model for end-of-life Nursing care utilizing the Delphi process
6. Department where the study will be conducted ICU, ED, Burns, Cardiology, (Nursing) Renal and Palliative Care Dept
   (Please attach copy of Abstract)
7. Endorsed by Research Coordinator of the Department where the study will be conducted.
   Name: Rosemary Mutwa Signature [signature] Date 22/11/2017
8. Endorsed by KNH Head of Department where study will be conducted.
   Name: Rosemary Mutwa Signature [signature] Date 22/11/2017
9. KNH UoN Ethics Research Committee approved study number P522/09/2017
   (Please attach copy of ERC approval)
10. I GLADYS WAMBUI MACHIRA commit to submit a report of my study findings to the Department where the study will be conducted and to the Department of Research and Programs.
    Signature [signature] Date 22/11/2017
11. Study Registration number (Dept/Number/Year) Nursing /18/2017
    (To be completed by Research and Programs Department)
12. Research and Program Stamp

KENYATTA NATIONAL HOSPITAL Research Resource Centre P.O. Box 20723 - 00202 NAIROBI

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

Version 2: August, 2014

APPENDIX VIII: RESEARCH CLEARANCE PERMIT



CONDITIONS

1. The License is valid for the proposed research, research site specified period.
2. Both the Licence and any rights thereunder are non-transferable.
3. Upon request of the Commission, the Licensee shall submit a progress report.
4. The Licensee shall report to the County Director of Education and County Governor in the area of research before commencement of the research.
5. Excavation, filming and collection of specimens are subject to further permissions from relevant Government agencies.
6. This Licence does not give authority to transfer research materials.
7. The Licensee shall submit two (2) hard copies and upload a soft copy of their final report.
8. The Commission reserves the right to modify the conditions of this Licence including its cancellation without prior notice.

REPUBLIC OF KENYA

NACOSTI

National Commission for Science, Technology and Innovation

RESEARCH CLEARANCE PERMIT

Serial No.A 18725

CONDITIONS: see back page

THIS IS TO CERTIFY THAT:
MS. GLADYS WARINDI MACHIRA
of THE UNIVERSITY OF NAIROBI, 0-400
Nairobi,has been permitted to conduct
research in *Nairobi County*

on the topic: *DEVELOPING AN EVIDENCE-BASED COMPETENCY MODEL FOR END-OF-LIFE NURSING CARE UTILIZING THE DELPHI PROCESS*

for the period ending:
25th May,2019

Permit No : NACOSTI/P/18/02959/22813
Date Of Issue : 25th May,2018
Fee Recieved :Ksh 2000

.....
Applicant's Signature

.....
Director General
National Commission for Science, Technology & Innovation

APPENDIX IX: RESEARCH AUTHORIZATION

Republic of Kenya
MINISTY OF EDUCATION
STATE DEPARTMENT OF BASIC EDUCATION

Telegrams: "SCHOOLING", Nairobi
Telephone; Nairobi 020 2453699
Email: rcenairobi@gmail.com
cdenairobi@gmail.com

When replying please quote

REGIONAL COORDINATOR OF EDUCATION
NAIROBI REGION
NYAYO HOUSE
P.O. Box 74629 – 00200
NAIROBI

Ref: RCE/NRB/GEN/1 VOL. I

DATE: 29th May, 2018

Gladys Warindi Machira
University of Nairobi
P O Box 30197-00100
NAIROBI

RE: RESEARCH AUTHORIZATION

We are in receipt of a letter from the National Commission for Science, Technology and Innovation regarding research authorization in Nairobi County on "**Developing an Evidence-Based Competency Model For End Of Life Nursing Care Utilizing Te Delphi Process**".

This office has no objection and authority is hereby granted for a period ending **25th May, 2019** as indicated in the request letter.

Kindly inform the Sub County Director of Education of the Sub County you intend to visit.

MINISTRY OF EDUCATION P.O. BOX 74629 NAIROBI
29 MAY 2018
NAIROBI
NYAYO REGIONAL COORDINATOR

MAINA NGURU
FOR: REGIONAL COORDINATOR OF EDUCATION
NAIROBI

C.C
Director General/CEO
Nation Commission for Science, Technology and Innovation
NAIROBI