

# Exploring Nurses' Experiences of Providing Palliative Care:

## A Literature Review

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Abstract <p>This study intends to explore the experiences of nurses' who work in the field of palliative care. The purpose of the study was to examine what kind of emotions and thoughts nurses' experience when facing a common issue in palliative care, which is patients' mortality and death. The aim of this study was to use literature sources and previously done researches to collect and summarize nurses' experiences about providing palliative care. Exploring those experiences and finding out what coping mechanisms nurses use in the face of death can be useful for nursing students and nurses who are likely to experience the death of their patient during their professional life.</p> <p>The used study method was literature review, and the literature was collected by using different databases such as Cinahl, Google Scholar, PubMed and MedScape. The articles that were accepted were mainly published between years 2000-2014, but in addition one older article was included also. The selected literature was then analyzed by using the method of inductive content analysis.</p> <p>The main results of the study indicate that there are indeed many emotions and issues that patients' mortality and death awakes in nurses. Nurses seem to be going through such emotions as hopelessness, powerlessness, emotional attachment and relief when working with dying patients. Moreover, other difficulties that nurse experience when working in palliative care are communicating with patients and their families, and being influenced by the patients' age and relating too much to them. It was found that nurses who work in these care settings may also develop symptoms of depression. However, there were coping mechanisms found which help nurses to manage the stress caused by death. These mechanisms included changes of perception about death, talking with colleagues and balancing the work and personal life.</p> <p>A recommendation for the future research could be a larger study of various coping mechanisms that nurses use when dealing with patients' deaths, or the distress in nursing job in general.</p>		
Keywords palliative care, nurses' experiences, literature review		



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<p>Tiivistelmä</p> <p>Tämän opinnäytetyön tarkoituksena oli selvittää millaisia kokemuksia ja ajatuksia sairaanhoitajilla on palliatiivisesta hoitotyöstä ja siihen usein liittyvästä potilaan kuoleman kohtaamisesta. Opinnäytetyön tavoitteena oli aiemmin toteutettujen tutkimusten pohjalta tehdä tiivistelmä yleisimmistä sairaanhoitajien kokemuksista ja potilaan kuoleman herättämistä tunteista palliatiivisen hoidon alalla. Tarkoituksena oli myös saada selville sairaanhoitajien käyttämiä selviytymiskeinoja kuolevan potilaan kohtaamiseen ja kuoleman käsittelyyn liittyen, siinä toivossa että tästä olisi hyötyä sairaanhoidon opiskelijoille tai jo valmistuneille sairaanhoitajille, jotka kohtaavat kuolemaa työssään.</p> <p>Tutkimusmenetelmänä käytettiin kirjallisuuskatsausta. Aineistoa kerättiin tietokannoista, joihin kuuluivat Cinahl, Google Scholar, PubMed ja MedScape. Valitut aineistot olivat pääasiassa julkaistu vuosina 2000-2014, mutta myös yhtä aikaisemmin tehtyä tutkimusta käytettiin. Tutkimus suoritettiin induktiivisena sisältöanalyysinä.</p> <p>Tutkimuksen tulokset osoittavat, että potilaan kuolema herättää sairaanhoitajissa monenlaisia tunteita ja ajatuksia, esimerkiksi toivottomuuden ja voimattomuuden tunteita, kiintymystä potilaaseen sekä myös kuolemasta seuraavaa helpotusta. Sairaanhoitajat myös kokevat kuolevien potilaiden sekä heidän perheidensä kohtaamisen vaikeana, erityisesti silloin kun potilas on nuori. Tämän kaiken seurauksena sairaanhoitajat voivat kokea masennus oireita.</p> <p>Tutkimuksessa selvisi myös että yleisimpiä sairaanhoitajien keinoja käsitellä kuolemaa ovat näkökulman vaihto, collegojen kanssa puhuminen sekä työ- ja henkilökohtaisen elämän tasapainottaminen.</p> <p>Tulevaisuuden tutkimuksissa sairaanhoitajien käyttämiä selviytymiskeinoja voitaisiin tutkia vielä syvemmin, niin potilaan kuolemaa kohdatessa, kuin muissakin hoitajia mahdollisesti stressaavissa tilanteissa.</p>		
Avainsanat (asiasanat) palliatiivinen hoitotyö, sairaanhoitajien kokemukset,		
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## INTRODUCTION

The nursing code of ethics prescribes that nurses, and other health care professionals, have to work towards improving the living condition of the clients they take care of and provide the best care possible. (Finlex 2010) It is therefore natural for nurses to expect and hope for an improvement of their patients' condition. However, there are situations where the possibility of curing a patient becomes unlikely as the disease progresses. For highly life-threatening conditions, such as cancer, chronic cardiovascular diseases and chronic obstructive pulmonary disease, the idea of healing is already challenged by the gloomy statistics associated with those diseases. (WHO 2014, 25) In relation to cancer for instance, the five year after diagnostic survival percentage for prostate and skin cancers, is relatively good (superior to 98%), while other cancer types, such as esophagus and pancreas cancer, have a relatively pessimistic out-come (3-10%). (Suomen syöpärekisteri 2011) On their part, COPD patients have to face the fact that the progressive nature of the disease eventually leads to a complete loss of autonomy. At this stage, the only available type of care for the patient is provided with the purpose of managing the symptoms and maintaining some sort meaningfulness and life quality. (National Heart, Lung and Blood Institute 2013)

The care which is provided to patients as a way of managing the symptoms of a life threatening disease and to maintain their life quality, or possibly prepare them for the coming death, is called palliative care. (WHO 2014, 2) The history of palliative care goes hand in hand with oncological care, as palliative care was invented to be part of the care for cancer patients whose disease has gone to the terminal stage, and was not longer able to be cured. Nowadays, palliative care has been developed as a separate field of care which is not only given to dying patients, but also used to alleviate pain and suffering. (Pavlish & Ceronsky 2007, 794)

Of the palliative care patients, majority consist of cardiovascular and cancer patients with 38.47 % and 34.01 % respectively. Patients with the COPD come at the distant 3th place with about 10% of the cases referred to palliative care. Other diseases including diabetes, Alzheimer's disease, neurological diseases and HIV/AIDS also can lead patients require palliative care in the end of life. (WHO 2014, 14)

The life expectancy in developed countries has been increasing which means that more and more people are living older. In addition, the amount of infections leading to death has decreased, while serious chronic conditions have become more common causes of death. This means that health care services need to be able to provide care which aims to maintain patients' life quality and independence, and treats the symptoms as the disease itself is not curable. The increased need of this kind of services also increases the need of health care personnel who have the skills and knowledge to provide quality care for the patients with chronic conditions. (WHO 2004, 8) To give a practical example of this kind of development, according to Tilastokeskus (2011), in Finland population has increased from approximately 4 446 million to 5 375 million between 1960 and 2010. During the same period, the yearly cancer diagnostics have grown from 4407 to 14051. (Suomen syöpärekisteri 2011)

Even though, the care and hospital services in our culture are cure oriented, in a case of a progressive disease, the patient should be referred to palliative care already in the beginning of his treatment. (Mahon & McAuley 2010, E142) This means that even though the hope and aim of recovery is kept alive, the patient and nurses also have to consider that the possibility of death is around the corner. (Leung, Esplen, Peter, Howell, Rodin & Fitch 2011) As the patients having chronic progressive diseases can be going through difficult times and suffering in their lives, it often hides the more subtle situation that nurses in palliative care have to face. It is indeed them, who spend a considerable amount of time with the patients dealing with the emotional, psychological and physical pain that the disease inflicts on them. (Boyd, Merkh, Rutledge & Randall 2011, E230; Mahon & McAuley 2010, E141)

In this study the palliative care is explored from the nurses' perspectives to understand their experiences of providing this psychologically demanding care. Also the palliative care nurses' ways of coping with the possible stressors are examined. The method of literature review is used as in purpose of gathering data from the numerous previously done researches concerning the topic of palliative care nurses' experiences and ways of coping.

## 2 PALLIATIVE CARE

### 2.1 Defining Palliative Care

Palliative care is defined to be an approach of care which is provided to patients and their families going through a progressive, life-threatening disease, such as cancer, AIDS or some neurological disease, in mean of relieving the symptoms of the disease. (Center to Advance Palliative Care 2014, 1) Other concepts of care which might be used simultaneously with palliative care are called ‘terminal care’, ‘hospice’ and ‘end-of-life care’. The difference is that whereas palliative care can be given for years in mean of managing the symptoms of a disease and the death of a patient is not yet imminent, these other terms are used when the estimated life expectancy of a patient is only weeks or months. (Lindström 2012, Saarto 2009, 1)

The very principle of palliative care is to maintain the life quality and meaningfulness of the patient, and his or her relatives. (Viitala 2014, 36; ) To reach this aim, a multidisciplinary care is needed in the mean of being able to fulfill the patient’s needs and to be able to provide the kind of care which is the most suitable to the patient, and provides the kind of death that the patient wishes for. (WHO 2014; Lindström 2012; Mallat 2014, 8) Instead of measuring and treating the patient’s body functions, the emphasis of the care is on listening and comforting, and being present and available for the patient. (Korhonen & Poukka 2013, 440-5)

The patient should be seen as a unique individual who has his own culture, beliefs, values and habits, and those should be respected and nourished in the care of the patient. A patient, who is going through a progressive, life-threatening disease, is not only experiencing the fear of death, but might also struggle with pain, changed body image and worries about his family and their future. (Mallat 2014, 8) Also depending on the patient’s religious background, the patient may see the disease as a punishment, which can bring guilt and shame to the patient. The terminal care should take all the worries of the patient into account, in the mean of being able to provide the patient a comforted and peaceful death. (Matzo and Sherman 2006, xix-15) What is important to remember, is that for each patient a good care, as well as a good death is a personal issue, and as the law of patient’s rights states, a patient has a right to receive quality

care, which must be planned together with the patient. (Sosiaali ja Terveysministeriö 2010, 49)

Making the announcement of transferring the patient into the palliative care is done when the possibility of cure becomes non-existent, though it is recommended that patients who are struggling with progressive diseases should receive palliative care, in addition to curative treatments, to alleviate the symptoms of the disease and improve their life quality. (Saarto 2009, 1)

The decision of starting the palliative care is done by a physician together with the patient and the family of the patient, and it is written down to the patient's care files. (Viitala 2014, 36) As the disease is not able to be cured, the treatments may be stopped, and the emphasis of the care moves on managing the pain and other symptoms. A 'Do Not Resuscitate' order is usually done, as the patient is considered to be in the final phase of the disease, and prolonging the death would not cause any benefit in improving the patient's life quality. (Korhonen & Poukka 2013, 440-5) However, the DNR order alone does not mean that the patient is receiving palliative care. For avoiding confusions in the patient's care, enrolling and reporting about the patient's palliative care plan should be done clearly, so that every staff member in the ward knows exactly what kind of care to provide to the patient, and how to cope in an emergency situation. (Lindström 2012)

As any care that is provided to patients, palliative care should be so called 'holistic'. The term 'Holistic' is generally defined as a philosophical belief that parts of something are intimately interconnected and explicable only by reference to the whole. Additionally, in medical context the term holistic is used to describe a treatment that concerns a person as a whole. Therefore, instead of paying attention only to the physical symptoms of a disease, the palliative care, as a holistic method, also focuses on the patient's mental, social and spiritual needs. (Oxford Dictionaries 2014; Boyd, Merkh, Rutledge & Randall 2011, E229) In the following paragraphs, these aspects are explained in greater detail. Even though these aspects of care are presented separately, it is important to understand that they are related to each others. For example, emotional factors, such as depression that is caused by the fear of loss and death, can increase the physical pain that the patient experiences. (Lair 1996, 93)

### 2.1.1 Physical Aspects

Physical care of a progressive disease in the terminal phase concentrates mostly on managing the symptoms and pain that the disease causes. (Pavlish & Ceronsky 2009, 410) Often the actual treatment of the disease is stopped, as it may not bring any additional benefit, but cause adverse effects and suffering. For example, the treatments of cancer may be more painful to a patient than letting the disease progress, but manage the pain. Sometimes, however, the treatment is continued in aim to maintain the patient's condition and life quality for longer. (Janes 2013)

The symptoms, that a palliative care patient goes through, vary depending on the disease, environmental factors, the type of treatment that have been given and individual differences. Some common symptoms that patients in the terminal care experience are, for instance, neuropathic pain and shortness of breath. Other quite often occurring symptoms are bad appetite, skin problems and swelling. Also, the patients are often tired and weak, which is partly caused by the strong pain medication that can be used. There has been research done about the patients' experiences of their symptoms, and ranking which symptoms they find the most frustrating. The top 3 of the most disturbing symptoms were found to be: fatigue, changes in the patient's physical appearance and pain. It was also found that the relatives of the patient perceive the patient's symptoms to be more dramatic than what the patients experience themselves. Thus supporting and educating the grieving family is also important. (Hänninen 2003, 29-30)

In the terminal care of a disease, the care plan should be done together with the patient, to show respect to the patient's wishes and preferences. In addition, the patient's family should be included into making the plan, and they should be explained about the consequences of medications and treatments, and what to expect in the future. (Korhonen & Poukka 2013, 440-5) Often the medical treatment of physical symptoms is not the most important part of the care in the patient's opinion. Even though pain management can increase the life quality of the terminally ill and treating the symptoms may help to maintain the patient's autonomy and activity longer, it is not the part of the treatment that matters the most for a dying patient. Emotional support and close relationships, as well as spiritual hope, often more likely give the patient satisfaction during their last days. (Hänninen 2003, 28)

### 2.1.2 Psychological Aspects

A patient who has a short life expectancy is often going through a lot of psychological stress and fear, which may cause anxiety, depression, insomnia and delirium.

(American Psychological Association 2005) Multiple medications may also predispose the patient to disturbances of the psyche. What makes it quite challenging to notice and treat the patient's mental health problems, is the difficulty in determining which symptoms are caused by the normal weakening of a palliative care patient, and which are part of the normal grieving. Additionally, the patient may be going through a diagnosable psychiatric disease. For example, loss of appetite and passivity are very common problems with weak palliative care patients, but those are also known as symptoms of depression. (Hänninen 2003, 206-208; Onyeka 2010)

Often a medical treatment is started if a palliative care patient is suspected to suffer from depression or anxiety. However, some antidepressants need to be taken regularly for few weeks before the wanted effect is reached. That is why a patient, whose life expectancy is very short, may not benefit from that kind of medication. Also some sedatives, that are used to treat anxiety, can in too big doses make the patient feel extremely weak, and in that way disturb the life quality of the patient. That is why, finding the right dose is very important. Another, maybe more useful, way to treat mental health problems, as well as just normal grief and fears, is therapy. In therapy, the patient can be heard, supported and helped to relax and solve problems. (Hänninen 2003, 208-214; Kelly & McClement 2006)

Palliative care patients are often feeling tired and they sleep a lot, but sometimes due to depression, anxiety or other reasons, they may suffer from insomnia. Sometimes the patient may feel it difficult to sleep because of a noisy, non-peaceful environment or some physical problems, such as an increased need of urination, or pain. (Tanchel 2003, 1-4) Therefore, it is again important to find out the reason behind the insomnia, to be able to solve it. The first thing to do, when treating insomnia, is to guarantee a sleep pattern that is suitable and natural to the patient, and arranging a quiet, safe environment. If the patient cannot sleep because of fears or disturbing thoughts, talking about them can help. One solution in treating insomnia is also using sleep medication, if natural ways do not improve the situation. (Hänninen 2003, 214-215)

### 2.1.3 Social Aspects

As already mentioned, an important part of palliative care is including the patient's family and relatives into making the care plan. The grief and sorrow that death brings touches the patient's family as much as the patient. (Pavlish & Ceronsky 2009, 410) Both sides may have worries about each other's coping in the difficult situation of loss. The patient can feel guilty for 'leaving' his family and causing emotional stress to them. The same time the patient may feel afraid of being left alone, as it is understandable that the family may find it uncomfortable to face their dying relative, and trying to behave in a way that supports the patient and does not let him down. Already seeing the physical changes in the patient's body can feel heartbreaking to the ones who are close to him. Also the patient may have worries about family's managing in the future, when the patient will not be able to support and help them again. Besides relieving the patient's worries and anxiety, the family of a palliative care patient should as well be provided emotional support in form of a support group or a pastor, for example. (Lindström 2012)

In the mean of helping the patient and the family to manage their relationship, and arrange and plan the future after the patient's passing away, they should be given time to discuss confidentially about these issues, without any outsider listening. Also the family should have a right to see the patient any time, as long as the patient agrees with the arrangement. Taking care of the legal and practical issues due to the death, such as writing out the testament or planning the funeral before hand, are also good ways to help the patient feel that everything is under control, and there will not be arguing needed after his passing away. (Pavlish & Ceronsky 2009, 410)

### 2.1.4 Spiritual Aspects

Spirituality can be found in every human community and culture group. It does not necessarily refer especially to religious views, but it can be seen as thoughts concerning such terms as soul, life after death and meaning of life. For some people these concepts are present through-out their life, additionally for some people these issues are not so important. However, it is common that a person becomes more interested in spiritual aspects of life when they realize that they do not have much time left. For a dying person, the idea of getting into a better place after this life can be a carrying force during difficult and painful times. However, fears of failing this life and

ending up into hell can make waiting for the becoming death even worse than it would otherwise feel. (Matzo and Sherman 2006, 4-5; Patient.co.uk 2010)

In palliative care settings, the health care professionals should be extra sensitive to the patients' religious views and ways of expressing spirituality, as it is important to provide patients an environment where their beliefs are respected, and they are given the right to talk about their religion, and to pray for example. (Pavlish & Ceronky 2009, 410) A patient's spirituality can be seen as a resource of creating hope and relieving fears, thus the nurses should be open to discuss with the patient without judging or discriminating their beliefs and values. The patient should be also provided the possibility to meet their 'spiritual leaders' or some people who they talk about spiritual issues and be supported and understood. (Karvinen 2012)

## **2.2 Nursing Challenges in Palliative Care**

### **2.2.1 Communication**

Just as in any other area of nursing care, communication in the care of palliative patient is extremely important, as there are a lot of emotional issues involved. One of the main challenges comes from the difficulty of talking about death, when the patient or the family members might not be ready or willing to discuss it. According to Boyd et al. (2011), patient and family unwillingness, changes in patient's status, physician hesitancy to engage in discussions about death and the nurses' discomfort and desire to maintain hope for their patients and their family members actually led to patients not being told that they were dying, or not being referred to hospice.

An additional challenge that nurses face in relation to palliative care patients comes from the fact that the doctors who are responsible for making the agreement with the patient, about starting the palliative care, sometimes are not willing to do so as it is a sign of 'failure' and therefore might be willing to 'keep fighting'. (Boyd et al. 2011, E233) Additionally, there might be a feeling from some physicians that the palliative care doctors will steal their patients. Nurses who are responsible for advocating for the best possible care of the patient, might sometimes find themselves in the middle of that strive. (Mahon & McAuley 2010, E146)

### 2.2.2 Education of Palliative Care for Nurses

The Finnish Social and Health Ministry has been suggesting that the professionals in every field of medicine and nursing should be receiving education about how to care for patients in the terminal phase of their disease. Palliative care must be practiced in hospital wards, health centers, nursing homes and in home care settings, so that every patient in need is able to receive well-planned palliative care. (Sosiaali ja Terveysministeriö 2010, 63; Lindström 2012)

Some of the actions that are taken to provide this quality palliative care, are arranging the possibility for health care staff to receive an additional palliative care education, starting special units for palliative care in the biggest cities and areas, financing the university hospitals and biggest central hospitals to provide units of palliative medicine to give and develop the terminal care, and to create sufficient care paths for patients who need to be transferred from other units to receive palliative care. The ones who are responsible for these actions are the hospitals, municipalities and health care units. (Sosiaali ja Terveysministeriö 2010, 63)

Some studies have suggested, however, that even for nurses who have very inclusive and supporting approaches to their everyday practice of nursing, that includes most elements of palliative care, the understanding of what palliative care is, is very approximate. (Mahon & McAuley 2010, E144) Pavlish et al. (2007) came to the same realization, as they observed that for many nurses palliative care seemed to mean anything and everything at the same time; end of life for some, hospice care for others, oncology care for someone else and even surgical removal of tumors for others.

### 2.2.3 Emotional Stress

Numerous clinical scenarios can elicit intense emotional distress in palliative nurses. Work-related stress, for instance, emanating from close interpersonal contact with patients with end-stage chronic diseases and their families may indeed result in physical, emotional, social and spiritual adversity in nurses. (Aycock & Boyle 2008, 183) Nursing is not only about clinical skills, but also about using one's personality as

a working tool. Because of the natural human drive to feel empathy towards the people we interact with or care for, nurses are likely to feel too compassionate about the suffering of the patients and the families which they interact with. That puts nurses at a risk of compassion fatigue, which may show as lack of interest, depression and inability to work. (Palmunen 2011, 5; Koistinen 1994, 12)

Another great source of emotional stress for nurses could be their interaction with babies and children. The majority of nurses are women who seem to naturally feel more for the pain of a little one than they might do for an adult. Many nurses easily identify with kids as they can actually see their own children in them. Additionally, the idea that these young ones who have not had time to live already find themselves in palliative care can be completely heartbreaking for any individual. (Koistinen 1994, 13-14)

#### **2.2.4 Time Management in Care**

Palliative care in comparison to other forms of care demands more from the nurse in terms of presence, conversation, listening, comforting, as well as attending to the families' needs. This implies that in addition to performing the ordinary nursing tasks, including medications and other technical activities, the nurse has to find time to attend to all the other patient's and family needs. Considering that nurses take care of more than one patient at a time, the possibility that some things are left undone and some others neglected is ever present as we can see in the following quote: '*We're doing all the mechanical things. I mean it's all a rush, there's no personal time.*' (Pavlish & Ceronsky 2007, 799)

### 3 PURPOSES, AIMS AND RESEARCH QUESTIONS

The purpose of this study is to examine nurses' personal experiences of providing palliative care. The study intends to find out what kind of emotions and thoughts nurses have while they are providing palliative care, and thus facing terminally ill and dying patients.

The aim of this research is to examine and summarize previously done studies about nurses' experiences, in the mean of providing a tool of identification for nursing students and for other nurses, who are likely to face a patient's death for the first time.

The following questions are to be used for researching and reaching the purposes and aims that are set for this report:

- How do nurses experience working with palliative care patients?
- How do nurses cope with the stress generated by providing palliative care?

## **4 RESEARCH METHODOLOGY**

### **4.1 Literature Review**

Literature review, which is our chosen methodology for this research, is defined as ‘A systematic search of published work to find out what is already known about the intended research topic.’ (Robinson & Reed 1998, 58) In other words, literature review is a study method which summarizes and explains the information and knowledge that is found in previous researches. The chosen researches and articles are limited to the ones that most likely give answers to the research questions that are previously set. (Writing a Literature Review 2004)

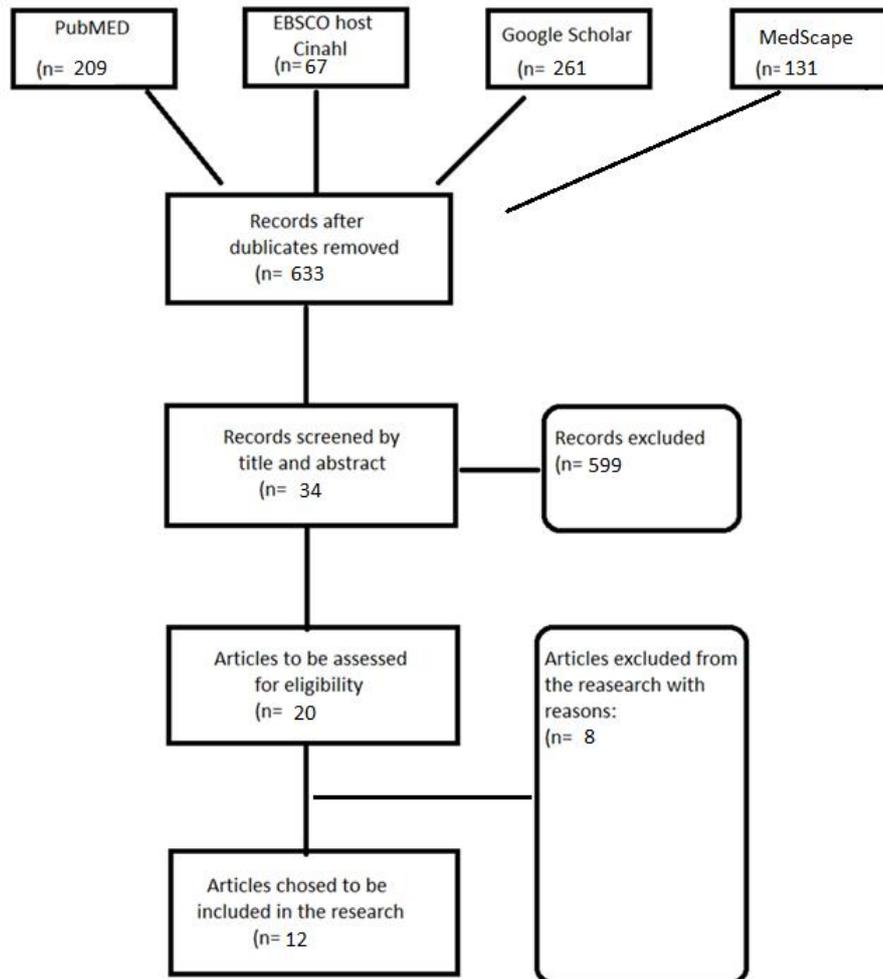
The reason, why literature review is used as the research method in this report, is that there have been multiple studies and researches already done concerning the palliative care nursing and how nurses experience the patient passing away. Thus, instead of collecting new data of the previously studied subject, it would be more meaningful to summarize and synthesize the already existing knowledge. Literature review, as a describing, summarizing, evaluating and clarifying research method would work well for reaching this purpose. (Purpose of the Literature Review 2014)

### **4.2 Literature Search**

The articles and previous researches that were used in conducting this literature review were searched from the internet by using digital libraries of academic journals and electronic databases, such as PubMed and EBSCOhost CINAHL which were systemically researched. In addition, Google Scholar was searched and reference lists of included articles were checked. The key words, which were used to search material that would relate with the chosen topic and the research questions, were such as palliative care, palliative nursing, hospice, patient’s death and oncology. Out of all the reports which were found by using these key words, ten articles were selected based on how close they matched the research criteria.

<b>Criteria for the included articles:</b>
Language: English or Finnish
Article published between 2000-2014
Article has free access, Full text
Scientific origin, reliable sources
Contains nurses' perspective of palliative care
<b>Criteria for the excluded articles:</b>
Concerns death in an acute care
Contains only the patient's perspective of palliative care
Article is not available as free, full text

The selected articles were preferred to be published quite recently, between the years 2000-2014, but also one older article was included because of its' relevance. This choice was motivated by the fact that nursing is a dynamic field where there is a constant drive to update knowledge and therefore the more recent the publication the likelier it is to fulfill current nursing practices. Out of the articles that were found by using the previously mentioned key words (n= 633), 34 were screened by title and abstract. From those, 20 potential looking articles were selected for a read-through. After reading the texts, 12 articles were found to be the most related to this study, and thus were selected to be analyzed. The following Diagram of Article Selection concludes this selection process.



**The Diagram of Article Selection**

### 4.3 Data Analysis

The data collected through the selection criteria can be placed into different categories based on the themes found in the articles. Content analysis can be divided in two: inductive and deductive. Inductive content analysis uses categorization that arises from the data collected. Whereas, the deductive content analysis relies on categories that arise from theory. (Kankkunen & Vehviläinen-Julkunen 2009, 135) In this study, an inductive content analysis is used.

The first step in inductive content analysis is called ‘open coding’. It means that the data is read through multiple times, and notes are taken down in the mean of understanding the main ideas and aspects in the text. The following step is to create categories that describe those aspects, and which will be used as a tool to compare and summarize the data collected from various articles. The final phase, called abstraction, is to give a complete picture or model of the results that are found. (Elo & Kyngäs 2007, 109-110)

## **5 RESULTS**

As mentioned earlier in the research methodology, this study retained 12 articles for analysis. All those articles were found to be convenient for this study as they could help in answering the research questions that were previously set. Although many of the articles had some similarities as they dealt with the issue of patients’ death in palliative care, but they also had differences in the methodological approaches, research samples and environments. This increased the difficulty of analyzing the articles, and necessitated an approach, such as categorizing the data as in the following Table of Categories.

Sub-categories	Main category	Research Question
<ul style="list-style-type: none"> <li>*Hopelessness</li> <li>*Powerlessness</li> <li>*Relief</li> <li>*Emotional attachment to the patient</li> </ul>	Emotional Issues	1) How do nurses experience working with palliative care patients?
<ul style="list-style-type: none"> <li>*Depression-like symptoms</li> </ul>	Impact on Health	
<ul style="list-style-type: none"> <li>*Communication with the patient and family</li> <li>*Influence of the patient's age</li> </ul>	Nurse-patient interaction	
<ul style="list-style-type: none"> <li>*Change of perception</li> <li>*Talking with colleagues</li> <li>*Work-life balance</li> </ul>	Coping Mechanisms	2) How do nurses cope with the stress generated by providing palliative care?

**Table of Categories**

## 5.1 Emotional Issues

### Hopelessness

One of the most recurring themes of nurses' experiences of patients' mortality in the chosen articles has been hopelessness. Hopelessness is expressed by many nurses as they talk about the ambivalent situation that they face while dealing with their patients. On one hand, there is a nurse's understanding that the patient's situation cannot be improved, while on the other hand the nurse has to deal with the patient's and the family's possibly unrealistic expectations about the treatment, and 'burst the bubble of hope', as one of the studies said. (Leung, Esplen, Peter, Howell, Rodin & Fitch 2011, 2175) Nurses know that for many of these patients acceptance of death and taking measures to have a peaceful death is the best that can be hoped for in such situations.

### Powerlessness

Nurses spend a considerable amount of time with patients and families. They are the ones administering all the medications with whatever side-effects those medications may have. This means that the consequences of actions taken during patient's treatment are more felt by the nurses than anyone else. Also it was expressed that nurses experience lack of power in the face of the activities they are involved in during patient's care. The following quote exemplifies the feeling of powerlessness that some nurses experience: *'It feels like you have failed... like you could not do enough. We are taught to save lives, and then you have to withdraw everything.'* (Espinosa, Young, Symes, Haile & Walsh 2010, 277)

### Relief

The concept of relief emerges to express some sort of sentiments that nurses feel at some point in the care of their patients. Relief, in some cases, is felt at the stage where the patient has passed away and the nurses perceive it as an end to a long suffering by the patient, the family and even some nursing staff. (Koistinen 1993, 31-32) Relief has also been expressed in some studies at the stage where the patient went from curative to palliative care. For one specific nurse relief was 'switching to palliative, as it is

almost a sense of being able to breathe or to relax and not be so rushed'. (Espinosa et al. 2010, 277)

### **Emotional Attachment to the Patient**

Emotional attachment to the patient is also one common theme which has been highly discussed in the articles about nurses' perception of patients' mortality. Many nurses express the idea that the longer the period of care between a nurse and a patient, the stronger the bond between them and the family is, and the harder it is to deal with the patient passing away. (Fitch 2014, 11) It was also found that nurses' relationships with patients evolved into friendships and that they became part of the patient's family. Four specific elements tended to help establish the bond between the patient and the nurse namely: understanding the patient's needs, displaying caring actions and caring attitudes, providing holistic care and acting as the patient's advocate. (Mok & Chiu 2004, 478-479)

## **5.2 Impact on Health**

### **Depression-like Symptoms**

Professor Stephen Zarit, who has been studying depression and stress among care givers and palliative care, claims that between 40 and 70 percent of care givers suffer from significant stress, and show symptoms of major depression. These symptoms are such as sad, anxious and empty feelings, hopelessness and pessimism, restlessness, loss of interest, fatigue, insomnia, overeating or appetite loss and difficulty in concentrating. (WebMD 2014)

In most of the articles, nurses reported going through at least some of these symptoms related to depression. For example, they expressed sadness, crying and thinking about death. In addition, their performance in both work and home had decreased in some cases, and some also found a negative impact on their relationships and social life. (Wilson & Kirshbaum 2011, 6; Leung et al. 2011, 2180; Aycock & Boyle 2008, 184-186) Nurses' level of vulnerability to the stressful event in palliative care was reported to be correlated to the time they had been working in contact with palliative care

patients. In that respect, the longer nurses' work experience is in that setting, the better she seemed to handle the stress of that work environment. This could be attributed to either of two factors: nurses' changed tolerance to stress or more developed coping mechanism to handle the stress. In connection to this idea, nursing students practicing in such settings were said to experience relatively lot of sadness and concern about the patients they worked with. (Gallagher, Saunders & Tambree 2012, 4)

### **5.3 Nurse-Patient Interaction**

#### **Communication with Dying Patients and Their Families**

The theme of communicating with the patients and their families was also one of the most common ones in the articles that were reviewed, mainly due to the reason that nurses spend a remarkable amount of time with the patients and families. The issue that arose was, related to the previous theme of hopelessness, nurses' struggling to have realistic conversations with patients and families who the physicians had not been honest about the prognosis and treatments. However, the hardest patients and families were said to be the ones who had not accepted the reality of becoming death, even though they had been discussed about it. (Fitch 2014, 10)

#### **Influence of the Patient's Age**

In multiple articles, nurses expressed their frustration and increased emotional sensitivity to death, when young patients were involved. What makes it more difficult to care for children in palliative care, is that a young patient is easy to relate to one's own child. Also the idea of death of a young patient, who has not 'lived life to the fullest' made nurses feel intensified sadness. Indeed the death of a child or that of a young family man, for instance, was more likely to be perceived as a tragedy, leaving them with a feeling of an unfulfilled mission. In addition to child patients, nurses also found it harder to care for patients who were closer to their own age, or who had the same life situation with them. (Fitch 2014, 11; Espinosa et al. 2010, 277; Wilson & Kirshbaum 2011, 6-7)

## 5.4 Coping Mechanisms

### Change of Perception

Every single article which dealt with the nurses' experience of patients' death mentioned, in one form or another, the nurses' changing perception about life and death. One way of changing one's perception was accepting death as a natural part of life, even seeing beauty in it. For example, in one article a nurse explained the changed perception as: *'Death is an ultimate healing for a terminally ill person....It is our honor to and privilege to be invited to share this journey with them.'* (Miller 2013)

Some researches also show that in the face of their experience with patients' deaths, some nurses moved towards a more spiritual perspective of life and death, therefore they make *'a shift from a life directed by outer authority to one directed by inner authority; a shift from a life of answers to a life of questions; from scientific certainty to an openness towards life's mysteries; and from emotional detachment to integration.'* (Sinclair 2011, 183)

Another more negative way of changing perception was becoming emotionally closed and uncompassionate. In one of the articles this, so called 'crusty nurse attitude' was not only seen as disconnecting with the patients but also with colleagues, causing problems in the work place as they also make it difficult for other nurses to have an open discussion about their concerns and emotions. (Espinosa et al. 2010, 279)

In the articles, it was also found that nurses who had worked with dying patients for long started to change their focus into more positive things than death or suffering. For example, in Miller's (2013) article a nurse claimed that: *'At first all I saw was death everywhere... Then after some time I saw stories, battles and incredibly beautiful souls of both patients and staff.'* Sometimes the nursing coping strategy consists in changing their focus from the pain and suffering that they see to emphasize more the positive actions that they are taking in helping the patient experience a peaceful end-of-life.

### Talking with Colleagues

The support that nurses receive from their colleagues was found to be an important coping mechanism in all of the studies. Articles showed that talking about difficult experiences with other nurses and sharing feelings is a useful tool to increase nurses' ability to cope. In addition, it makes the nurse team stronger and more cooperating, which again relieves stress that the work may cause. Multiple articles claim that nurses actually receive more support from their colleagues than from individual counseling, for example. (Wilson & Kirshbaum 2011, 11-12) Talking to other people but nurses was also mentioned to be helpful in some studies, but others showed that nurses do not feel comfortable talking about death with their partners or friends, unless they are also in medical professions. In addition, in some articles it was mentioned that institutions may provide support for nurses in distress, although it was not mentioned what kind of support it was. (Espinosa et al. 2010, 278)

### Work-Life Balance

Among the coping mechanisms described by nurses in various studies examined, the theme of work-life balance proved to be a quite recurrent one. Many nurses indeed underlined the importance of having complementary activities which would add some perspectives in the nurses' lives. One of the impacts of patients' mortality on the nurses has been the effect that it has in the nurses' personal life, leading some of them to carry the worries of the work place back home with them. In their research Leung et al. (2011) recorded the importance of balance between work and personal life in nurse's words: *'In your balance, you got to get it right. Otherwise, you are really going to burn out emotionally, mentally. If you have the balance, you are going to survive it and you can be a better person with those patients.'* Personal activities such as yoga, walking in nature, dancing, music, socializing, provides the nurse with an opportunity to take her mind off the stressors and focus on something more relaxing which in term can help the stress alleviation after work. (Aycock & Boyle 2008, 187)

## 6 DISCUSSION

### 6.1 Reliability and Limitations of the Study

Whether a research is considered reliable depends on the author's way of presenting and explaining the used research methods, process and decisions made. When the used research method is a literature review, there should be reasoned criteria for the selected articles to explain what was included and excluded. In addition to reliability of an article, another important aspect of examining the results is the validity of the research. The term validity is used to describe how consistent the collected literature was. When the analyzed articles study the same phenomena using similar research methods, the valid results should be somehow identical. (Meadows & Billington 2005, 7)

During the making of this study, the process of literature search was continuously reported and carefully described. The used research method, systematic literature review, consists of literature search and summarizing and synthesizing the findings. This can be seen as a benefit of gaining the already existing information, which is seen valid. However, finding the right articles which support each others and answer the same research questions may be challenging, and there is a risk of the researcher giving new meanings and assumptions to the articles that are used. Also, if the articles used do not come to the same conclusion, it may be difficult to analyze and categorize the results. (Writing a Literature Review 2004)

Although the study gives the possibility to have a look at one aspect which is pervasive in the nursing profession namely losing patients, it's important to mention that there are possible limitations to this study. One of the first points to consider is the sample of the study itself as we have to remind ourselves that only about 12 articles were selected out of possibly thousands which could have been considered for analysis. It is therefore not controversial to suspect that the 12 studies selected might not be completely representative of all the studies available and therefore might not effectively represent the reality on the ground. Moreover dozens of extremely interesting articles could not be accessed for analysis purpose as they were part of paid

journals. Although paid is not always equivalent to better, it remains true that many articles which, based on their title and abstract, seemed extremely relevant for this study could not be included in the study.

In addition to the sample size we could also mention the diversity within the sample itself as it included articles representing nurses' experience in various on related settings. It is not difficult to argue for example that nurses' experiences in the pediatric cancer ward can be very different from that in a nursing home, which in its turn is different from a specifically designed palliative care unit.

One could also mention the fact that many of their studies included for analysis were conducted mostly in developed countries with approximately similar standards of living. The direct implication from this is that it would be difficult to generalize the results of this study to the entire nursing profession in other parts of the world, as cultural and living standard differences are likely to lead to different types of experiences by nurses.

One last aspect which would be considered as a limitation to the study is the inability to discriminate between stress directly related to patient deaths and other sources of stress that are inherent to the nursing profession as a whole.

## **6.2 Ethical Considerations**

Academy of Finland Guidelines on Research Ethics (2003) announces that in addition to research's reliability, the ethical aspects of a study must also be taken into consideration when recording the literature search and describing the research process, in mean of keeping the results truthful. If the research was conducted as an interview, it would also be ethically correct to keep the data private, but when using the method of literature review, that is not a concern as there is nobody's personal information or opinions collected. As mentioned in the previous part of research reliability, the research process and used methods were reported throughout this study, thus it follows the ethical guidelines given.

### 6.3 Conclusion and Recommendations for Future Research

This literature review concluded the information that was collected from 10 previously conducted researches. All these used articles talked about nurses who work with patients with a chronic progressive disease and who have to face death regularly because of their chosen field of health care. All of the nurses whose perspectives of patients' mortality was examined provided palliative care, but the wards they worked varied from such as oncology to pediatric wards and intensive care units.

As the theory behind the literature review explained, palliative care is very demanding for the nurses to provide, in both physical and psychological means, and there is a risk of burn-out and emotional fatigue. This study intended to search the literature to obtain nurses' subjective perceptions about how they experience the patients' mortality, and how do they cope with the deaths they have to face in their work. The most common themes that were found in the literature reviewed were divided into categories in purpose of representing the findings in an organized and clear way. The results showed that nurses working in palliative care indeed experience stress which can lead to depression-like symptoms, but it also showed how focusing to the positive can make one see the work meaningful and important, and how it can also make the nurses see life differently and 'grow' as humans.

This study attempted to explore the different types of emotional stress that nurses face in palliative care, their possible impacts on those nurses' lives and the various mechanisms that are used to deal with the impacts of patients' deaths. Although the study has clearly established that nurses indeed experience intense stress in their work in palliative care, the various coping mechanisms used by those nurses have not been extensively explored as they are beyond the scope of this research. A valuable recommendation for the future research would therefore be, for instance, the study of various coping mechanisms which could be used by nurses in the event of patient passing away. Considering the figures that show that 56% of people dying do that in hospital settings, and therefore in the presence of nurses and other health care professionals, a study that would examine the possible coping mechanisms could be very useful in helping all those health care personnel who would be exposed to patients' deaths. (Royal College in Nursing 2012, 2)

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### Appendix 1: Table of Articles Included in the Review

	<b>Authors, year, country, title</b>	<b>Purpose /Aim</b>	<b>Research Method</b>	<b>Main results</b>
1)	Sinclair 2011. Canada. Impact of Death and Dying on the Personal Lives and Practices of Palliative and Hospice Care Professionals	Understanding the impact of death and dying on the personal lives of health care professionals	Semi-structured interviews	Working with dying patients develops nurses' perceptions about life and death, meaningfulness and spirituality
2)	Foster, Bell, McDonald, Harris & Gilmer 2012. United States. Palliative Nursing Care for Children and Adolescents with Cancer	Understanding the factors that nurses experience to be important when providing palliative care for children and adolescents with cancer	Literature Review	Nurses feel honored to have the chance of sharing the last journey of joy, as well as sorrow, with the children in palliative care.
3)	Aycock & Boyle 2008. United States. Intervention to Manage Compassion Fatigue in Oncology Nursing	Understanding the phenomenon of compassion fatigue related to oncology nursing, and examining the interventions that are used to cope with it	A National Survey	Because of the nature of their work, oncology nurses have an increased risk of compassion fatigue. Emotional support from colleagues and balancing work and personal life were found to be the most effective ways to cope with it.
4)	Wilson & Kirshbaum 2011. United Kingdom. Effect of Patient Death on Nursing Staff: A Literature Review	Exploring how the death of patients in a hospital setting impact on nursing staff	Literature Review	Themes arising from the review: theoretical context, the emotional impact, culture of health care setting, staff's previous life experiences and support available for health care staff
5)	Leung, Esplen, Peter, Howell, Rodin & Fitch 2011. Canada. How Haematological Cancer Nurses Experience the Threat of Patients' Mortality	Exploring how cancer nurses experienced the threat of patients' mortality	Focused observations & Individual interviews	Nurses experience internal conflict related to their will to help the patients but simultaneously having to 'let them go' and 'bursting the bubble of hope.'
6)	Miller 2013. In Their Own Words: How Do Nurses Deal With Death?	Collecting nurses' advises and experiences related to 'how to deal with death and	An open interview	Nurses regardless of their work experience in years experience sadness when facing death and dying. Each

		dying'		nurse has their own individual ways of balancing the work life and personal life. Showing the negative emotions by talking and crying was seen to relieve the stress.
7)	Gallagher, Saunders & Tambree 2012. Australia. Nursing Student Experiences of Death and Dying During Palliative Care Clinical Placement: Teaching and Learning Implications	Examining the psychological challenges of nursing students practicing in palliative care setting	A survey containing both open-ended and multiple choice questions	Palliative care settings can provide a positive learning experience for students, if the feelings of sadness and anxiety are dealt with and there is emotional support available throughout the practical placement.
8)	Boyd, Merkh, Rutledge & Randall 2011. United States. Nurses' Perceptions and Experiences with End-of-Life Communication and Care	Characterizing oncology nurses' attitudes towards end-of-life care and their experiences of caring for terminally ill patients	An adapted version of the 'Caring for Terminally Ill Patients Nurse Survey'	Nurses had positive experiences about providing terminal care, but they recognized some difficulties in communication with the patient and family, as well as between the medical staff.
9)	Lehto & Stein 2009. United States. Death Anxiety: An Analysis of an Evolving Concept	Defining attributes, antecedents and consequences of the concept of death anxiety.	A concept analysis	Antecedents of death anxiety include stressful environments, experiencing unpredictable circumstances and experiences with death and dying.
10)	Espinosa, Young, Symes, Haile & Walsh 2010. United States. ICU Nurses' Experiences of Providing Terminal Care	Exploring the experiences of ICU nurses who are providing terminal care	Individual interviews & focus groups	Providing terminal care is a significant personal and professional struggle. Nurses experienced frustration related to the decision making and involvement in care, lack of education, and difficulty in facing death
11)	Koistinen 1994. Finland. Ammatillinen surutyö: Lapsipotilaan kuolema sairaanhoitajan kokemana	Exploring how do nurses experience the death of a child and what kind of emotions it awakes	Theme Interview	Nurses providing terminal care for children empathize with the parents of the child and experience more emotional distress than nurses working with

				adult patients.
12)	Mok E. & Chiu P. 2004. China. Nurse-patient relationship in palliative care	Exploring aspects of nurse-patient relationships in the context of palliative care	Interviews	The relationships between nurses and patients develop trust and mutual attachment.