



# **Palliative care and the ethical challenges in home care**

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Degree Thesis  
Nursing 16  
2019

DEGREE THESIS	
Arcada	
Degree Programme:	Bachelor's degree in Nursing
Identification number:	20027 and 19962
Author:	Marjama Omar and Warda Zahir
Title:	
Supervisor (Arcada):	Emilia Kielo
Commissioned by:	Raasepori homecare
Abstract:	
<p>The purpose of this literature is to explore and discuss the role of nurses in palliative care and common ethical challenges, and to create and understanding in the important aspects of nurses' role and ethical challenges. The design of this study is a literature review in which two main electronic database search engines are used to retrieve the data. EBSCO and Google scholar. The literature review is designed with inductive content analysis in which 21 articles were selected to be the relevant for conducting this literature review. Humanistic nursing theory (HNT) was used as theoretical framework for this literature review. Each article addressed the research questions in different perspectives; what are the nurses role in palliative care and what are common ethical challenges in palliative care. Some of the issues addressed include the role of nurses in Palliative care and ethical challenges. The most common issues that were addressed by the articles include Improvement of nursing knowledge, culture, several of factors within nursing role, Understanding of end of life care, pain management, dignity and common ethical challenges. The articles, therefore, outlined the important aspects of nursing role and ethical challenges. Overall nurses play a significant role in providing good quality care within palliative care and overcoming ethical challenges.</p>	
Keywords:	Care, palliative, end of life care, nurse, ethical, challenges.
Number of pages:	45
Language:	english
Date of acceptance:	

EXAMENSARBETE	
Arcada	
Utbildningsprogram:	Bachelor degree in nursing
Identifikationsnummer:	20027 och 19962
Författare:	
Arbetets namn:	Emilia Kielo
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Uppdragsgivare:	Raasepori homecare
<p>Sammandrag:</p> <p>Syftet med denna litteraturundersökning är att utforska och diskutera sjukskötarens roll och gemensamma etiska utmaningar i palliativ vård, samt att skapa förståelse för viktiga aspekter av sjukskötarens roll och dess etiska utmaningar. Metoden i denna studie är en litteraturöversikt, där två huvuddatabasers sökmotorer används för informationssökning, EBSCO och Google Scholar. Litteraturöversikten är utformad som en induktiv innehållsanalys där 20 artiklar valdes som relevanta för genomförandet av denna litteraturgranskning/översikt. Humanistisk omvårdnads-teori (HNT) användes som teoretisk ram för litteraturöversikten. Varje artikel behandlade forskningsfrågorna ur olika perspektiv. Några av de behandlade problemen är sjukskötarens roll i palliativ vård och etiska utmaningar. De vanligaste frågorna som behandlades i artiklarna är förbättring av omvårdnads kunskap, kultur, flera faktorer inom omvårdnadsrollen, förståelse för livs-vård, smärtlindring, värdighet och gemensamma etiska utmaningar. Artiklarna tecknade därför viktiga aspekter på omvårdnadsrollen och dess etiska utmaningar. Överlag spelar sjukskötarens en viktig roll för att kunna ge vård med god kvalitet i palliativ vård och för att övervinna etiska utmaningar.</p>	
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Sidantal:	45
Språk:	english
Datum för godkännande:	



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## **FOREWORD**

We would like to thank our supervisor Emilia Kielo. We would also like to thank our families and friends. I am grateful to the God for the good health and wellbeing that we needed throughout this thesis.



# 1 INTRODUCTION

Palliative care is defined by the WHO as a multidisciplinary approach that improves the quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual/existential problems. While palliative care was foremost offered to cancer patients in the past, it has been recognized that older people with age-related, chronic and mental health problems can also benefit from an early integration of a palliative care approach in the disease management according to WHO i.n (n.d).

Palliative care is a patient-oriented and is aimed at maintaining the patient's quality of life, alleviating and minimizing the symptoms of physical and psychological and treatments of the disease, and supporting the patient and their families and close friends. Every patient has the right to good palliative care and its significance is expressed when the disease is progressing or recurring according to HUS (2019).

Palliative care is not an alternative to treatments, but should be applied at the same time with the focus shifting between effective treatments and minimizing the symptoms. Palliative care is continued in the form of support and pain management when treatment to prevent, inhibit or slow the growth of disease or cancer has been discontinued. Potent analgesics and other drugs offer several means of providing relief from distressing symptoms. For example, radiotherapy can be used to effectively relieve the symptoms in patients with painful or otherwise distressing metastases according to HUS (2019).

This thesis was commissioned by Raasepori homecare. The authors chose this particular topic from working within the homecare's in Finland. The authors have found this topic interesting because of the past experience the authors had within palliative care, the authors found many problems and were unable to understand the nurses role within palliative care and many ethical questions were unanswered, the topic and the authors two research questions focus on answering common issues and roles within nursing care.

## **2 BACKGROUND**

### **2.1 Ethics in nursing**

All actions in health care should be driven by the desire to promote the patient's best interest, taking into account ethical and legal principles (Nursing and Midwifery Council (NMC) 2008). In legal cases, whenever decisions have been made on behalf of patients, the principle of best interest has been foremost (Mason et al 2006). This includes decisions that have been made on behalf of patients who lack the capacity to decide for themselves. In terms of ethics, practitioners are seen to have an obligation to do the best they can for patients in their care. This might, for example, be expressed as beneficence (to do good) (Gillon 1994). Consent as well as acting in the patient's best interest, the nurse should ensure that he or she obtains informed consent, whenever possible (NMC 2008). All practicable steps must be used to help patients make their own decisions and patients with capacity are free to make unwise decisions, which must be respected. (Allmark & Tod 2009)

In ethics, discussion of consent is typically framed in terms of autonomy (Dworkin 1988, Allmark 2008). Autonomy describes a person's ability to create and act on decisions. Nurses got to respect patients' autonomy. this could be achieved by guaranteeing that patients are able to decide what happens to them and so to respect those choices. additionally, the mental capacity Act makes clear that people's advance choices ought to be taken into consideration in decision making; people's advance refusal of treatment should be respected. Duty of care Nurses have a legal duty to avoid foreseeable harm to others. This is the duty of care, which covers omissions as well as actions. A patient who is harmed when a nurse negligently omits the right action, such as giving drugs on time, has as good a case to sue as one who is harmed when a nurse negligently performs a wrong action, such as giving the wrong drugs. Homicide where someone has a duty of care, homicide could occur through an act, such as giving a lethal injection, or an omission, such as failing to give life-saving treatment. There are

different types of homicide, including murder, infanticide, and voluntary and involuntary manslaughter. The notion of intention plays an important part in deciding the category of homicide. Murder and voluntary manslaughter require an intention to kill or harm. Involuntary manslaughter requires recklessness or criminal negligence (Law Commission 2005).

The hermeneutic interpretation illuminated the nurses' experiences of uncomfortable feelings. One way to offset such feelings is to create comfort in end-of-life care, which means building a good relationship with the patient, in the same way as constructing a bridge between two walls. Building a bridge in the context of care is based on communication, competence, caring, mutual contact and respect, all of which characterise professional nursing. However, due to ethical problems arising from uncomfortable feelings and lack of cooperation, it was not easy for the nurses in the present study to build such a bridge with the dying patients and their relatives. (Karlsson et al. 2013)

The ethical problems related to feeling uncomfortable and lack of cooperation led to the nurses experiencing lack of security. In an uncomfortable situation such as when they experienced feelings of loss of control in end-of-life care in the patient's own home, it was not easy for the nurses to establish a good relationship not only with patients and relatives but also with colleagues and the physicians in charge. For nurses to feel secure while caring for patients in end-of-life home care, all staff members must respect the patients' autonomy, privacy and dignity. (Karlsson et al. 2013)

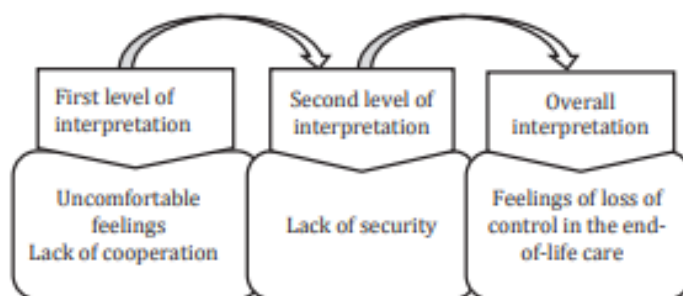


Figure 1 Illustrates the hermeneutic interpretation to gain a deeper understanding of community nurses experiences of ethical problems in end-of-life care in the patient's own home. (Karlsson et al. 2013)

## 2.2 Palliative care in nursing

Palliative care is a patient-oriented approach to maintaining the quality of life of the patient, helping to improve and relieving the physical and psychological life threatening illnesses and treatments, as well as continuing to support the patient, friends and family. Each patient has the right to good quality palliative care. (Wallerstedt et al. 2019)

A previous study was made according to the Medical research council framework, for the development of complex interventions within palliative care. The palliative care process may take different forms, with several phases consisting of key functions and activities. Reporting is not shown as a separate activity, because it is regarded as an important element of each stage in the process. (Scheerens et al. 2018)

Research suggests that palliative home care should be integrated early into standard care for end-stage COPD patients. Patients also express the wish to be cared for and to die at home. However, a practice model for early integration of palliative home care (PHC) into standard care for end-stage COPD has not been fully developed. (Scheerens et al. 2018)

### **3 THEORETICAL FRAMEWORK**

This study has been conducted using one theoretical framework. The usage of a theoretical framework is significant to the understanding the importance of the nurses' role in the patients care and how palliative care is an important aspect of it. It aids in the research as a guidance by providing on how nursing role, ethics and palliative care correlate within the theory and the research.

Humanistic Nursing Theory (HNT) examines the relationship of the nurse to the patient and the importance that both are unique individuals, but are working towards the same end goal. The relationship between the patient and the nurse and the ability to be open and interact are crucial in providing effective humanistic nursing. Every relationship is different and nurses and patients may differ in opinion on a wide variety of topics ranging from values to expectations. (Wu & Volker 2011)

The humanistic nursing theory was used to answer the both question "What are the nurses' role in palliative care?" and "What are the most common ethical challenges in palliative care?" The authors use this particular theory because it provides a similar aspect of the nurses role within palliative care as well as it is a general theory so it will provide a lot of information on nursing role and palliative care.

#### **3.1 Humanistic nursing theory**

Humanistic nursing theory has a foundation in the belief that the patient can grow in a healthy and creative way. The model was created by Josephine Paterson and Loretta Zderad. Both researches believed nursing education should be founded in experience, and that nurse should interact with patients, based on knowledge, scientific, medical background and care. All of this contribute to the bettering the nurses' role in creating an understanding. (Wu & Volker 2011)

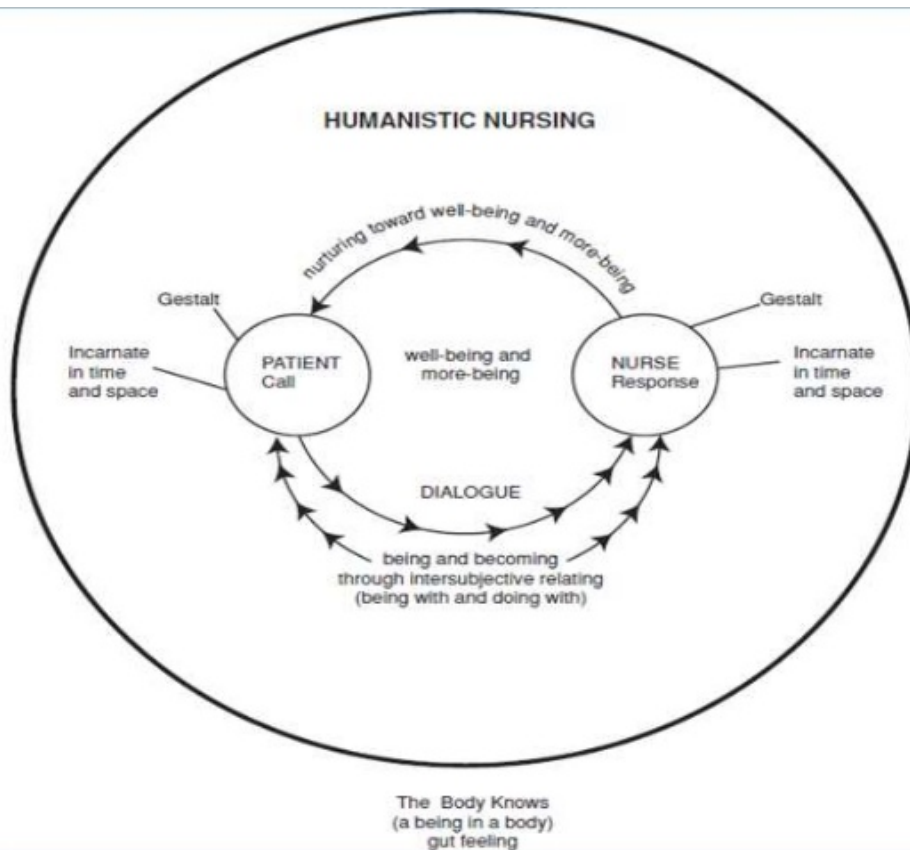


Figure 2 humanistic nursing model (wu&Volker 2011)

*Moreness-choice* – When looking at many nursing home and palliative care nurses, it was seen that many use the Humanistic nursing theory model. This expressed their motivation and purposes to practice within their specific field. Several nurses showed similar motivations for hospice care such as relieving patients who are in the end-of-life care. Moreness-choice refers to the preference of every nurse as to a way to respond to field situation. HNT finds that many of these nurses actually prefer to work within the hospice care. (Wu & Volker 2011)

*Call and response* – The phrase “Call and Response” means the relationship between the patient and a nurse in a sense of patient seeking care. This is quite a specific situation even though the patient is going through several forms of discomfort and pain, the patient asks for treatments in which could minimise symptoms and the nurse provides the best quality care for the patient. (Wu & Volker 2011)

*Inter-subjective Transaction* – As shown by researches when medical care takes place patient and nurses have their own unique viewpoints. however, it is actually outlined within HNT that two independent individuals Nurse and patient trusting as well as having respectful relationship so that the nurse may promote comfort self-determination and a sense of dignity that this relationship may be strengthened by demonstrating compassion reliability and establishing good quality care. (Wu & Volker 2011)

*Uniqueness-otherness* – The HNT model encourages and focuses on the individual basis of the nurse. Nurses are empowered to reflect on their own feelings and prejudices that cause them to face some of their own fears, insecurities and weaknesses HNT argues that this helps the nurse understand themselves better as care providers, allowing them to be more effectual in patient care situations. (Wu & Volker 2011)

## **4 AIM AND RESEARCH QUESTIONS**

The aim of the literature review is to look at the common nurses' role in palliative care and the most common ethical challenges in palliative care. The goal of the research is to create and understanding in the important aspects of nurses' role and ethical challenges.

Following research questions were selected:

1. What are the nurses' role in palliative care?
2. What are the most ethical challenges in palliative care?



## **5 METHODOLOGY**

In the chapter of methodology, both authors will use 20 articles to do a literature review study using inductive content analysis to provide an answer to the two research questions. The methodology used in this study is qualitative literature approach. Every article was rigorously selected based on the topic chosen.

### **5.1 Data Collection**

During collecting the researched data, the authors first developed and focused on the aim and research questions. The data collection method used for the research was systematic collection. Numerous amount of search engines were provided by Arcada University of Applied sciences. Common search engines that were used were: EBSCO and Google scholar. There were several keywords used to find the appropriate articles such as: “palliative care”, “Nurses role”, “ethics”, “ethical challenges”, “Issues”, “end of life care”, “home-care”, “Ethical challenges”, “Studies”. The Boolean operator was used for to combine words such as AND, NOT, OR. This aids in getting more accurate results. The articles were chosen based on reading the text in full, If the article was peer review as well as within 1985-2019, the authors chose one article that was from 1985 due to ethics in nursing not changing between those years. The first time the authors were searching for the articles it was not successful due to the ethical issues to the research of “Palliative care”. However when used words like: “Communication” AND ”Palliative care” or “Diversity” AND “Palliative”. The authors used “ethics” AND “palliative” AND “nurse” Then the authors found more articles successfully.

Inclusion	Exclusion
Articles since 1985	Nurses non-led role in palliative care
Language written must be in English	
Nurses role in Palliative care	Not peer-reviewed
Ethical challenges in palliative care	Ethically problematic articles
All genders and ages	Abstract in the full text only
All geographical areas	
Commonly in home-care setting but can also be in hospital setting.	
Peer reviewed and full text	

Figure 3: Inclusion and exclusion criteria

Table 1: EBSCO

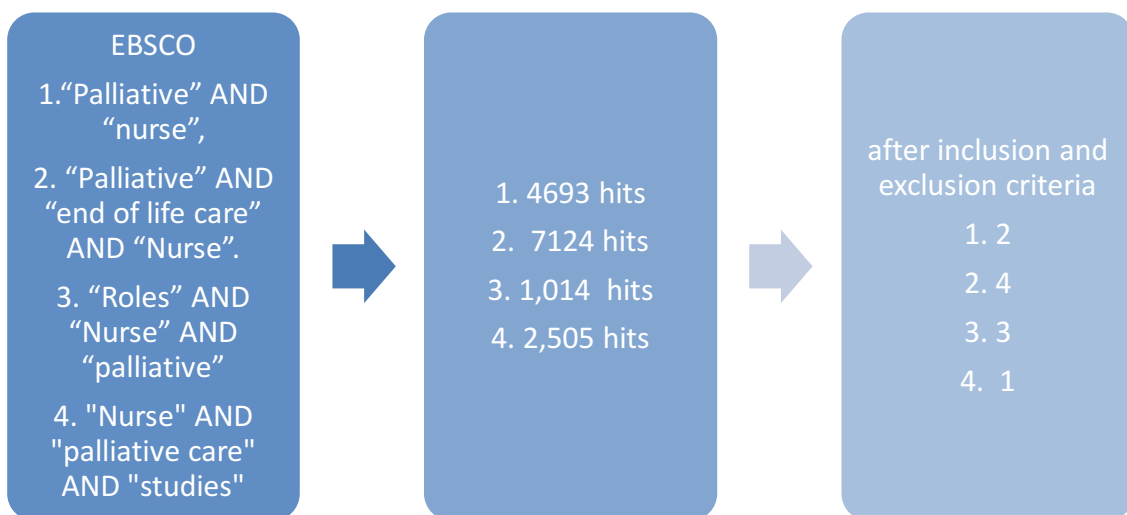
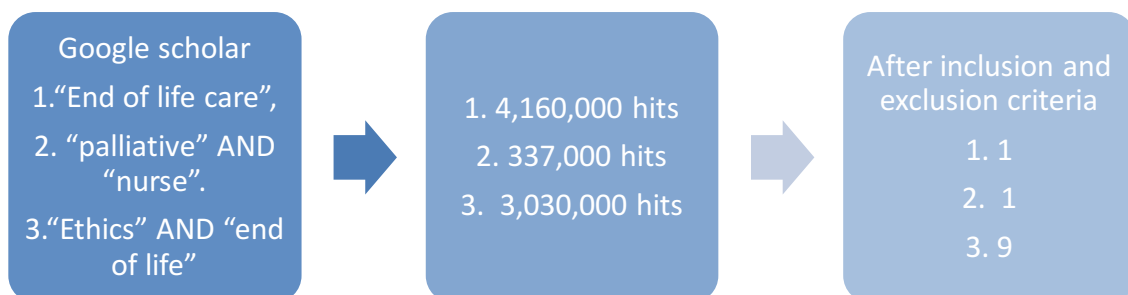


Table 2: Google scholar



Since the hits from the key words were a large amount, the authors chose 36 articles to review, from EBSCO, 25 were reviewed, from these, 9 articles were chosen for the first question and 1 articles for the second research question. From google scholar only 11 were reviewed and 9 article was chosen for the first question, and 2 articles were chosen for the second question. The authors numbered the hits for each combined search words because of the large number of articles that were received.

## 5.2 List of articles chosen

Author, year	Objective	Method	Main findings
Harden, K. <i>et al.</i> (2017)	'Palliative Care: Improving nursing knowledge, attitudes, and behaviors	This project had a pre-/post-test design to assess <b>knowledge, attitudes, and behaviors</b> at baseline and one month after implementation of an established education curriculum.	Results showed a statistically significant difference after the educational intervention for <b>knowledge, attitudes, and behaviors</b> . The number of conversations with patients and caregivers about <b>palliative</b> and end-of-life <b>care</b> increased significantly.
Goldsmith, J. <i>et al.</i> ,2013	Palliative Care Communication in Oncology Nursing	The National Consensus Project (NCP) for Quality <b>Palliative Care</b> developed clinical practice guidelines to establish quality standards for the practice of <b>palliative care</b> .	The COMFORT <b>communication</b> curriculum, a holistic model for narrative clinical <b>communication</b> in practice developed for use in early <b>palliative care</b> , is posed as a resource for <b>oncology</b> nurses with a series of practice case examples presented against the backdrop of NCP's eight domains of quality <b>palliative care</b> .
Mitchell, A. and Jozwiak-Shields, C. 2017	Cultural perspective and palliative care. <i>Nursing and Palliative Care</i>	Qualitative research	. Creating an environment that fosters open communication in a respecting, trusting atmosphere is crucial to understanding and providing culturally based nursing care. As a patient journeys through their illness their cultural identity and all that it entails may become more and more important to them, their beliefs and traditions may bring them comfort and strength as their illnesses progress.

Abrahm, J. (2017)	Involve the Palliative Care Team Early to Minimize Symptom Impact	Qualitative research and patient and nurse experiences	Oncology nurses should continue to use their resources in symptom management practice. Consider consulting on-site palliative care specialists, engage patients in nonpharmacologic options like acupuncture and holistic treatments, and use organizations like ONS, the American Society of Clinical Oncology,
Lewis, K. (2013)	'How nurses can help ease patient transitions to end of life care	Qualitative and quantitative research	New nurses who plan to work with dying patients need to be educated about the reality of end of life work and equipped with coping methods before starting their jobs. Novice nurses should feel that their unit acknowledges death as a difficult event and that discussion of death is acceptable in their workplace. Comprehensive end of life education should be provided for nursing home workers as death is an inevitable part of their job (
Hughes, L. (2012)	Assessment and management of pain in older patients receiving palliative care	underpin good practice in the <b>assessment</b> and <b>management</b> of <b>pain</b> syndromes in <b>older patients</b> with advanced, life-limiting illnesses.	An understanding of <b>pain</b> and approaches to treating it will help ensure that nurses in different clinical settings are able to support <b>patients receiving palliative care</b> and their families.
Aubin, M. et al. (2006)	Impact of an Educational Program on Pain Management in Patients with Cancer Living at Home	The <b>educational</b> intervention included information regarding <b>pain</b> assessment and monitoring using a daily <b>pain</b> diary and the provision of specific recommendations in case of loss of <b>pain</b> control. <b>Pain</b> intensity data were collected prior to the intervention, and reassessments were made two and four weeks later. Data on beliefs were collected at baseline and two weeks. All data were collected by personal interviews.	An <b>educational</b> intervention can be effective in improving the monitoring and relief of <b>pain</b> in <b>patients</b> with <b>cancer living at home</b> . Implications for Nursing: Homecare nurses can be trained to effectively administer the <b>educational program</b> during their regular homecare visits

Harst�de, C. W. <i>et al.</i> (2018)	Dignity-conserving care actions in palliative care: an integrative review of Swedish research	An <b>integrative literature review</b> was conducted using the databases SwePub and SweMed+. Articles published from 2006 to 2015 and theses published from 2000 to 2015 were searched for using the terms ' <b>dignity</b> ' and ' <b>palliative care</b> '. Result sections of articles and theses were reviewed for <b>dignity-conserving care actions</b> synthesised by thematic analysis and categorised under themes and subthemes in Chochinov's model of <b>dignity</b> .	Fifteen articles and 18 theses were included together providing suggestions of <b>care actions</b> in all themes and subthemes in the <b>dignity</b> model. Suggested <b>care actions</b> included listening, communication, information, symptom control, facilitating daily living and including patients in decision-making. Additionally, nurses' perceptiveness towards the patients was a core approach.
Lugton, J. and McIntyre, R. (2006)	<i>Palliative care: The nursing role</i>	Qualitative research	Importance of nurses' role and different aspects of it, gaining knowledge and pin-pointing the importance of good quality care
Raines, M.L. (2000)	Ethical decision making in nurses. Relationships among moral reasoning, coping style, and ethics stress	Correlational design using survey techniques was used as a study design with a nationwide sample of 229 oncology nurses.	The results indicated nurses experienced an average of 32 different types of ethical dilemmas within the past year on a daily basis. Pain management is the most frequently cited ethical dilemma, followed by cost containment issues and making quality of life and other decisions in the patient's best interest.
Ulrich, C.M. <i>et al.</i> (2010)	Everyday ethics: ethical issues and stress in nursing practice.	A self-administered survey was sent in 2004 to 1000 nurses in four states in four different census regions of the United States of America. The adjusted response rate was 52%. Data were analysed using descriptive statistics, cross-tabulations and Pearson correlations.	A total of 422 questionnaires were used in the analysis. The five most frequently occurring and most stressful ethical and patient care issues were protecting patients' rights; autonomy and informed consent to treatment; staffing patterns; advanced care planning; and surrogate decision-making. Other common occurrences were unethical practices of healthcare professionals; breaches of patient confidentiality or right to privacy; and end-of-life decision-making. Younger nurses and those with fewer years of experience encountered ethical issues more frequently and reported higher

			levels of stress. Nurses from different regions also experienced specific types of ethical problems more commonly.
Lo B et al. (1985)	'Do Not Resuscitate' Decisions: A Prospective Study at Three Teaching Hospitals	Studied prospectively 3,282 patients admitted to	The utilize of care pathways permits this circumstance to be seen in an unexpected way. When a persistent is passing on it is the nurse's obligation to mediate within the patient's best interest.
Wainwright, P. and Gallagher, A. (2007)	Ethical aspects of withdrawing and withholding treatment	Qualitative research and discussion of different scenarios	Nurses have a key role in decisions about the withholding and withdrawal of treatment. Their duty of care extends to their omissions as well as their actions. There are circumstances when treatment will be considered futile. However, it is never the case that nursing care is futile. Nursing care extends beyond treatment contributing to enhancing the patient's comfort and quality of life, whatever the prognosis. T
Lachman, V. (2010)	'Do-Not-Resuscitate Orders: Nurse's Role Requires Moral Courage'	Qualitative research, discussion on DNR and the nurses' role.	Nurses are on the front line of clinical situations in which lack of DNR orders creates ethical dilemmas requiring moral courage to advocate for the patient and family. According to Sulmasy and colleagues (2008), nurses are ready to take a more active role in initiating these discussions. With nursing intervention, perhaps the partial DNR orders and the late timing of the discussions can be eliminated and the truth about CPR will be told
Allmark, P. and Tod, A. (2009)	End of life care pathways: ethical and legal principles	Qualitative research	responsibility to develop and maintain an effective approach to ethical decision making and the skills to implement the correct moral action. At the heart of this process is the experience and knowledge of particular conditions and their outcomes, alongside excellence in

			communication skills and working with colleagues.
Bollig, G. <i>et al.</i> (2015)	Ethical challenges in nursing homes - staff's opinions and experiences with systematic ethics meetings with participation of residents' relatives.	The study used a two-tiered approach, using a questionnaire on <b>ethical challenges</b> and <b>systematic ethics</b> work, given to all employees of a Norwegian <b>nursing</b> home including nonmedical personnel, and a registration of <b>systematic ethics</b> discussions from an Austrian model of good clinical practice.	Ninety-one per cent of the <b>nursing</b> home staff described <b>ethical</b> problems as a burden. Ninety per cent experienced <b>ethical</b> problems in their daily work. The top three <b>ethical challenges</b> reported by the <b>nursing</b> home staff were as follows: lack of resources (79%), end-of-life issues (39%) and coercion (33%).
Mohanti, B. (2009)	Ethics in Palliative Care	Guideline and qualitative research	Progress in palliative care will come out of good research and medical professionals should undertake trials and studies in a legal and ethical manner. The delivery of palliative care and medical ethics are complementary, and use of the two together maximizes the protection and satisfaction available to the vulnerable patient and family members.
Cheon, J., Coyle, N <i>et al.</i> (2015)	Ethical Issues Experienced by Hospice and Palliative Nurses	Survey aimed to identify ethical issues experienced by hospice and palliative nurses, identify resources available to them and barriers if any to their use, and to identify how HPNA can be of support to hospice and palliative nurses.	Approximately two-thirds of the nurses used resources in an attempt to resolve the ethical issues, including a formal ethics consultation, involvement of the palliative/hospice team, consulting with other professionals, and use of educational resources. One-third of the nurses said there were institutional or personal barriers that prevented the ethical dilemma from being resolved. Participants suggested ways that HPNA could help them to effectively manage ethical dilemmas.
Wasserman, L. S. (2008)	'Respectful Death: A Model for End-of-Life Care	The model is a process method commencing with the establishment of a therapeutic relationship with the dying patient and his or her family and, as a result, their stories	Other topics addressed are the current culture toward death in the United States, the roles of nurses in the RDM, and the barriers and benefits of the RDM. Recommendations for

		are heard and incorporated into the care plan.	future research in end-of-life care also are addressed.
Betcher, D. K. (2010)	'Elephant in the Room Project: Improving Caring Efficacy through Effective and Compassionate Communication with Palliative Care Patients'	The project used role-playing methods with simulated patients and <b>palliative care</b> scenarios.	Improve compassionate and effective <b>communication</b> between <b>nurses</b> and <b>palliative care</b> patients.
Webb Second Radcliffe 2005	<i>Cancer Nursing Practice,</i>	Qualitative research	Selective truths and honesty was discussed.

### 5.3 Data analysis

The role of iteration in qualitative data analysis not as a repetitive mechanical task but as a reflexive process, is key to sparking insight and developing meaning. In this paper, the authors present a simple framework for qualitative data analysis comprising three iterative questions. The authors developed it to analyze qualitative data and to engage with the process of continuous meaning-making and progressive focusing inherent to analysis processes. They briefly present the framework and locate it within a more general discussion on analytic reflexivity. They then highlight its usefulness, particularly for newer researchers, by showing practical applications of the framework in two very different studies. (Bruce.C 2007)

The authors created a coding by making a table where a row is a unit for which data was collected. Every article was placed into the each of the columns with the objective, findings, method and quality. The content analysis was carried out by reading through each article to create a theme. The advantages of this method is that it aids in creating themes and sub-themes by using the articles. Every article was grouped into a theme and sub-themes. Both authors used four steps when creating themes for the articles: Look at all



the articles with the similar study or research, define theme for the articles, create coding scheme, evaluate the themes and finally create the themes in the result.

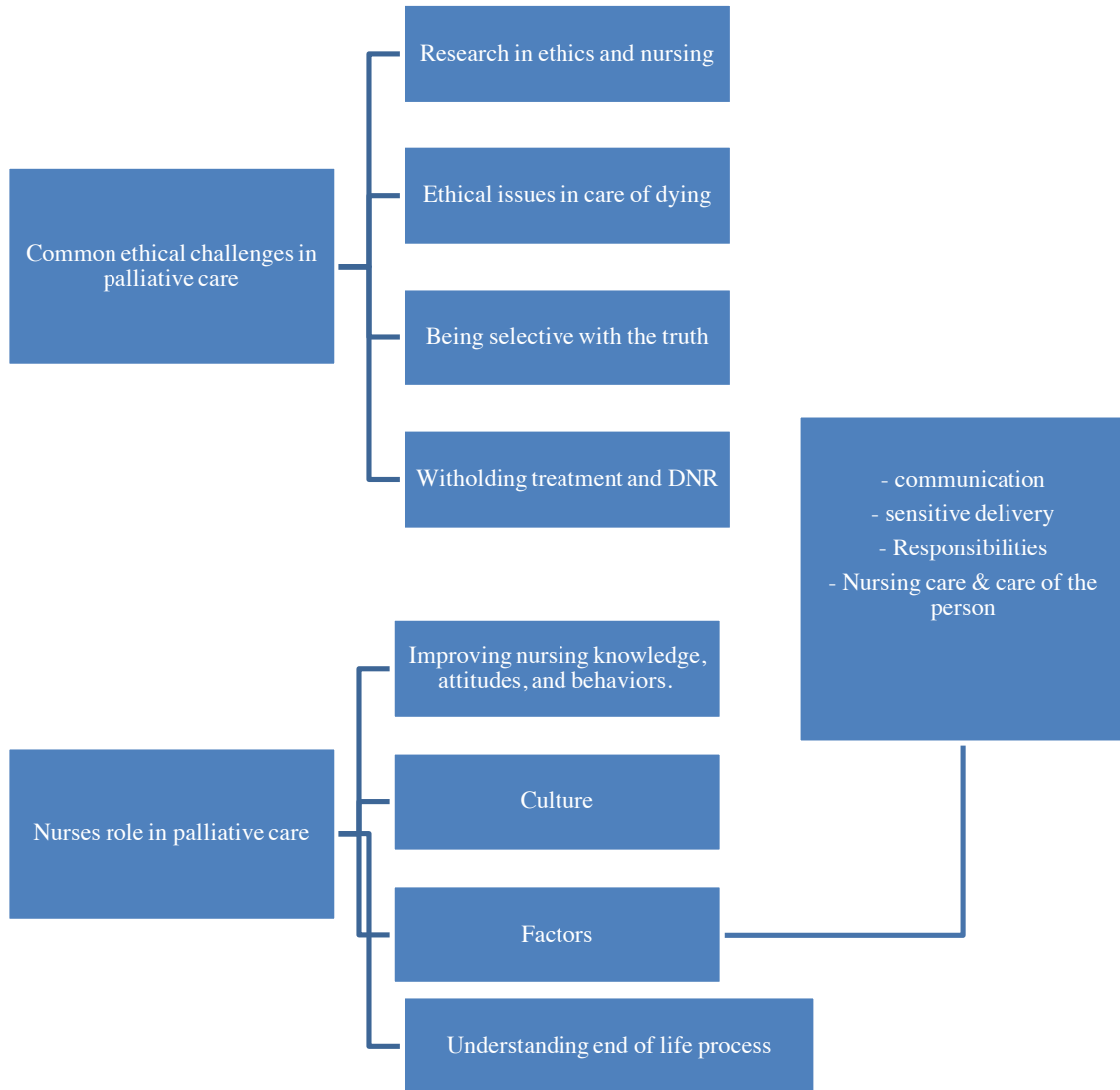


Figure 4: Themes and sub-themes

## 5.4 Ethics

Ethical rules are practical rules in a particular study. Research ethics provides information, truth and prevents mistakes while protecting against manufacturing, counterfeiting or distortion. (Das & Biradar 2016) In this thesis, ethics is taken into account by writing a guide and rules Rules and regulations issued by Arcada University of Applied Sciences. Research work ethical principles were made, so both authors have acted honestly and followed the principles of research ethics to avoid plagiarism, counterfeiting and manufacturing. The scientific articles used in the research were searched for scientific databases to ensure the validity and reliability of the research. Ensuring research Ethics, the authors mention and refer to all the information used School Guidelines and Harvard Reference Style to avoid plagiarism. (Arcada, 2019)

## **6 RESULTS**

### **6.1 Nurses role in palliative care**

In this literature review, twenty articles were used where all of them met the inclusion criteria indicated above. However, each article addressed the research questions in different perspectives. Some of the issues addressed include the role of nurses in Palliative care and ethical challenges. The most common issues that were addressed by the articles include Improvement of nursing knowledge, culture, several of factors within nursing role, Understanding of end of life care, pain management, dignity and common ethical challenges. The articles, therefore, outlined the important aspects of nursing role and ethical challenges.

#### **6.1.1 Palliative Care: Improving nursing knowledge, attitudes, and behaviors.**

From the specific literature review Nurses influence understanding of care at each point along the cancer journey. When medical attendants persistently give input almost the benefits of palliative care and advocate for it, it is more likely to be integrated into a patient's care. In any case, numerous healthcare providers and pioneers are not recognizable with the concept of palliative care or select not to grasp it in their home. Subsequently, healthcare suppliers are not prepared with the information or certainty to lock in in important discussions around palliative care with patients and their caregivers in a way that will give patients with that additional layer of palliative care instruction and bolster. Pretesting of nursing populaces almost palliative care concepts proceeds to appear that medical caretakers are not arranged to back patients utilizing palliative care information, abilities, and assets. (Harden et al. 2017)

#### **6.1.2 Culture in palliative care**

Palliative care is exceptionally individualized care, it is care that's comprehensive holistic nursing care that meets the patient's needs (Harden 2017). Palliative care is "patient

and family-centered care that optimizes quality of life by expecting, avoiding and treating suffering”. Meeting a patient’s personal needs can in some cases be a challenging task, but meeting a patient’s palliative care needs within the setting of cultural differences can be indeed more of a challenge for those unaccustomed to doing so. A study by Mitchell & Jozwiak-Shields, (2017) has shown that social information and mindfulness in nursing is amazingly critical and the need of it may cause shortfalls in practice as a result and nurses may have different and stereotyped attitudes toward patients and cultural competencies as nurses care for multicultural patients in practice. The type of care a patients that are willing to get and partake in is regularly directed by strong social and faith beliefs conventions which will not appear to be effortlessly caught on by those exterior of the culture. Activity or inaction on the part of the understanding in needing to know their conclusion, accepting their diagnosis, seeking care or denying care are intertwined in this complexity of a patient’s culture. (Mitchell & Jozwiak-Shields, 2017)

### **6.1.3 Factors within nurse’s role**

#### **communication**

Communication could be a crucial component of nursing within the provision of end of life care. When nurses taking care of a patient who is dying it becomes vital and beneficial to communicate clearly, and therefore it is fundamental to open up these discussions (Betcher, D. K. 2010). The article by Goldsmith et al (2013), clarifies that it uses the ‘COMFORT’ show offers clinical communication tools empowering nurses to engage patients and families at moments of perceptible pressure within the course of care.

Good communication enables staff to establish the person’s priorities and wishes, supporting them to make informed decisions (Harden et al. 2017). It also provides an opportunity to understand and learn about any anxieties or gaps in understanding of the situation, can help the patients and their families, and reduce anxiety and distress. (Goldsmith *et al.* 2013)

The care of family members becomes ever more central to the holistic care of the dying person. Their prime need is to be reassured of the patient's comfort, provide regular opportunities for the family member to understand or be updated on the condition, treatment and or care given to the patient. (Abraham 2017) Considering at what pace family members may like to know what changes to expect and how they will be managed. Make the family feel welcome at all times and consider what arrangements can be made to offer them space to rest and eat and drink close by Betcher (2010). Some family members may wish to stay with the patient continuously or others may wish to be called back if death is close by. Some may wish to be involved in direct care giving. Provide advice and support as needed. (Goldsmith et al. 2013)

### **Sensitive delivery**

In delivering end of life care there will likely be a number of sensitive conversations with individuals approaching the end of their life and those close to them. It is important to be able to initiate, facilitate and respond in these sensitive situations. Less experienced nursing staff are likely to find these conversations difficult on their first few occasions, and may struggle with what to say or how to say it. The care of family members becomes ever more central to the holistic care of the dying person. (Harden et al. 2017) Nurses' prime need is to be reassured of the patient's comfort. (Goldsmith et al. 2013)

### **Responsibilities**

Staff have many responsibilities in end of life care which will range from having a sensitive conversation with an individual about their care and preferences, recognising any changes in condition and offering compassion and support to the patient and those important to them. This will require a broad variety of skills and an awareness of the values which underpin this behaviour. Compassionate care has to be at the forefront of all nursing care but is even more fundamental in the provision of caring for dying people and those close to them. (Goldsmith et al. 2013)

### **Nursing care and care of the person**

Although challenging and emotionally demanding, when one is supported to have the right skills, knowledge and attitude, end of life care can be very rewarding. End of life care is provided in a range of settings which include care in the community, a hospital, care home, hospice etc. Regardless of care setting, the quality of care should be of the highest standard. When it is recognised by nurses and doctors that a person may be dying, this needs to be communicated in a sensitive and compassionate way to the dying person (as appropriate) and those close to them. How we communicate with the person who is dying will depend on each individual case. This is an extremely sensitive area and should be patient led, with gentle, honest answers using language the person understands. (Goldsmith et al. 2013)

When nurses provide good nursing care for those at the end of their life, nurses should be providing holistic care including providing physical, emotional, psychological and spiritual support. The individual may be a patient, but remember they are also another human being that may be feeling lost, confused and have questions about their nutritional and hydration needs. Equally, the person may not come to nurse with questions, preferring to keep them to him or herself, or discuss with another person of their choosing. It's important to let the person remain in control of who they wish to share these issues with. (Goldsmith et al. 2013)

Lewis (2013) found that 87 per cent of patients would prefer to discuss end of life options when they are well or recently diagnosed rather than when severely ill. Nurses can begin discussing end of life care options in outpatient clinics and settings so that patients have time to think about their preferences before their quality of life declines.

With caring of the person also comes responsibilities for example in the article Goldsmith et al. (2013) it says that nurses have many responsibilities in end of life care which will range from having a sensitive conversation with an individual about their care and preferences, recognising any changes in condition and offering compassion and support to the patient and those important to them. This will require a broad variety of skills and an awareness of the values which underpin this behaviour. Compassionate care has to be at the forefront of all nursing care but is even more fundamental in the provision of caring for dying people and those close to them. (Goldsmith et al. 2013)

#### **6.1.4 Understanding and caring during end of life process**

Caring for a person during the last few weeks and days of life can be stressful and demanding. Many different feelings and emotions may surface from all those involved. Recognition of dying is actually quite complex. This is acknowledged in the literature and in reports regarding end of life care. (Abrahm 2017)

A key part of the nurse's role is being able to come alongside the person who is dying and those close to them and to support them throughout what is a natural process. The time before death is generally peaceful for patients, and there is a gentle winding down that may take several days. Many people are concerned that death will be a painful experience for the person, but the body just starts to 'let go' of life. At times a person can become restless, but this can be treated. (Abrahm 2017)

Patients with cancer experience many feelings: they're frightened and they're hopeful, but mostly they're in a new world. Symptoms associated with cancer and its treatment are taxing on patients' physical, emotional, and spiritual well-being. In some cases, cancer related symptoms and side effects are so debilitating that providers struggle to manage them just to get patients to a point where they can continue their treatment. Oncology nurses can lead the extraprofessional care team to work together to proactively manage symptoms to ensure patients can endure treatment and come out as themselves on the other side. Proper symptom management doesn't just promote quality of life but the best possible chance for patient survival. Healthcare teams can work together in numerous ways by communicating openly during symptom assessment and management quickly and early on. A healthy respect for the roles of everyone on the care team can make working together easy. Having the conversations early about who is responsible for which assessments, when those assessments will take place, and how to follow through to relieve symptoms enables efficient and effective team-based symptom management. By identifying challenging problems early, the healthcare professionals can also involve palliative care early and often, from diagnosis on, to address symptoms and other concerns as they arise. (Abrahm 2017)

Having a low threshold at which healthcare teams engage palliative clinicians can be beneficial to patients. Research has shown that integrating palliative care early for patients with advanced lung cancer and for stem cell transplant recipients resulted in better quality of life and less anxiety and depression than in those without palliative care interventions and the patients with lung cancer lived longer. By integrating palliative care early in the treatment plan, healthcare teams can give patients the best shot at survival while also maintaining the important focus on well-being and quality of life. (Abraham 2017).

These findings are supported by Hughes (2012) who explained the importance of pain management. Palliative care attempts to enable patients to achieve a 'good death' in which a decision making and medical management where possible. The aim is to avoid a 'soulless death' and support the patient medically, physiologically, socially and psychologically they have control, autonomy and independence. (Hughes 2012). Also, palliative care is the total care of patients with active progressive, advanced disease for whom prognosis is limited (Aubin et al. 2006).

Furthermore an article by Harst ade et al. (2018) adds depth to understanding end of life process by significantly showing the importance of dignity, The article makes the distinction between, even though closely linked to each other, an other-regarding and a self-regarding value, that is embracing respect for the dignity of others and having respect for one's own personal and professional dignity. There is a distinction between subjective dignity, everybody's awareness or belief and objective dignity, regardless of the subject or the object someone else's awareness of it. Identity is not standard, but others can threaten it human behavior and attitudes and diseases, impairment and old age.

General dignity is the foundation for the other two human dignity, it is the dignity of earnings moral growth and dignity. The dignity of earnings refers human placement in life through merit while moral dignity. Reputation refers to the respect of people who are held in accordance with the act of moral law. (Harst ade et al. 2018). Furthermore, in the article by Lugton et al. (2005), it talks about the importance of the nurse-patient relationship, that the nurse-patient relationship in the centre of the role of the nurse in palliative care. This relationship should be beneficial for the patient. The nurse should be self-aware or at least try to grow towards the goal. Studies have shown that there are



four different kinds of nurse-patient relationships, the four types were clinical, connected, therapeutic, and over involved relationships. This is an important factor as it shows important aspects of understanding and caring in the end of life process and what is important. (Lugton et al. 2005)

## **6.2 Common ethical challenges in palliative care**

### **Research in ethics and nursing**

Nurses face ethical challenges in their clinical practice, especially nurses who work with palliative and the end of life care. Hospice and Palliative Nurses Association (HPNA) members were asked to take part in an investigation about ethics. The study aimed at identifying ethical problems experienced by hospice and palliative nurses, identifying resources available to them and barriers to anyone for their use, and identifying how the HPNA can support hospice and palliative nurses. The data from each of the surveys was carefully examined, and the responses collapsed into 6 themes. The ethical dilemmas included insufficient communication, provision of non-beneficial care, patient autonomy, usurped / threatened, problems with managing symptoms and use of opioids, issues related to decision making and issues related to interruption of life-prolonging therapies. About two-thirds of the nurses used resources in an effort to solve the ethical issues, including a formal consultation, engagement of the palliative / hospice team, consultation with other professionals, and the use of educational resources. One third of the nurses said there were institutional or personal barriers that prevented the ethical dilemma from being resolved. Participants suggested how HPNA could help them effectively manage ethical dilemmas. (Cheon et al. 2015)

As for the results, there were 128 reactions to this address yielding the taking after 6 subjects: lacking communication, arrangement of nonbeneficial care, quiet independence usurped/threatened, issues with side effect administration and the utilize of opioids, issues with choice making, and ceasing life-prolonging treatments at the EOL. Nurses depicted moral issues related to lacking communication that happened when patients and/or surrogates were given clashing data or when objectives of care were not tended to. Several examples were shared by nurses of care given to patients that they perceived as nonbeneficial or futile. Nurses moreover experienced moral issues when a

patient's independence was usurped or debilitated. A number of concerns were shared related to families and suppliers not supporting understanding wishes. In truth, for numerous, medications were given that were precisely the inverse of what patients expressed that they needed. A few of the choices approximately these medicines were made by families, and a few of these choices were made by staff individuals. Nurses moreover portrayed issues that they experienced as they attempted to oversee troubling side effects. Most of the moral predicaments included the utilize of opioids. A few of the illustrations shared were related to doctors, and a few were related to families. (Cheon et al. 2015)

Nurses also described ethical dilemmas related to decision making. Some dilemmas were focused on challenges faced when trying to determine if patients had capacity to make their own decisions, and others were related to issues with surrogate decision making. Nurses encountered ethical dilemmas that involved discontinuing life-prolonging therapies at the end of life. In summary, nurses' comments reflected an understanding that different issues were frequently implanted in 1 moral problem, a prepare was included in sorting the issues out, which an understanding of the setting was basic. Two-thirds of nurses detailed that they were able to resolve the problem by utilizing accessible assets and procedures counting morals interview, family gatherings, supporting the family, supporting persistent independence, palliative medication inclusion, clarifying objectives of care, including the family in care of the quiet, staff and family instruction almost moral standards, and honouring the rights of the quiet to have their wishes honoured. In a few cases, the issue was settled by the patient's passing. Cheon et al. 2015)

### **Ethical issues in care of dying**

One of the biggest ethical issues, that nurses face is the lack of knowing the best approach to ethical decision making. There are four moral principles that have been suggested, they are:

- Respect for autonomy
- Beneficence: the duty to provide benefit

- Non-maleficence: the duty to not harm
- Distributive justice: the fair use and distribution of resources.

(Ellershaw 2011)

There are practical moral challenges which ought to be settled. Truth telling, put of care, continuity of effective palliative care till the final days of life, confidentiality, utilize of anti-microbials and blood transfusion, nourishment and progress mandates can be the key focuses which go up against a palliative care group. Advance in palliative care will come out of great investigate and therapeutic experts ought to embrace trials and studies in a legitimate and moral way. The delivery of palliative care and restorative morals are complementary, and utilize of the two together maximizes the assurance and fulfilment accessible to the powerless persistent and family members. (Bidhu 2009).

Everyday ethical issues in nursing practice draw a little attention but can create a big amount of stress for nurses. Nurses frequently feel uncomfortable in tending to the ethical issues they experience in patient care. (Ulrich et al. 2010). Stress related to ethical decision-making could be a genuine result of visit experiences with moral problems for nurses. (Raines 2000). Webb (2005) discusses the importance of honesty and being selective with the truth. It is not dishonest to keep unsolicited opinions to ourselves. Knowing where to draw the line here as a nurse in palliative care can be one of the biggest challenges.

### **Being selective with the truth**

The advantage of thinking in terms of honesty, rather than to tell the truth, is that we can draw a distinction between being blunt and truthful, and between honest and dishonest selective truthfulness. It is not dishonest to keep unsolicited opinions to ourselves. Knowing where to draw the line here as a nurse in palliative care can be one of the biggest challenges. (Webb 2005)

Nurses experienced difference and need of participation approximately how best to supply end-of-life care. Need of participation included both colleagues and patients. Hence,

the quality of care was impeded and the medical caretakers felt that this circumstance made moral issues for the quiet and relatives. (Webb 2005)

### **Withholding treatment and DNR**

Do-not-resuscitate (DNR) orders were initiated as a method to give competent patients the chance to determine under what circumstances they still choose life (Lachman 2010).

Rules for "do not resuscitate" (DNR) orders prescribe joint choices by doctors and competent patients or families of incompetent patients. Be that as it may, some doctors fear that talking about DNR orders with patients may be neglectful or brutal and advocate that the doctor alone make these choices. It isn't known how actual practice conforms to the prescribed rules or whether these rules are doable. Little is known almost how frequently patients and families take part in choices, how frequently assentation is conceivable, and what issues happen when doctors share choice making with patients or family. (Lo et al. 1985). From the literature review, the article by Wainwright & Gallagher (2007), showed that the nurses have a key part in choices approximately the withholding and withdrawal of treatment. Their obligation of care expands to their exclusions as well as their activities. Nursing care amplifies past treatment contributing to upgrading the patient's consolation and quality of life, anything the forecast.

## 7 DISCUSSION

The aim of the research was to look at the common nurse's role in palliative care and the most common ethical challenges in palliative care. Especially with the increasing of palliative care in the home, and the aim being that the patient should be able to be at their own home until the end, if possible. The theory used was the humanistic theory. There were two research questions answered and twenty articles to help answer them. Research question no. 1: What are the nurse's role in post-palliative care? Research question no. 2: What are the most ethical challenges in post-palliative care?

### 7.1 Importance of nurses' role in palliative care

In the findings, there were two articles explaining different types of communications and what aspects are important when caring for patient who is in palliative care. (Goldsmith et al. 2013, Harden et al. 2017). Studies also explained how nurses can provide good communication among others such as paying attention to sensitivity when communicating. Palliative care has been seen as an ongoing process due to the limited amount of research done. However, this research looked at different ways that these method of communicating and factors have worked. The categories in one of the articles were communication, communication between teams, sensitive delivery, roles, nursing care and care of the person. -(Goldsmith et al. 2013,

There was a particularly interesting article, that was about a project that had a pre-/post-test design to assess knowledge, attitudes, and behaviour's at baseline and one month after implementation of an established education curriculum. The teaching strategy included one four-hour class for oncology RNs with topics about the definition of palliative care, pain and symptom management, and how to have palliative care conversations. It found that nurses lack proper education on the assessing the patient who is on palliative care as well as the attitude towards the patients on the end of life care was hostile. (Harden et al. 2017)

In the previous articles it was shown that nurses tended to be more hostile with patients that are under the palliative care, this has caused lack of knowledge and the right attitude when taking care of a patient. The article by Harden (2017) explained the importance of the right knowledge and attitude to give a good quality care.

Cultural awareness has always been important when it comes to palliative care because, patients have different values and beliefs that could alter when it comes to agreeing to treatments. When it comes to culture, the nurses should be aware of each individual patient needs and beliefs when caring for them, from what they eat to what they will wear to if they want to receive blood transfusion according to (Pirschel 2017). Showing respect of these differences is vital to giving holistic palliative care – care of the mind, body and soul according to Mitchell & Jozwiak-Shields (2017).

Also, one aspect was that healthcare teams can work together in numerous ways by communicating openly during symptom assessment and management quickly and early (Abrahm 2017). A healthy respect for the roles of everyone on the care team can make working together easy. In the articles it said that nurses play an important role in highlighting to patients the importance of their quality of life to the treatment process. By encouraging them to report their symptoms—not just the dangerous ones like fevers, but their mental and physical states—nurses can help patients and their families understand that symptom reporting is never considered a burden. By asking and assessing patients often, nurses can work to normalize the symptom reporting process and patients will likely feel less inclined to withhold symptoms that are affecting them. (Abrahm 2017). This was one of the important factors within nurses' role, being able to work with other professionals and families in order to give good quality care for the patient.

Lastly, assessing pain accurately and communicating the diagnosis and plan to the healthcare team are important for effective pain management in patients receiving palliative care (Aubin et al. 2006). This enables the team to start a regimen that over time, with adaptations, will hopefully control the patient's symptoms. Spending time with patients and discussing their pain and how it can be reduced promotes a therapeutic healthcare professional patient relationship Pain assessment models can be useful in history taking because pain can be difficult for patients to describe (Aubin et al. 2006). This was an important aspect of the nurses role because there was a huge stigma towards the idea of

giving patients high doses of pain medication, as many nurses felt that too much pain medication meant patients suffering further but this article proved how pain management in actuality aids in end of life care. The nurses should also not be biased towards pain medication due to their own belief that certain medication are too much, therefore they minimize the amount of medication a patient is able to receive. This is one of the aspects of nursing role due to the biased and ignorance towards pain management. The authors chose the humanistic nursing theory, because it was the closest theory that had any particular relation to palliative care. The theory broke down into different aspects of nurse-patient relationship. The theory showed the importance of nurse-patient relationship, as well as the importance of care.

## **7.2 Importance of ethical challenges**

The findings of the study have confirmed that, there is an imperative and growing need for nurses to know their role and know about the ethical challenges they are facing or might start facing. Majority of the chosen articles for this study have recognized that there are several ethical challenges nurses face, and there are some more common ones. Most of the articles showed that the ethical part of nursing is very crucial not only for the patient, but also for the nurse, to be able to give the best nursing that they can to the patient, and that it leads to stress, even more if there are no guidelines for how to manage the ethics. Although there were many common reasons, the main one, which came up on most of the articles was ethics in practice; the four principles of basis for the reasoning.

The first one being, justice, is it just to respect and provide what are seen as a person's rights, in this context, good palliative care services, in the knowledge that a person has the right to medical treatment and healthcare or not. For example, someone who was been smoking cigarettes for a long time, should they be entitled to cure for lung cancer or not. Second one is justice and autonomy, meaning that with there being so much rhetoric given to the notion of autonomy in today's consumer services. Justice, rights and responsibilities, are often knows and portrayed as someone having the right, and the nurse having the responsibility to provide them. Although patients have a lot of right, they also have some responsibilities, for example, when a care plan is made, it is to be followed. The third basis is doing good (beneficence), meaning that nurses should try to make it comfortable, or give a comforting environment, which is an achievement of palliative care provision,

but only this may not provide the best quality of life possible for an individual with palliative care needs. They need to know what might be possible if they ask for it. The fourth one, in doing harm (maleficence), and that nurses should do non-maleficence work. What is the definition and the meaning of doing harm? If the whole moral nature and point of palliative care is to make the best of whatever life is left then the relative risks, and benefits of all proposed treatment and care need to be considered by the patient, (with or without family or relatives, however they prefer), and the profession care givers. Harm might be interpreted in different ways between health professionals. (Karim 2005)

The authors chose the humanistic nursing theory, because it was the closest theory that had any particular relation to palliative care. The theory broke down into different aspects of nurse-patient relationship. The theoretical framework that was chosen, called the holistic or humanistic approach, helps foster mental and emotional health, and also physical health. Humanistic nursing theories have an establishment within the conviction that patients can develop in a solid and inventive way. The HNT model had strong connection with the themes of the articles, because it focuses on the nurse and patient relationship. One of the articles (Harst ade et al. 2018), talked about dignity and that relates to the “*Inter-subjective Transaction*”, because it discusses dignity and compassion.



## **8 CONCLUSION**

The aim of the literature review is to look at the common nurses' role in palliative care and the most common ethical challenges in palliative care. There is one theoretical framework chosen to support this, which is the humanistic theory, is conducted by many theorists, we decided to look into the nursing model, between nurse-patient relations. The articles studied for this thesis showed that there are many ethical challenges for the nurse within palliative care such as DNR, withholding treatment and selective truths and the nurse's different roles in palliative care. Ten out of twenty articles were about ethical challenges, and the remaining ten articles were about the nurse's role in palliative care. Many different models or approaches to nursing look at the patient as a whole person, not just an illness or an injury. The theoretical framework that we chose, called the holistic or humanistic approach, helps foster mental and emotional health, and also physical health. Humanistic nursing theories have an establishment within the conviction that patients can develop in a solid and inventive way. The model was made by Josephine Paterson and Loretta Zderad. Paterson and Zderad accepted nursing instruction ought to be founded in encounter, which a nurse's preparing should centre as much on the nurse's capacity to relate to and associated with patients as a logical and restorative foundation. Although this subject can be taught, the best way to learn is through experience, and through different ways of learning in school, with different cases, and discussions.

### **8.1 Strength, limitation and recommendation**

This study was conducted over a period of 12 weeks. Ideally, a study that is to assess and investigate would be conducted for a longer period of time. The authors used twenty peer-review articles which strengthens the findings. One of the strengths of this qualitative research is that it helps in understanding then nurses' role in palliative care, and the most common ethical challenges. The second strength of this study is that there were two authors, and each was resigned with a question to research and to focus on, but still having the possibility to work on both questions together. This helps give focus on and explore as much as possible following the inclusion and exclusion criteria. A limitation that was faced with this study was that articles that were found were accessible due to ethical reasons such as what types of methods were used. As well as it would

have made a big difference to the study if more articles were accessible. It was also noted that there were difficulties finding articles that were written about “The nurses’ role in palliative care”, this made it challenging for the authors to find information about the topic. There was not enough research done on this topic previous to this one, which also made it more challenging. A recommendation for a future research would be to do a survey for nurses within the homecare, taking care of patients in palliative care, and what they feel is their biggest ethical challenge. By doing this, it would be easier to focus on helping the nurse face these difficulties in their profession. However, the twenty articles and a short period of time all the information that was important, was not covered, with that said, further research on this topic would be required.

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**/ APPENDICES**