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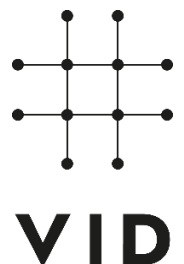
## Dignity in end-of-life care

How can nurses contribute to a dignifying death for palliative patients in the hospital setting?

### Bacheloroppgave i Sykepleie

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## **Abstract**

**Theme:** Palliative care, end-of-life care and dignity.

**Aim:** The purpose of this thesis is to explore how nurses can preserve dying patients' dignity.

**Study question:** How can nurses contribute to a dignifying death for palliative patients in the hospital setting?

**Method:** This paper is a literature study which uses four selected research articles to cast light on the study question. To substantiate these findings, I will apply already-existing theory, literature, curriculum, ethics and legislations, as well as personal experiences.

**Results:** The focus in all the articles closely relates to dignity in palliative and end-of-life care. The relevant topics discussed in the papers are communication and information sharing with patients, including patients in decision-making, being respectful and compassionate. The physical environment also plays an important role when it comes to the dignity of the patient.

**Conclusion:** It is crucial for nurses to establish a good, professional relation with the patient and their family. Being conscious about our communication, providing them with necessary information and include them in decision-making safeguards their dignity. Nurses can also facilitate the physical environment to the benefit of the patient's dignity.

## Sammendrag

**Tema:** Palliasjon, terminal pleie og verdighet.

**Hensikt:** Hensikten med denne oppgaven er å undersøke hvordan sykepleiere kan ivareta verdigheten hos døende pasienter.

**Problemstilling:** Hvordan kan sykepleier bidra til at palliative pasienter får en verdig slutt på livet på sykehus?

**Metode:** Oppgaven er en litteraturstudie som benytter fire selvvalgte forskningsartikler for å belyse problemstillingen. For å underbygge disse funnene vil jeg anvende allerede-eksisterende teori, litteratur, pensum, etikk og lovverk, samt dra inn egne erfaringer.

**Resultater:** Fokuset i alle artiklene relaterer til verdighet innenfor palliasjon og omsorg i livets slutfase. De relevante temaene som blir diskutert i disse artiklene er kommunikasjon og overrekking av informasjon til pasienter, inkludering av pasienter i avgjørelsesprosesser, være respektfull og vise medfølelse og forståelse. Det fysiske miljøet har også en betydning for verdigheten til pasienter.

**Konklusjon:** Det er avgjørende for sykepleiere å etablere en god, profesjonell relasjon med pasienter og deres familie. Å være bevisst på vår egen kommunikasjon, dele all nødvendig informasjon med pasienter og inkludere dem i avgjørelsesprosesser sikrer verdigheten deres. Sykepleiere kan også legge det fysiske miljøet til rette for pasientenes verdighet.

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## 1 Introduction

Caring for the sick and dying is something humans have been doing since the dawn of time. The phrase “cure rarely, comfort mostly, but console always” probably dates back to 16<sup>th</sup> century France, although the inspiration for the quote might be taken from Greek physician Hippocrates from 300 BCE (Hem, 2003). Due to lack of technology and knowledge, curative options in medicine have for a long time been limited. Health care professionals’ main job has been to relieve pain and suffering. In fact, it was not until after World War 2 that the focus in the medical community shifted from alleviating symptoms, to curing illness (Kaasa & Loge, 2018, s. 34).

Although palliative care is perhaps one of the oldest practices within medicine, I am still under the impression that there are certain aspects we do not possess enough knowledge about, for instance dignity. Everyone agrees that dignity in any kind of patient care is vital, but what does this indicate for nurses? What role does nurses play in assuring that patients’ dignity remains intact, even in their final moments? This is what I will explore in my thesis.

### 1.1 Background

Taking care of the sick and dying takes a special kind of person, someone who can endure others’ suffering. This requires safety, courage and competence (Sønning, 2021). As nurses, we are almost guaranteed to encounter a dying patient at one point in time. According to numbers from Statistisk sentralbyrå published on FHI’s website (Raknes, 2022) 42,002 people died in Norway in 2021. If we take into account that around 31% dies at a hospital (Helsedirektoratet, 2018), then that means around 13,020 people died in Norwegian hospitals in 2021, around 35-36 people on a daily basis.

There is no statistics available of how many of these people died with or from an illness, but we can assume it is a larger portion. Almost 11,000 of everyone who died in 2021 had a cancer-diagnosis, 10,715 had a heart and coronary disease and 2202 suffered from chronic obstructive pulmonary disease (Raknes, 2022). These are just some examples of patient groups who typically suffers heavily from symptoms due to their disease, and especially in end-of-life when additional problems can arise such as pain, nausea and fatigue (Mathisen, 2019, s. 426-427; Norsk Palliativ Forening & Norsk forening for palliative medisin, 2016).

In more modern time, palliative care has mostly been an offer primarily reserved for cancer-patients (Clarke, 2007; Fisher, 2017, s. 26). Today, palliative care includes a variety of different diseases and conditions where the patient is in need of symptom alleviation and a better quality of life (Tuhus et al., 2021).

I have experience working at a palliative care unit in a hospital. While we saw most cancer-patients, we also received people with other diseases such as chronic obstructive pulmonary disease (COPD), motor neuron disease (MND), Huntington's disease, cystic fibrosis and intestinal ischemia, to mention some.

While some of the patients I met were in need of for example better pain management before getting discharged home, we did have many patients who died in our unit. When working with terminally sick and dying patients, you meet them and their families at perhaps their most vulnerable. I experienced early how essential it is for nurses to be competent when meeting these kinds of patients. Through my experiences, I found that I think treating patients with dignity is one of the most important things to consider in palliative and end-of-life care.

## 1.2 Study question

In light of this I have come up with the following question:

“How can nurses contribute to a dignifying death for palliative patients in the hospital setting?”

## 1.3 Delimitation of the study question

I wish to focus on patients with a terminal illness, but for my thesis I will not target patients with a specific disease. This is because I want my main focus to be on end-of-life care and dignity, and not on the diagnosis. I will exclude for example patients who have been in a fatal accident or other cases where death comes unexpectedly. The patients must be aware of their disease and their short life-expectancy.

I will include patients of both genders in my thesis, and adults of any ages above 18 years of age, focusing on patients dying in the hospital. I will focus on the palliative phase, mainly on the final days of life and patients spending these days in the hospital.

The term “death with dignity” is often associated with euthanasia, or assisted suicide. This is not what this thesis will explore. I will discuss care actions nurses take in order to promote, safeguard or conserve dignity in a patient’s end-of-life.

#### 1.4 Definition of subject terms

**Palliative care:** “Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.

Palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Integrates the psychological and spiritual aspects of the patient care” (World Health Organization, 2020; Kaasa & Loge, 2018, s. 36).

**End of life care:** “Treatment, nursing and care in the last days or weeks of life” (Norsk Palliative Forening & Norsk forening for palliativ medisin, 2016).

**Terminal phase/dying:** “When the patient suffers from an incurable illness and will likely die in the foreseeable future (days or hours)” (Norsk Palliative Forening & Norsk forening for palliativ medisin, 2016; Helsedirektoratet, 2018).

**Dignity:** “A subjective experience of worth, a confirmation of self-value, respectfully acknowledging who we are and the purpose of our lives” (Gustafsson, 2022).

**Patient:** “A person who approaches the health care service with a request for health care, or that the health care service provides or offers health care in the individual case” (Pasient- og brukerrettighetsloven, 1999, § 1-3).

## 1.5 Disposition

In the following chapter I will introduce relevant professional knowledge and theoretical perspectives, which will later be used to discuss my study question. Afterwards, I will present the thesis' methodology in chapter 3 where I will describe the search process and how I have discovered and selected applicable research articles. Towards the end of chapter 3 I will evaluate these articles with criticism. Ethical considerations will then be mentioned.

In chapter 4, I will present the articles and their findings, as well as explain why I believe them to be relevant for this paper. The discussion in chapter 5 will be based on these research articles and studies, as well as the theory from chapter 2 and my personal experiences from practice. Finally, I will come to a conclusion at the end of my thesis.



## 2 Theory

In this chapter I will present relevant theory for my study question. This theory is retrieved from curriculum, theoretical books, online sources, legislations, as well as official and unofficial guidelines. First, I will present knowledge about palliative and end-of-life care, before moving on to dignity in end-of-life care. Further on I will present professional knowledge regarding communication, before exploring theory from Kari Martinsen which I find relevant for the study question. Ethics and legislation will finish off this chapter.

### 2.1 Palliative and End-of-life care

Canadian surgeon Balfour Mount was the first person to introduce the term “palliative care” in the early 1970’s. World Health Organization first defined palliative care in 1990 as:

“the active, total care of patients at a time when their disease is no longer responsive to curative treatment and when control of pain, of other symptoms and of social, psychological and spiritual problems is paramount” (Kaasa & Loge, 2018, s. 36).

Their new definition from 2002 (World Health Organization, 2020) has many of the same elements, but centers around improving quality of life of the patients and their families, and the importance of early identification of symptoms so they can be relieved.

Many of Norway’s hospitals write about palliative care on their websites. Sykehuset Østfold (u.å.) write that their task is to take care of patients who have not received optimal relief of their symptoms such as nausea or pain. The main focus of palliative care in hospitals is to prevent and relieve symptoms, as well as give patients advice and help when it comes to spiritual challenges (Akershus Universitetssykehus, 2020; Universitetssykehuset Nord-Norge, 2020).

In palliative care nurses screen for and assess symptoms and other issues. They must also possess basic knowledge about symptom-management and relieve these symptoms as best as possible. Communication and providing information are also a part of nurses’ jobs. They must also look after the relatives and help them process their grief (Haugen & Aass, 2018, s. 114).

It is important to acknowledge when a patient is dying, and it must be agreed upon by a doctor and a nurse (Helsedirektoratet, 2018). "People are considered to be dying when something threatens their prospect of living, such terminal illness or acute trauma, but also when they approach old age" (Nyatanga, side 7). Nyatanga's definition is perhaps a little nuanced, because dying, or the terminal phase, is a definition more commonly reserved for the last days or hours of someone's life (Norsk Palliative Forening & Norsk forening for palliativ medisin, 2016; Helsedirektoratet, 2018).

Towards a patient's end-of-life there arises some changes in their overall condition. Typically, they have an increased need for sleep and bedrest, their physical function starts to falter, and they can experience more fatigue than usual when it comes to minor activities such as rising up from a chair or going to the bathroom (Saunders, 1986; Norsk Palliative Forening & Norsk forening for palliativ medisin, 2016). Decreased interest in their surroundings, lack of ability to orientate and focus, as well as being less responsive to the people around them are typical signs to look for when a patient enters terminal phase. Eventually, swallowing oral medications and tablets becomes a problem, and they will stop eating and drinking (Norsk Palliative Forening & Norsk forening for palliativ medisin, 2016).

"Optimal palliative care is achieved the best by planning and initiating necessary measures at the right time during the course of the illness" (Kaasa & Loge, 2018, s. 43). It is crucial to get the patient's understanding of the situation and input on different options if they are still able to communicate. At the same time relative's perception should be valued, as well as the staff's (Helsedirektoratet, 2018).

## 2.2 Dignity in end-of-life

Dignity is a subjective feeling regarding our understanding of our own self-value. How we view dignity and other people's worth is therefore often based on our own experiences, attitudes and values (Kristoffersen, 2019, s. 17). "The idea of dignity is so important to the patient and yet it is least understood by health care professionals" (Nyatanga, 2017, s. 16). Concerns like pain-relief and symptom management, well-being on a spiritual and psychological level, and caring for family members are all aspects that help patients die with dignity. According to Nyatanga (2017, s. 16) patients can struggle with maintaining dignity

when it comes to for example odorous tumors. Some patients can isolate themselves due to this and other factors, and require nurses' support and help to restore their social network. Living with a terminal illness might impact the patient's experience of self-worth in a negative way, making them feel helpless when they require assistance with intimate issues. Patients might also feel like their lives are worthless due to their disease (Øhrstrøm, 2011, s. 139)

Dame Cicely Saunders is seen as a pioneer in palliative care. Not only was she the person to first introduce the concept of hospices, but her idea that pain can be more than just a physical ailment became widespread in the medical communities in multiple countries. She came up with the term "total pain", which centers around psychological, social, emotional and spiritual problems a patient can experience when approaching death (Morland, 2016). Saunders (1986) writes throughout her entire book about relieving "total pain" and how it preserves the patient's dignity.

She also writes about the importance of being available to the patient and their families to answer questions, provide information or accommodate their needs (Saunders, 1986). Nurses being present when caring for a dying patient, holding their hand and providing a therapeutic touch, ensures that patients does not die alone, which demotes dignity (Luckhurst & Clarke, 2017, s. 128).

Allowing patients to partake in decision-making can open for both the patient and health care professionals to make more informed choices. This can allow for better alleviation of symptoms and help patients work through the issue of their life coming to an end (Chochinov, 2002). It can also help health care professionals get a better understanding of what dignity is to the individual patient and their families.

### 2.3 Communication

Communication is an ability that all human beings possess. It evolves from birth and is everchanging in the way that we learn new words and phrases, how to use our body when we speak and how to change our language depending on the people we are talking to (Eide & Eide, 2014). Eide and Eide (2014, s. 12-13) write that our ability to communicate as a professionals can be trained. We need to be conscious about our communication skills and

how that competence can affect other people and how we communicate with them. We must be aware that as nurses, we are not communicating as private persons, but rather as health care professionals (Eide & Eide, 2014, s. 18).

Although we are professionals with medical knowledge, it is important to regard that the patients we are talking to, probably are not. The patients we meet probably do not have the same understanding as we do. We must therefore adapt our communication, use a language the patients understand in order to “convey information in a clear and understandable way” (Eide & Eide, 2014, s. 21). We must be aware of the way we pass on information, and think about why we do it that exact way (Eide & Eide, 2014, s. 292).

In their book, Eide and Eide explain that as nurses the aim of our communication should be to “promote health, prevent disease, restore health and relieve suffering” (Eide & Eide, 2014, s. 18). This is in accordance with the International Council of Nurses and Norsk Sykepleierforbund’s ethical codes and guidelines (ICN, 2021; Norsk Sykepleierforbund, 2019). Empowerment is an aspect to consider when communicating with patients. Empowerment is explained by Eide and Eide as letting the patient keep as much power and control over the situation as possible, and urging patients to participate in decision-making. This is best achieved by meeting the patient with respect and valuing their perspectives, opinions and feelings (Eide & Eide, 2014, s. 19).

### 2.3.1 Nonverbal communication

Nonverbal language is big part of our form of communication. In fact, about 55% of our communication comes in the form of body language (Fisher, 2017, s. 26). Nonverbal communication has to be interpreted. As nurses we do this all the time, intentionally or not, when we are talking to patients, but our interpretations are rarely entirely accurate. We must therefore consciously assess the patient’s body language to catch the information that comes from their nonverbal communication. Just as easily as we nurses can misinterpret a patient’s body language, they can also misinterpret ours. We should be aware of how we act in interactions with patients (Eide & Eide, 2014, s. 198).

Eide and Eide (2014, s. 198-199) have summarized six points to consider when it comes to nonverbal communication:

1. “Maintain eye contact, but without staring

2. Have a receiving, open posture (and avoid crossing legs and arms)
3. Lean forward towards the other person, act addressed through the posture
4. Follow the other person's statements by nodding understanding, give affirmative "mm", or through soothing touches
5. Be relaxed, natural and friendly in the tone of voice and movements
6. Let the facial expression express calm, presence and interest".

Touch is also a form of nonverbal communication that can have a big impact on the patients' feeling of safety, meaning and validation (Eide & Eide, 2014, s. 210). A caring touch conveys empathy. This might be a good tool to use when having complex or difficult conversations with patients (Fisher, 2017, s. 29). Using touch as part of communication has many strengths. In addition to conveying empathy and sympathy, it can also be used to get the other person's attention and keeping their attention throughout the duration of the conversation (Eide & Eide, 2014, s. 210).

As nurses, we might be more comfortable with body contact than the patients. Patients might act differently to touches than we do. Some might find it intruding and disrespectful to be touched without permission (Eide & Eide, 2014, s. 210; Fisher, 2017, s. 29).

Using touch correctly as a communication skill can be difficult. Dilemmas can arise when we are caring for sick and dying patients. As nurses we might feel tempted to squeeze a patient's hand as a sign of comfort, or give a hug to grieving family members who have just lost a loved one. Assessing whether the situation calls for body contact might be hard. A rule to keep in the back of the mind is that "when you touch a patient/family member it should be because you believe it will help that person, not because the touch helps you feel more comfortable" (Fisher, 2017, s. 29).

#### 2.4 Kari Martinsen on being professional and seeing the human being.

In her book "Øyet og kallet", Kari Martinsen writes about the importance of seeing the patient as a human being, and not as a medical case. "A problem that is always present, is that it is easy to shift away from sensing to registering" (Martinsen, 2000, s. 10). She explains this by saying that "registering" is taking an outside-position and classifying, and that it

reduces the human to an object. She says that this is damaging because it can make us as nurses become unattached and indifferent to patients' value and importance.

She explains that becoming registering might be an unfortunate side effect of trying to be professional. She explains that being professional when it comes to nursing is usually understood as distancing yourself and not become overly involved emotionally, in order to be objective and impartial. Martinsen writes that she agrees with this definition, but argues that being professional does not exclude being sensitive in communication with patients. Being professional is also listening to the patient about their own understanding of their disease and feelings (Martinsen, 2000, s. 11-12).

Martinsen further claims that as human beings we all have an expectation about how we want to be met: how we want to be accepted and taken seriously. "We appeal to the other for attention, to be seen as valuable" (Martinsen, 2000, s. 24). As nurses, it is important to keep this in mind when interacting with patients.

## 2.5 Ethics and legislation

Nurses and other health workers have a morally, ethical and legal responsibility to give responsible healthcare to patients. "Health personnel shall conduct their work in accordance with the requirements to professional responsibility and diligent care that can be expected based on their qualifications" (Helsepersonelloven, 1999, § 4).

Norsk Sykepleierforbund worked out a set of ethical guidelines for the first time in 1983. They were last updated in 2019 and says the following about how nurses must:

"2.3 Take care of each patient's overall need for care.

2.5 Encourage patients' opportunity to make independent choices by giving sufficient and adjusted information and make sure the information is understood.

2.10 Have a responsibility to give care and relieve suffering.

2.12 Contribute to a natural and dignifying death, and that the patient does not die alone." (Norsk Sykepleierforbund, 2019).

Patients also have a series of rights in accordance with the Norwegian Patients and User Rights act of 1999. By § 2-1b they have the right to necessary health care by the specialist health services. They also have the right to an individual plan of care, jfr. § 2-5. Patients have the right to participate in decision making, as well as being provided necessary information to get an insight into their health condition, jfr. §§ 3-1 & 3-2. § 4-9 says that dying patients have the right to oppose treatment that can prolong their lives. If the patient is no longer capable of giving consent to stop all life-prolonging treatment, the healthcare providers should consider the next of kin's wishes. (Pasient- og brukerretighetsloven, 1999).

The Norwegian government released a White Paper in 2020 where the aim was to "contribute to more openness about death". They also write that people in need of palliative care must be treated holistically to have the best possible quality of life and increased liberty when it comes to decision-making (Meld. St. 24 (2019-2020)).

## 3 Method

In this chapter I will present the methodology of my thesis. I will present inclusion and exclusion criteria and how I have used these actively throughout the entire search process, which will also be described. Towards the end of this chapter, I will present source criticism and ethical considerations I have done regarding the articles I have chosen.

### 3.1 Literature study as method

My thesis uses a literature study as a method. A literature study means using already existing literature, research and theory to cast light upon a certain topic and discuss a question (Dalland, 2022, s. 199).

All the articles I have used in this thesis use a qualitative method, which is mostly effective to capture opinions and experiences that cannot be reflected by numbers and statistics. To achieve this, qualitative studies often use questionnaires or conversations with open questions that allow the interview-subject to fully explain their thoughts on the matter at hand. Studies of a qualitative character delve deeper into a certain topic and explores what is special, or deviant about the case (Dalland, 2022, s. 54-56).

I have chosen to include a literature review (Harst ade et al., 2017) in my thesis. This review is in itself a qualitative study and most of the papers included in the review also have a qualitative method. However, 4 out of the 31 papers included in the review had a quantitative approach. Quantitative methods are often more effective to cast light on what is measurable by collecting and using data and statistics. The quantitative approach can also utilize questionnaires, but they are often systematic and standardized with multiple-choice answers (Dalland, 2022, s. 54-56). Using an article for my thesis consisting of both qualitative and quantitative studies means I can collect more information and comes to a wider understanding of the topic.

### 3.2 The search process

Further on in this chapter I will present my inclusion and exclusion criteria, search process in CINAHL with Full Text, how I selected an article using the Snowball method and my search in PubMed.



### 3.2.1 Inclusion and exclusion criteria

When searching for and selecting articles, I had set certain criteria to the literature. I have used the criteria systematically throughout the entire selection process and I will explain in the following chapters exactly how I have used them. The criteria are presented in the table below:

*Table 1 – Inclusion and exclusion criteria*

Inclusion criteria	Exclusion criteria
Peer-reviewed research articles on level 1 or 2 in Kanalregisteret.	Articles that have not been peer-reviewed.
Focusing on adults above the age of 18 years of age.	Focusing on children below the age of 18 years of age.
Written in English.	Studies from countries that are not relatable to the Norwegian health care system.
Articles published after 2013.	Articles older than 10 years.
	Articles discussing “death with dignity”, euthanasia, assisted suicide.
	Articles where the patient group died unexpectedly, from for example accidents or post-operative infections.

### 3.2.2 CINAHL with Full Text

Taking my study questions into account, I started by trying to find appropriate MESH-words I could use in my searches. Unfortunately, MESH did not provide words for all the terms I wanted to use. Therefore, I ended up using words already suggested by Cinahl, as well as using their option to “Suggest Subject Terms” to see if Cinahl used other terms for the words

I wanted to search for. “Terminal care or palliative care or end of life care” is an example of a term suggested by Cinahl.

After trying a few different combinations, I ended up using the following words and combinations that are presented in *Table 2*.

*Table 2 – Search in Cinahl*

Search	Search words and combinations	Inclusion and exclusion criteria	Results
S1	Terminal care or palliative care or end of life care		71,253
S2	Human dignity or dignity		7,778
S3	Respect		3,990
S4	Hospital units		107,781
S5	Hospital		468,415
S6	S4 OR S5		537,094
S7	S2 OR S3		11,250
S8	S1 AND S6 AND S7		194
S9		Only include articles from 2013-2023	132
S10		Only include articles written in English	118

S11		Only include peer-reviewed articles	112
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Seeing as I do not want to focus on children, I tried to narrow my search down to age groups “All adult”, but that resulted in only 84 articles, which I thought was a too slim sample pool.

I assumed that not all the articles were marked with age groups, so I decided to not use this exclusion criteria in my search, not wanting to risk losing articles because they might not have been marked with right focus group. Instead, I made sure when I read through the articles that they were not focusing explicitly on children.

Table 3 shows how I worked through the sample pool of my final search.

Table 3 – Results from Cinahl

Headings read	Abstracts read	Articles read	Articles selected
112	25	4	<ul style="list-style-type: none"> <li>• Hansen et al. Factors affecting quality of end-of-life hospital care – a qualitative analysis of free text comments from the i-CODE survey in Norway. 2020.</li> <li>• Harståde et al. Dignity-conserving care actions in palliative care: an integrative review of Swedish research. 2017.</li> </ul>

### 3.2.3 Snowball method

Initially, I planned on using an article from 2022 written by Agom et al. called *Placing care: the impact of the physical environment on experiences of providing and utilizing palliative care*. This was one of the articles I found and read through my search on Cinahl.

Their article discusses the importance of a good physical environment for palliative patients receiving end of life care, which I thought was an interesting aspect to explore further.

However, as I read through the article, I discovered that the setting is based in Nigeria and that their health care system was not very relatable to Norway. I decided not to use Agom et al.'s article, but in the study's introduction they wrote that their research was conducted with inspiration from a similar study done in the United Kingdom.

The article linked to a study done by Gardiner et al. in 2011 called *Exploring health professional's views regarding the optimum physical environment for palliative and end of life care in the acute hospital setting: a qualitative study*.

Seeing as the United Kingdom's healthcare system is more similar to ours than Nigeria, I decided to use Gardiner et al.'s study for my thesis. It was not available online, so I had to order it in paper-format from my school's library.

### 3.2.4 PubMed

I decided to use PubMed as my second search-database. I first tried using the exact same words and combinations from *Table 2*, but this gave me too many results in PubMed. I figured I had to use fewer or-combinations to narrow the field down, which also meant I could find articles that were more spot-on the topic of my study question.

The table below shows my search.

*Table 4 – Search in PubMed*

Search	Searchwords and combinations.	Inclusion and exclusion criteria	Results
1	Terminal care		68,318

2	End of life care		10,385
3	Dignity		483,347
4	Hospital		6,677,502
5	Hospital unit		755,476
6	Search 1 OR 2		102,385
7	Search 4 OR 5		6,717,232
8	Search 3 AND 6 AND 7		1,836
9		Excluding articles older than 10 years	1,277
10		Only include articles written in English.	1,235
11		Only including the age group "Adult: 19+ years"	471

PubMed did not have an option for me to exclude non peer-reviewed articles from my search, so this criteria was met later on the process by checking the journal of the article I selected in Kanalregisteret.

Out of these 471 results, I read all the headings, 12 abstracts and 2 articles. I recognized that some articles had also been posted on Cinahl and skipped over these. I could also see from the headings alone that many of the results were neither studies nor research papers, so I skipped past those as well. In the end, I chose to include this article in my paper:

Butkevičiene et al.'s *Being Heard: A Qualitative Study of Lithuanian Health Care Professionals' Perceptions of Dignity at the End-of-Life* from 2021.

### 3.3 Source criticism

According to Dalland, being critical to sources means to evaluate the literature you have found, as well as explain the criteria you have used in the selection process. "The purpose is for the reader to partake in the reflections you have done about the relevance and validation the literature has to cast light on the study question" (Dalland, 2022, s. 152).

The articles I have chosen to include in my thesis are based on health care system in different countries, respectively Norway (Hansen et al., 2020), the United Kingdom (Gardiner et al., 2011) and Lithuania (Butkevičiene et al., 2021). I have also included a Swedish literature review (Harståde et al., 2017). Although not all the papers included in the review are from a Swedish health care perspective, the authors made sure in their selection-stage that the articles have a similar health care system to Sweden.

Similarly, I also researched the health care systems in Sweden, the United Kingdom and Lithuania, finding that although there are a few minor differences in for example the number of staff and some of the tasks nurses do, it is still very relatable to how the Norwegian health care system works.

I have chosen to include articles with perspectives from relatives (Hansen et al., 2020) and health care personnel (Gardiner et al., 2011; Butkevičiene et al., 2021). Harståde et al.'s (2017) review consists of multiple papers with perspectives from family members, health care professionals and patients. This ensures that views from multiple sides' are explored. From experience, I have learned that health care workers, patients and relatives tend to have different opinions and values. Including articles where multiple sides are considered ensures that I can come to a conclusion where both opinions are equally valued.

Unfortunately, I could not find any articles where a patient was an interview-object. It was not specified in Harståde et al.'s (2017) study which of the views explored were from patients. In some of the articles (Hansen et al., 2020; Butkevičiene et al., 2021) the nurses and relatives does make a comment about what they think the patient would wish if they

were alive to tell, seeing as the studies most likely conducted after the patient's death. This means, however, that some patient-opinions might be neglected in my thesis.

The only article older than 10 years I selected, was the one by Gardiner et al. It was published in 2011, which is only two years older than what our guidelines suggested, so it is not exceedingly outdated. The reason I decided to include the article regardless of the publication-date, was because it discusses the importance of physical environment in palliative care, something I personally think is very important. I felt that none of the other articles I selected (Harst ade et al., 2017; Hansen et al, 2020; Butkevi iene et al., 2021) covered this aspect well enough for a proper discussion.

All the articles I have used are peer-reviewed (Gardiner et al., 2011; Harst ade et al., 2017; Hansen et al, 2020; Butkevi iene et al., 2021). Using Kanalregistert, I found that all of the journals where the articles were published are rated either as either number 1 or number 2.

### 3.4 Ethical considerations

Dalland (2022, s. 167-168) explains that ethical considerations is about following a set of rules and norms about what is right and wrong. When it comes to research ethics, it is important to make certain that privacy is considered and that the interview-subjects will not be affected negatively by participating in the study. It also important to preserve the interview-object's anonymity. Keeping this in mind, I have anonymized all stories and personal experiences I have used in the discussion. This is so no-one can find out which patients, relatives, health care personnel or colleagues I am discussing.

All peer-reviewed articles published in journals should already have been approved by an ethical committee. I have also checked this myself. All the articles (Gardiner et al., 2011; Harst ade et al., 2017; Hansen et al, 2020; Butkevi iene et al., 2021) I have chosen includes information about being ethically approved and by which committee. When it comes to the review, all the studies included in the paper "have ethical approval in accordance with the Swedish act concerning the ethical review of research involving humans" (Harst ade et al., 2017).

## 4 Results – presentation of articles

In this chapter I will present the articles, their results and main findings, and why I find them relevant for my thesis and study question.

### 4.1 Article 1

**Factors affecting quality of end-of-life hospital care – a qualitative analysis of free text comments from the i-CODE survey in Norway.**

**Authors, year of publication and journal:** Hansen, M. I. T., Haugen, D F., Sigurdardottir, K. R., Kvikstad, A., Mayland, C. R., Schaufel, M. A. 2020. BMC Palliative Care.

**Purpose:** Explore which factors improve or reduce quality of end-of-life care.

**Method:** Qualitative study in Norway. Based on a questionnaire given to relatives of patients 6-8 weeks after the patient died in a hospital. 104 of 194 participants added free text responses to the otherwise standardized questionnaire. This study is based on those free text comments.

**Main findings:** Nurses being attentive towards the patient and relatives' practical needs promoted dignity in end-of-life. Relatives valued feeling welcomed, respected and being informed by the health care personnel regarding the patientcare. Staff-continuity was seen as important.

**Relevance for the study question:** Gives an understanding of relative's experiences regarding the care their loved ones received in their final moments. Although the dignity-aspect is not the main topic of the study, it is still central in many of the responses from the relatives.



## 4.2 Article 2

### **Exploring health professionals' views regarding the optimum physical environment for palliative and end of life care in the acute hospital setting: a qualitative study.**

**Authors, year of publication and journal:** Gardiner, C., Bereton, L., Merry, G., Ingleton, C., Barnes, S. 2011. *BMJ Supportive and Palliative Care*.

**Purpose:** Explore the perspectives of health care professionals regarding the optimum physical environment for palliative and end-of-life care.

**Method:** A qualitative study with focus group interviews conducted in the United Kingdom. One focus group took place at an acute hospital with 7 participants, and one at a community hospital with 6 participants. Not all the participants were nurses, but all were health care professionals who worked with providing care to patients in end-of-life.

**Main findings:** Informants mention how things such as the right color scheme and pictures on the walls made the environment feel more “comfortable and homely”.

The informants had divided opinions about whether single rooms or multi-bed accommodations were the best for the patient. Single rooms were more dignifying, according to the informants, providing privacy and a calmer environment. But, it was mentioned that sharing a room with other patients assured that patients are not alone in their last moments if they do not have relatives present.

The optimal environment for the patient, might not be the best environment for the nurses. The lack of windows on the door provided privacy for the patients, but was a disadvantage for the staff who had to open the door to check in.

**Relevance for the study question:** Discusses how the physical environment affects the care, mental health and dignity of patients, seen from health professionals' point of view. Although not all participants were nurses, the article is still relevant because the other professionals add more information which makes for a broader discussion.

### 4.3 Article 3

#### **Dignity-conserving care actions in palliative care: an integrative review of Swedish research.**

**Authors, year of publication and journal:** Harstäde, C. W., Blomberg, K., Benzein, E., Östlund, U. 2017. Scandinavian Journal of Caring Science.

**Purpose:** Explore suggestions for care actions that conserves dignity.

**Method:** Integrative review including 15 articles and 18 doctoral theses. 29 of these were qualitative studies, and 4 were quantitative. All international articles included were checked and validated for being relatable to Swedish health care.

**Main findings:** The article discusses how death anxiety can be relieved by listening to patients talk about their feelings and past life. Using open questions when talking to patients created trust and let the patient elaborate on their feelings. Being honest and respectful also caused patients to trust the professionals.

The study also discussed the importance of patients being offered stimulation such as watching TV, listening to music and learning new things. This helps them uphold their level of independence and their cognitive acuity, even in their final moments.

Providing patients will all necessary information and including them in the decision-making process was crucial for their autonomy and dignity.

**Relevance for the study question:** The entire study in itself is not directly focused on the hospital setting. I still find the review relevant to answer my study question, because it gives such a wide understanding of dignity-conserving care actions in general, many of which are relatable to hospitals. It also includes views from health care workers, relatives and patients in a palliative phase.

#### 4.4 Article 4

##### **Being Heard: A Qualitative Study of Lithuanian Health Care Professionals' Perceptions of Dignity at the End-of-Life.**

**Authors, year of publication and journal:** Butkevičiene, R., Kuznecovienė, J., Harrison, D., Peičius, E., Urbonas, G., Astromskė, K., Kalėdienė, R. 2021. MDPI.

**Purpose:** Explore health care professionals' attitudes, experiences and opinions concerning dignity in end-of-life care.

**Method:** A qualitative study conducted in Lithuania. The interview-objects were 21 professionals, 7 of whom were nurses. All of participants worked with patients receiving end-of-life care.

**Main findings:** This study discussed that having a safe physical environment is important for dignity. So does having other people around, ensuring the patient does not die alone.

Denial and avoiding talking directly about death are a cultural phenomenon in Lithuania. Death as a taboo topic meant some patients had difficulty opening up and discussing their feelings.

The study concludes that for the patient to feel like they have been heard is the most important aspect when it comes to preserving dignity. It is of importance for patients to express themselves, for their voices to be heard, have their wishes be respected and being included in decision-making.

**Relevance for the study question:** I found this article relevant because it ties very closely to the dignity aspect of end-of-life care and covers many different underlying topics. It also casts light on professionals' attitudes regarding dignity and ethical challenges.

## 5 Discussion

In this chapter I will discuss the study question of my thesis; How can nurses contribute to a dignifying death for palliative patients in the hospital setting? I will be utilizing theory, literature and research, as well as empiricism and experiences from practice. I will first discuss the importance of providing patients and relatives with information, and how including them in decision-making safeguards dignity. From there I will discuss how creating and maintaining a good relation with patients affects their dignity. Rounding off the discussion, I will explore how the physical environment can benefit patients.

The relative perspective will be discussed throughout this entire chapter. This is because although my focus is on the patient, relatives are an important part of their social circle. I am under the impression that making sure relatives are well taken care of is an important aspect of the patient's dignity.

### 5.1 Information and decision-making

Providing necessary information to patients is not only a part of nurses' job, it is also set out in the law. Patients have a lawful right to receive all necessary information about their disease and medical condition (Pasient- og brukerrettighetsloven, 1999, § 3-2).

Receiving inadequate or unclear information adds stress to an already upsetting situation (Hansen et al., 2020). Relatives have explained their experiences with missing crucial information, and that information had to be repeated. Health care professionals would occasionally speak in "medical language", using words and phrases relatives did not understand. Eide and Eide (2014, s. 21) suggests that we need to learn how to adapt our language so patients, and relatives, understand what we are saying. After all, it is not enough to simply pass on information, the information also has to be understood (Norsk Sykepleierforbud, 2019).

Relatives in Hansen et al.'s (2020) study also said that the information they received could be inadequate at times. One informant claimed they were unable to be present when the patient died because it was never communicated clearly that the patient was going to die in the foreseeable future. According to Helsedirektoratet (2018) it is important to acknowledge

when a patient is dying. This information must be passed on to the relatives diligently in an empathic way (Harst ade et al., 2017).

According to the relatives in Hansen et al.'s (2020) study, there were often too many professionals involved with the patient care. It was experienced as disturbing when a doctor they had never met, imparted new information or made decisions such as changing medication without including the patient or the relatives in these decisions.

Unfortunately, this is a problem I have experienced many times as well, especially when patients are moved between different units. I have a feeling that what is regarded as the most crucial issues often change depending on which unit the patient is in, which doctor is assigned and how the nurses, who interact with the patient the most, views the situation. I remember in one case, we received a patient who was moved from the oncological unit. It was written in notes that we were to document food and drink intake. It was one of the first things we decided to remove from the care plan because we experienced the patient as pre-terminal and we did not see the point in watching the calorie and drink in-take. I can understand how this can be seen as stressing for the patient and their relatives, when we disregard something so quickly that has been viewed as important by other professionals. In cases like this, we should explain thoroughly why we as nurses and health care professionals do the things we do.

Patients not only has the right to information, they also have the right to participate in the decision-making process regarding their treatment, medication, or anything else that might affect their quality of life and health (Pasient- og brukerrettigheter, 1999, § 3-1).

Butkevi iene et al.'s (2021) study concluded that being heard was "an essential component of dignity". They specified "being heard" as the patient being allowed to express his or her feelings, thoughts and opinions, and for these to be valued. This thinking is also supported by Kari Martinsen (2000, s. 11-12). Also Harst ade et al. (2017) discuss the importance of maintaining the patient's autonomy. Health care professionals listening to and respecting their wishes is suggested as a dignifying care action. Being heard is also about partaking in decision-making, not only when it comes to big medical choices such as treatment options, but also letting the patient decide what they want to eat or when to take a smoke (Butkevi iene et al., 2021).

One of my colleagues mentioned that she had created a future will where she lists off everything that is important to her. It is everything from how she likes to wear her hair, to the kind of clothes she prefers and what types of food she does not like, everything that makes her *her*. She wrote this will in case she would ever get dementia, suffer an accident, stroke or anything else that could leave her unable to convey her wishes, to ensure that she would get treated with dignity. The basis of this idea can easily be transferred into our profession. It does not have to be an official document, but nurses can create a plan of care in cooperation with the patient and their relatives. I had a patient tell me once that she did not want to be wearing socks. She described it as feeling suffocated if she wore socks to bed, so she was said she did not want to wear socks when she died.

Another example was a pre-terminal patient we could see was going to die sometime within the next few days. She was still conscious and was also aware of this fact. We wanted to offer her Midazolam during the day so she could get some rest. She did not want it, saying she was expecting visitors that day and she was adamant to stay awake during their visit. We took her opinion into account, and she passed away later that day. I feel like she died with dignity because we respected her choice, allowing her to say her final goodbyes. There are things like these that we nurses will perhaps not think about, or understand the patient's feeling about, without cautiously communicating with them and asking "What is important to you?". This is essentially what Eide and Eide (2014, s. 19) describes as empowerment.

## 5.2 Nurses as part of the patient's social relations

When we are caring for patients, we have a professional relation to them. It is therefore crucial to establish a good line of communication, trust and respect to safeguard the patient's dignity (Eide & Eide, 2014, s. 19; Martinsen, 2000, s. 24). Nurses and other staff working with the patient should be easily accessible and trustworthy (Saunders, 1986). Multiple studies (Hansen et al., 2020; Harst de et al., 2017) show that it was easier for patients and relatives to ask questions and open up about their concerns when they trusted the health care personnel. Harst de et al. (2017) elaborate that trust is gained by the professionals showing interest in the patients as individuals. Kari Martinsen (2000, s. 10) supports this.

I also believe that trust is essential for establishing a good, professional nurse-patient relation. There are a variety of different approaches we can take for the patients to trust us, and I personally believe one of the most important things are to be honest. I will substantiate this with a personal experience. When my grandfather was diagnosed with terminal lung-cancer, he asked the doctor who delivered the message whether he would live longer if he stopped smoking. The doctor was honest in saying no, his life-expectancy would not increase, at least not substantially. My grandfather was then clear that he would not stop smoking, something the doctor supported.

By being honest and at the same time respecting my grandfather's choice, that doctor gained my grandfather's trust and respect from the very first conversation. I was under the impression that this single conversation set the tone of their relation up until my grandfather passed away.

As nurses our job is to care for patients (Haugen & Aass, 2018, s. 114; Saunders, 1986; Martinsen, 2000; INC, 2021, Norsk Sykepleierforbund, 2019). I am convinced that it is also important to *show* that we care about the patients as human beings. Actively using our body language like Eide and Eide (2014, s. 198-199) suggests, can show that we value what the patient has to say and that we are invested in the conversation. Adding comforting touches can convey empathy and compassion (Fisher, 2017, s. 29; Eide & Eide, 2014, s. 210). At the same time, we should consider that not everyone might be comfortable with physical contact.

Relatives in Hansen et al.'s (2020) study said that it was important with staff-continuity. It was easier to turn to familiar staff for advice, comfort or support. Harst de et al. (2017) also say the same, that staff-continuity makes patients feel safe and feel like they are taken seriously. It also makes it easier for the patient, the relatives and the health care personnel when the staff is familiar with the situation. On the other hand, I think the nurses should also have a say in how much they want to be involved with a particular patient. I have experienced patients and situations that can be physically or emotionally draining. It can be physically heavy patients or patients who are seen as "difficult" for different reasons. It can be dying patients with young children or other cases which affect us to the brink of what we can handle. As much as I understand the benefits of staff-continuity, I believe in some cases

it can be better to rotate on the nurses assigned to the patient to avoid them getting too emotionally invested, exhausted or burned out.

Many palliative patients suffer from death anxiety. It is very individual which approach can be the best to relieve anxiety. Some patients might benefit more from talking about their feelings, whereas others might see discussing death as a taboo topic (Harst de et al., 2017; Butkevi iene et al., 2021). I believe finding the best approach comes from taking the time to get to know the patient on an individual level. Harst de et al. (2017) suggest listening to patients talking about their lives. I believe this can help us understand which topics might be safe to discuss with the patient and which to avoid. In addition, reminiscing can help the patient see that they have lived a meaningful life (Harst de et al., 2017).

### 5.3 The importance of physical environment

When we are working in a hospital the physical environment is already set and there are some things we cannot change, even if we think it could benefit the patients. Aspects such as warm color schemes, calming pictures on the walls, windows that allow sunlight to enter and a tranquil view of the outside world are all things that are mentioned which could help create a comfortable environment for the patients (Gardiner et al., 2011). Obviously, it is not possible to relocate an entire hospital simply because the view outside is not optimal. I also suspect that changing the color of the walls is not something that is often prioritized as it requires a rather massive renovation. I still believe there are certain actions nurses can take to better the environment for the patient and their relatives.

Having basic needs met in a safe environment promotes dignity in end-of-life. "Eating, clean environment, warmth, comfort when you do not feel pain and when there are people around you" is seen as important (Butkevi iene et al., 2021). Having an environment that is calm and peaceful is essential (Hansen et al., 2020). Personalizing the room can help the patient's feeling of self-value stay intact (Harst de et al., 2017). I believe this can be done by bringing pictures from home or letting their belongings stay out in the open and visible, instead of tucking everything into closets. However, one of the informants in Gardiner et al.'s (2011) study questioned how much a homely environment actually benefits the patients, saying "the thing most of them (patients) say to me is this isn't home, the people



are lovely, they care about me, but this isn't home." As much as I understand the informant, I will argue that creating a comfortable space for patients is meaningful. I agree that a hospital-room will never be their home, but that does not mean we should not try to make patients as comfortable in their environment as possible.

One of the aspects that is discussed in all the articles is privacy and single rooms (Gardiner et al., 2011; Harstäde et al., 2017; Hansen et al., 2020; Butkevičiene et al., 2021). Being terminally ill and dying in a room shared with other patients not only deprives the patient of dignity, but also the relatives present (Hansen et al., 2020). Participants in Gardiner et al.'s (2011) study agreed that single rooms are more dignifying and allows for more privacy, however they had some divided opinions about whether single rooms or multi room accommodations were best for the patient. They argued that single rooms can become isolating when the patient has no relatives present. One professional claimed that most of the time, patients are placed in single rooms without being asked, due to assumptions from the staff that they would like a single room, depriving them of their autonomy.

I interpreted the latter view from Gardiner et al.'s (2011) study as being related to the palliative phase, when the patient is awake, contactable, communicating and might benefit from sharing a space with another patient. Personally, I do not think terminal patients should be placed in multi-patient rooms. In fact, I strongly believe it is the opposite of dignifying for a patient to die in a room right next to a stranger. I feel that dying patients should be prioritized above any other patient groups for a single room when they are hospitalized.

The physical environment does not just equal the space inside the patient room, but also the entire facility and how it can meet the needs of patients and their families. The relatives in Hansen et al.'s (2020) study discuss how some of their practical needs were not met and how it added stress to their situation. First of all, there was no free parking on the hospital grounds. Meals were not offered to relatives at the hospital units. This meant they had to leave the patient to move their car or obtain a proper meal. Patients could experience stress about feeling left alone for the time their relatives were gone. In Butkevičiene et al.'s (2021) study it was claimed that spending the last days in an institution increases the likelihood of dying alone. This can mean, in the worst case scenario, that a patient can end up dying alone

because their relative had to move the car in order not to get a parking ticket. Nurses might not be able to change the parking structure, but they can offer to stay with the patient while their relatives go out for short errands. At my workplace we also offer relatives the patient's meal if they are terminal or for other reasons not eating.

Relatives have said that it is important both for them and for the patient to feel welcomed when they are in the hospital (Hansen et al., 2020). They saw this as being allowed to sleep in the patient's room when death is impending, ensuring that they could be present throughout the remainder of the patient's life. Having family, friends or other loved ones around creates a safe environment and preserves dignity (Butkevičiene et al., 2021). I think nurses should make whatever arrangements necessary so relatives can sleep there, bringing them extra pillows and blankets. If the size of the room and other factors allow for it, then another bed can be brought into the room, or perhaps a leaning chair or a mattress that can be laid out on the floor to ensure family members can rest comfortably.

Relatives have also mentioned that they feel welcomed when they are allowed unrestricted access to facilities such as the kitchen (Hansen et al., 2020). I know from experience how important it can be for relatives to have access to a kitchen when they are visiting patients. When I started working at the palliative hospital unit, Covid-19 restrictions were in place. As a measure to prevent infection-spreading, patients or relatives were not allowed into the kitchen, only the staff. We tried our best to be helpful by bringing whatever the patient, or relatives, needed, but I did understand how some of them might feel like a burden about having to call us for a cup of coffee or a glass of water. We also took meal orders from patients who ate and drank, bringing their food to the room, which deprives the patients of their autonomy. In my opinion, it is important for ambulatory patients to be allowed access to the kitchen so they can see what their options are and what looks tempting, instead of nurses reciting the menu.

The best physical environment for the patient, does not always equal the best work-environment for the nurses. In Gardiner et al.'s (2011) study it was mentioned that the lack of windows on patient room-doors was troubling for the staff. One nurse mentioned that lack of insight gave the patient and the relatives more privacy, but there was no way for the staff to check in on them except for to knock and open the door, and risk interrupting a

private conversation. The relatives in Hansen et al.'s (2020) study also mentioned they would like the liberty to play music and light candles. Because of intern regulations live flames are not allowed in many institutions, due to fire hazard. My workplace has purchased multiple battery-driven candles which patients and relatives can borrow to decorate the room. Making compromises like this might seem like a small thing, but it promotes dignity in the way that we try to come up with alternative solutions that benefits the patient and their families.

## 6 Summary

The aim of my thesis was to research which factors promote, preserves and safeguards dignity for patients in a palliative or terminal phase. I wished to explore how nurses can use these factors and knowledge in practice to give patients a dignifying death. Using theory, research and personal experiences, I feel that I have come to a conclusion.

The studies and literature have a running theme regarding how nurses should meet patients and their families. Seeing them as human beings, conversing in a way that conveys respect and empathy safeguards the patients' dignity. A good relation is key to establishing trust with the patient and their relatives.

Providing patients with necessary information is an important aspect of dignity. Having patients participate in decision-making, and having their opinions heard and valued, is also crucial for their dignity. Having a say in bigger and smaller issues safeguards their autonomy, which the literature and studies supports as dignity-conserving. Lastly, the physical environment is crucial for the patients' dignity, as well as their family members'. Although we cannot change everything about a physical space, nurses can still make minor changes to improve the environment for the patient's benefit.

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