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Nurses' Support of a Dying Patient's Family

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Thesis abstract

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End-of-life care is becoming increasingly important as the population ages and the prevalence of chronic illnesses rises. Palliative and hospice care is necessary for a broad variety of illnesses and conditions. Registered nurses are essential for ensuring highquality treatment for patients and their families and should have enough education in palliative care and hospice care in addition to the necessary skills to offer treatment that is of high quality.

The purpose of this thesis is to describe how the families of a patient in hospice care are being supported and how to improve the grieving family's support. The thesis aims to make nurses aware of the importance of support to patients' families during and after hospice care. The research methods for this thesis are literature review and content analysis. A total number of ten (n=10) articles were used for content analysis.

The upper category results for this thesis are communication, nursing expertise, nurses' education, support, and preparation.

This thesis is beneficial for a reader who wants to have a deeper knowledge about supporting a family member of a dying patient during the dying process and afterwards. It also contains information on where the support is lacking and what needs to be done to boost the family members' support quality.

¹ Keywords: terminally ill, family health, nursing support, nurse's role, end of life, dying at home.

Terms and Abbreviations

WHO- World Health Organization

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1 INTRODUCTION

The need for palliative care grows as the population ages and the prevalence of chronic illnesses rises. End-of-life care includes palliative care and/or hospice. Hospice care is becoming more important, and people are becoming more aware of it. The field of hospice care is continually evolving on a societal level.

Palliative care is necessary for a broad variety of illnesses and conditions. According to WHO (2020) most persons who need palliative care suffer from chronic conditions, the most common of which are cardiovascular disorders (38.5%), cancer (34%), chronic respiratory diseases (10.3%), AIDS (5.7%), and diabetes (4.6%)

According to Better Palliative Care for Older People, (n.d.) most of the time, people with close family ties act as carers for the terminally ill. There isn't a lot of formal information about what they need, and their roles vary a lot. It could mean doing things like washing, helping someone get dressed, or going to the bathroom. Carers often live in the same house and do it out of love and a desire to keep the person out of an institution. But over time, the stress of caring for someone can cause conflicting feelings, personality and behavior changes, limits on the caretaker's own life, and a drain on money. Long-term care for seriously ill family members are unpaid and unsupported work that can hurt the caregiver's health, happiness, and finances. In a wide variety of settings, patients and their families rely heavily on nurses as the major source of palliative care providers for them and their loved ones. As a result, nurses should have enough education in palliative care in addition to the necessary skills to offer treatment that is of high quality.

It is essential to understand what palliative care and hospice nursing are and how it varies from other types of nursing. By doing this, nurses can learn how to teach and train other nurses and understand how unique this task is. Care for the "whole person," throughout the lifespan and in a variety of healthcare settings, is a hallmark of palliative care nursing. Care is delivered to the individual and their family as a whole. Care of the dying as well as grief support for the patient's loved ones is an integral part of palliative nursing's overarching mission to improve patient's quality of life during the whole course of their disease. Effective pain and symptom management; addressing psychosocial and spiritual needs of the patient and family; incorporating cultural values and attitudes into the plan of care; supporting those who are experiencing loss, grief, and bereavement; promoting ethical and legal decision-making; advocating for personal wishes and preferences; using therapeutic communication skills; and facilitating remembrance of loved ones who have passed away are all ways to alleviate suffering and improve quality of life.

Hospice nurses caring for patients' loved ones are the intended audience for this thesis. Nurses have many of the same duties as families when it comes to taking care of and protecting family members. According to Kaakinen et al. (2018, p. 10) nurses have to help families improve the care and growth of each family member and the family as a whole.

The thesis aims to create awareness among nurses of the importance of support to patients' families during and after hospice care. The starting point will be the introduction of what is hospice care, palliative care, bereavement care, and nursing inventions. The goal is to understand better where nurses could improve when it comes to taking care of family members of a patient in hospice and where the points in care nurses need to focus on more.

Less time is spent on the patients themselves, and more on the family members and the methods by which they are assisted, supported, and directed. The thesis's core goal is to identify sources of assistance for families coping with a loved one's hospice care, and after their family member has passed away.

2 Palliative Care, End-of-Life Care, and Bereavement Care

2.1 Palliative care and end-of-life

Kaakinen et al. (2015, p. 278) say that end-of-life care only addresses a person's final days, but palliative care includes end-of-life care and can last months or years (especially in children) alongside curative treatments. They say palliative care helps patients, and their families cope with a life-threatening illness. According to the author, palliative care prevents and treats pain and other physical, mental, social, and spiritual issues to help families cope. Palliative care is a team-based support system that helps patients to live as fully as possible and help families cope with illness.

Kaakinen et al. (2015, p.278), state that adult palliative care began to help cancer patients but is now also focusing on non-cancerous diseases that can kill like heart disease, muscular dystrophy, motor neuron disease, dementia, Parkinson's disease, and neurodegenerative diseases.

According to Kaakinen et al. (2015, p. 279) palliative care can be used in any setting with any family, regardless of how long a person lives or dies, and can accompany healing care. When there are no cures, treatments do not work, or the patient cannot handle them anymore care shifts from curing the illness to making the patient's remaining life quality better. Authors say it is well known that discussing the shift from curative to palliative care is difficult but necessary. It is crucial to discuss prioritizing quality over quantity. If someone is sick for a long time, this can be discussed slowly and repeatedly.

Ferrell & Paice (2019, p. 405), state that the entire family is affected when one member is diagnosed with a terminal disease. According to Kaakinen et al. (2015, p. 278) palliative care emphasizes family, especially when the patient is a child. They also say all family members must receive support and family development must be considered regardless of the patient's age. According to Kaakinen et al. (2015, p. 279) even when death is expected, palliative care is rarely discussed until the final days or weeks. Still, the patient, their family, and the health care providers must share the same goals and understand what "quality of life" means for them. Each family's goals and definition of "quality of life" differ in each situation and care should be tailored to the needs of each particular family.

According to Kaakinen et al. (2015, p. 279) palliative care principles should be the same, but how they are applied should vary by family and situation. They also say that these principles can be consistently applied to provide high-quality palliative and end-of-life care.

2.1.1 Bereavement care

At a death, many relatives will need time to grieve and recover. According to Rossi & Ortiz (2013, p. 68) the death of a loved one may be regarded as one of the most stress-ful and traumatic experiences in a person's lifetime. They say that people go through a lot of physical, emotional, mental, social, and behavioral changes after the death of a loved one (op. cit., p. 70). According to Ferrell & Paice, (2019, p. 390), bereavement may take many different forms, and culture has a big impact on it. McNiel & Gabbay (2018, p. 166) state that children especially have a tough time dealing with the death of a loved one.

According to McNiel & Gabbay (2018, p. 13), many family members and adults believe that youngsters mourn like adults do. Authors also state that parents or caregivers frequently believe that children are "little grownups" capable of dealing with sadness in the same manner that adults do. McNiel & Gabbay (2018, p. 13) address that children's grieving differs from adult loss. According to the authors, adolescents are still growing and developing cognitively and mentally, and they do not have the same amount of life experience as adults to respond to loss in the same manner. According to Kaakinen et al. (2015, p. 279) after a family member has passed away relatives may want to stay at the bedside to comfort or to carry out cultural rituals. Some families prefer to be involved in the final arrangements for their loved one's body, or at least to know that the deceased's remains will be treated with dignity. The authors also bring out that there is no need to be shy about touching the body, and there should not be any rush to relocate the person before everyone's had a chance to say their last goodbyes.

According to Kaakinen et al. (2015, p. 302) nurses' role is to notify any surviving relatives who were unable to attend the death before transporting the patient to the morgue or funeral home. They also say nurses can give grieving families as much time as they need and let them spend time together. Nurses' presence can help to grieve loved ones and form lasting memories. A grieving family may need pastoral care or other assistance with funeral planning.

Kaakinen et al. (2015, p. 302) found that if the deceased was a child, a keepsake box with photos, a lock of hair, and possibly the patient's hand or footprints may be appreciated by the family. The authors bring out that knowing what each family wants and needs can be difficult. Some may be upset if mementos are taken, especially pictures, against their wishes, while others may regret not taking them.

According to Kaakinen et al. (2015, p. 302) nurses and other medical staff may avoid family discussions about organ donors because they feel uncomfortable. The authors state If appropriate, medical staff should start these discussions or make sure someone does. Having the autopsy results delivered to the family promptly and sympathetic is also crucial.

According to Kaakinen et al. (2015, p.302), family members may wish to meet with medical staff to review autopsy findings, ask questions about what happened before and after the death, and gain confidence that appropriate actions were taken. Kaakinen et al. (2015, p. 303) state it was previously believed that to heal, one had to forget about the deceased and move on with one's life. It's now understood that there's no such thing as "getting over" a loved one's death. The authors bring out that nurses can help patients start the grieving process and learn the value of death. Everyone remembers the moment their loved one died. For better or worse, people remember names, words, and actions. The nurse was often present at a loved one's death or the first to respond to a family's call about a change in condition. The family vividly remembers the nurse's words and actions. Nurses can leave a lasting impression on grieving loved ones. Nurses should never treat death as "just a job" because while it may be one of many for them, it may be the first and only for the family. Authors bring out that remember that sayings like "this was meant to be" and "he/she is in a better place" or comparing the deceased to an angel may make the family feel like the nurse is down-playing the loss. "I'm sorry your husband is dying" is usually appreciated.

According to Kaakinen et al. (2015, p. 303) a nurse must understand loss, comfort grieving families, and care for the deceased. New nurses may feel awkward expressing their emotions to patients' families, but the authors bring out that family members are often moved to tears by a nurse's genuine emotional response.

Kaakinen et al. (2015, p. 303) bereavement care shows the nurse's value to the family. The authors mention that calls, cards, funeral attendance, and referrals to support resources are helpful follow-ups. Families may benefit from written information about practical issues like what to do next, grief, or other sources of support, and how to support extended family and friends. In some cases, community bereavement care can last forever. Medical staff may call or send a card on a patient's first death anniversary, especially if the patient was a child. This contract acknowledges the grieving process and helps families feel truly cared for.

2.2 Connections Between Families and Nurses at The End of Life

Kaakinen et al. (2015, p. 286) state that family-healthcare professional relationships affect palliative and end-of-life care. In practice, nurses talk about their "connections" with families, not their "relationships". Authors find that connecting with family members reveals their values and builds a human connection.

Kaakinen et al. (2015, p. 287) point out that understanding the family's situation without illness is crucial. Asking about their past experiences with death, recent life changes (e.g., new job, new house, new baby), or work and school responsibilities (e.g., self-employed, supportive work environment, nearing final exams) may help a nurse to understand and appreciate their creativity and ingenuity.

According to Kaakinen et al. (2015, p. 287) connecting lets family- health care to apply their general scientific knowledge in ways that are more likely to work for individual patients and their families, given their backgrounds, needs, and worldviews. The nurse and patient/family members connect and build trust through a two-way process. Trust helps families feel comfortable and nurses intervene and advocate (op. cit., p. 287).

According to Kaakinen et al. (2015, p. 287) communication and interpersonal skills affect patient-family relationships. The nurses must understand how their communication styles can build, maintain, and break relationships. Families rarely discuss death, and these relationships require ongoing care. Palliative assessment and intervention require a trusting relationship to allow difficult and emotional conversations.

(Kaakinen et al. (2015, p. 287) write that nursing interventions that promote connections and trust include careful listening to the family's experience with illness and suffering, asking good questions that encourage family members' understanding of the differences in their perspectives, demonstrating compassion by showing that you are touched by the family's suffering, remaining nonjudgemental, offering a new and honest communication, working with the family, perspective, and your attitude and behavior should demonstrate that you can and will help families. Healthcare professionals' security and trust can boost a family's resources. Addressing family members by name, smiling, making eye contact, showing emotion, and touching them on the shoulder can help family members connect with health professionals.

According to Kaakinen et al. (2015, p. 287) the nurse must build trust with families and create an open environment where everyone can ask questions. Writers say a brief family genogram can help nurses learn family members' names, relationships, and care involvement, including decision-making. Knowing each family member shows respect for the patient's and family's dignity, needs, concerns, and fears. It also acknowledges family differences.

Kaakinen et al. (2015, p. 287) highlight that making a connection takes time, but it requires attention and should not be taken for granted. Sometimes nurses instantly click with a family, but other times he/ she needs to work harder to connect. The nurse may feel like he/she needs to "prove" trustworthiness or overcome negative feelings toward a family member. Practicing reflectively and consulting an experienced nurse may help.

According to Kaakinen et al. (2015, p. 288) unfortunately, families often lack support and connection, which leads to negative experiences and dissatisfaction with care. Even one incident of poor communication and interpersonal skills by health professionals can cause long-term anxiety, depression, and guilt. Understandably, some nurses worry about saying the wrong thing. Listening carefully may help you know where to start, and sometimes there are no "good" words, but staying with the family can help.

Kaakinen et al. (2015, pp. 288-287) found that assessing humor receptivity before using it may help families connect. It's fine to laugh with families, but nurses may find it harder to start. If it fits the patient and family, humor can relieve tension, distract from the illness, and show respect.

2.2.1 Supporting families in Palliative Care

Coyle (2016, p 51) says a family is a collection of people whose relationships are dynamic and mutually supportive. Relationships based on emotional commitment as well as biological ties are all valid ways to define family. Furthermore, the most complete definition of family includes both the living and the dead, as well as the unborn

According to Coyle (2016, p. 31) palliative care is focused on the patient and the family. He notes that sickness affects both the patient and the patient's family, and the illness alters the patient's and family's qualities.

The members of the family expect that the medical staff will fulfill their need for information, emotional support, and aid with care (Coyle, 2016, p. 55). A recent study reveals that the most effective strategy to support family carers may be to assist them in achieving success in their job as caregivers rather than concentrating on the family caregiver's requirements.

Coyle (2016, p. 57) found it is crucial to find viable means of aiding family carers. The author states as the global population ages, a greater percentage of individuals will suffer from chronic, life-threatening, or severely debilitating conditions that will need medical attention. More and more often, families are expected to shoulder the burden of caring for such people. When looking for ways to lessen the load on primary carers, respite care is a common solution proposed. While it is important to provide families with options like respite and other programs, ultimately, it is up to each individual family to choose what they need. During the last year of life, inpatient respite programs may be helpful for certain families, while others may feel guilty or stressed out about providing enough care and turn to these services instead. Knowing that help is accessible might help caregivers feel more secure in their roles, even if they do not really utilize the aid. Coyle (2016, p. 61) empathizes when the patient received care at home with hospice services, the patient's family members reported higher levels of satisfaction with the treatment of the patient's symptoms as well as with the emotional support that was provided for both the patient and the family. He also said it was true regardless of whether the patient received care at home or in an institution. If care can be offered in the home, there are more chances for family members to be engaged in the process. The participation of the patient's family in the medical care that they get in the hospital is another factor that leads to better outcomes. Consequently, nurses working at any location where care is provided for terminally ill patients are obligated to consider the most productive methods to include families in the treatment of their patients' terminally sick loved ones.

2.2.2 Nursing Interventions

Coyle (2016, p. 64) states that even though cultures are different, people have the same basic needs for support, dignity, and connections with other people. He notes a lot of the nursing literature, which gives care guidelines, talks about the importance of four major interventions that are important for everyone on the palliative care team: Maintaining hope, involving families, offering information, and open communication.

According to Coyle (2016, p. 64) it's important to keep the patient and their family members' hopes up. As the illness progresses, families' hopes change. At first, they hope for a cure. Then, they hope for remission and for comfort. Finally, they hope for a good death. A simple way to give hope to people who are dying is to reassure their families that everything will be done to make sure the patient is comfortable. Talking about the past can also help some families by reminding them of the good times they have had together and the strong bonds they will always have. Hope can also be kept alive by looking beyond the immediate suffering and emotional pain. (Coyle, 2016, p. 64) believes it is crucial to include the family in every decision about care. He also says it is important to include them in the decision-making process and promote active engagement in the patient's physical care. Because it is their life, they have the right to direct its course in whatever they see fit. Coyle (2016, p. 64) writes that when a member of the family is severely sick, it is very vital for the youngsters in the family to be involved. Children are better equipped to handle the loss of a loved one and the activities that follow the passing of the person when they are actively engaged in the care that is provided during the terminal period and in the activities that take place after the passing.

Coyle (2016, p. 64) states that Informing the patient's loved ones about what is going on in clear and concise language, as well as what they may anticipate will take place, focusing especially on the patient's health and the process that their family member or friend will go through. In addition, doing so gives families the feeling that they oversee the situation. Starting a conversation on important topics that individual family members may be hesitant to bring up on their own.

Coyle (2016, p. 64) mentions that having the ability to communicate openly and honestly with nurses and other medical professionals is generally cited as the single most crucial need for families. He says they have a right to be educated, they have a right to chances to ask questions, and they have a right to have their questions answered in language that they can understand. Coyle (2016, p. 64) notes that communication that is open and honest among the team is essential to maintaining that same level of communication with the families.

3 AIM, PURPOSE, AND QUESTIONS OF THE THESIS

The purpose of the thesis is to describe how the families of a patient in hospice are being supported and how to improve the grieving family's support.

The thesis aims to make nurses aware of the importance of support to patients' families during and after hospice care.

Research questions:

- How are the families of the patient supported by the nurse during hospice care?
- What is the importance of supporting the family member of a patient in hospice care?

4 METHODS

Qualitative research, literature review, and content analysis:

According to (University of Texas Arlington Libraries, 2022) qualitative research is a process of naturalistic, investigation that aims to comprehend social phenomena in-depth within their natural context. Instead of concentrating on the "what," it emphasizes the "why" of social phenomena and depends on the first-hand accounts of people to serve as the primary interpreters of their daily experiences. For the study of human phenomena, qualitative researchers employ a variety of systems of inquiry, such as biography, case study, historical analysis, discourse analysis, ethnography, grounded theory, and phenomenology, as opposed to logical and statistical methods.

(Davis et al., 2014) says literature reviews are a means of synthesizing research findings to answer a particular research question in a way that is transparent and reproducible. They have been foremost developed within medical science and are considered the gold standard among reviews. A literature review can not only be used as a research method and process for finding and critically evaluating relevant research but is also used to collect and analyze data from the said research. A literature review aims to identify all observational evidence that fits the pre-established inclusion criteria to answer a particular research question or hypothesis. Therefore, this thesis adopted content analysis in the literature review as a research method with inclusion and exclusion criteria written below.

According to (Kyngäs et al., 2020, p. 13) content analysis is a research tool used to determine the presence of certain words, themes, or concepts within some given qualitative data. Using content analysis, researchers can quantify and analyze the presence, meanings, and relationships of certain words, themes, or concepts. As an example, researchers can evaluate language used within a news article to search for bias or partiality. Researchers can then make inferences about the messages within the texts, the writer(s), the audience, and even the culture and time surrounding the text.

For this thesis articles were found by using SeAmk Finna, Cinahl, PubMed & Google Scholar. Words used to find the articles were: Terminally ill, family health, nursing support, nurse's role, end of life, and dying at home. 10 articles were selected which were relevant to the topic of this thesis research and contained certain words, themes, or concepts (figure 1).

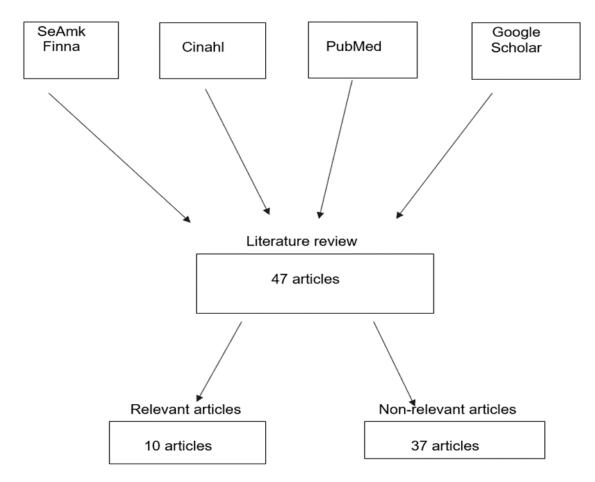


Figure 1. The data selection process

5 **RESULTS**

From the 10 articles that were selected main categories and sub-categories were generated. The main categories contain themes such as communication, nursing expertise, nurse's education, support, and preparation (table 1).

Research question		Main Category	Sub-category
• How are the fa	amilies of		Family-focused
the patient su	pported	Communication	Information strategies
by the nurse of			Open communication
hospice care?	?		Prioritizing family needs
		Nursing expertise	Experience
			Competence
			Skills
			Knowledge
			Positive attitude
		Nurses' education	Professional programs Carers education Training in communica-
			tion skills
• What is the in			Therapeutic assistance
	portance of supporting the family member of a patient in hospice care?		Empowering
		Support	Humanized approach
			Emotional support
care?			Hope and suffering con-
			versations
			Holistic care
			Psychological support
		Preparation	Avoidance of negative
			emotions
			Perception for death
			Death counseling

Table 1. Nursing interventions for support.

5.1 Support for family members during end of life

In the final days of life, patients either go to the hospital or are discharged from the hospital to die at home. These transitions can be stressful for the family members and Duke et al. (2020, p.146) studies found that there is not enough support for the family members from the healthcare staff during that time. The study also found the lack of information during discharge left family members confused about their role at the end-of-care discharge. Duke et al. (2020, p.146), research results also showed that healthcare workers who implemented family-focused support which enables family members to participate in discharge planning by providing a method that is practical, approachable, and acceptable made family members more involved in discharge and end of life care planning.

Nurses play a key role in end-of-life care for patients and their loved ones, and therefore, are expected to have effective communication skills. Matos & Borges (2018), studies however showed that nurses do not understand that good communication results in therapeutic support, and therefore family members felt like the information received from their nurses was limited. According to Chiplaskey (n.d.), there's evidence that most nurses do not get appropriate training in communication skills.

A study by Hökkä et al. (2022) showed that undergraduate nursing students felt unprepared to provide high-quality palliative care. Students also wished for possibilities for practical training or visits to palliative care wards during their studies. The research also highlights that palliative care education should be conducted by highly skilled teachers as undergraduate nursing students lack the competence and feel unprepared for palliative care and facing death. According to Achora & Labrague (2019), there is a need to strengthen palliative care education by establishing expert nurse support networks to serve as role models for excellence in palliative care.

Another study conducted by Angelo et al. (2013) showed that family members that act as caregivers at home lack experience in this role and therefore need plenty of help from a nurse to be able to provide support for a dying family member. They also found out that the caregiver needs to be empowered. Empowering a carer means assisting caregivers in developing plans to fit self-care into their daily schedules, teaching them practical routines tailored to their circumstances, and preparing them for what to expect as the patient approaches death. A research by Gunilla & Saveman (2013) also indicates that talking to nurses about existential matters like hope and suffering was a therapeutic experience and it provided carers with a chance to unburden themselves as well as a means of learning and discovering new techniques for coping with daily life.

5.2 Support for family members during grief

Healthcare workers in hospice care units help patients and their families prepare for death with dignity and decrease the shock they may feel in panic-inducing situations at the end of life by offering knowledge about the events and qualities before and after death. Bloomer et al., (2021) found that family needs should be prioritized in end-of-life care. According to Anderson et al., (2019) effective communication between healthcare providers and families of patients nearing the end of their lives is critical to ensuring a 'good death'.

According to Chiplaskey, (n.d.) unfortunately, most nurses are uncomfortable counseling patients and families about end-of-life decisions due to identified barriers such as a lack of knowledge, a lack of practical experience, the mistaken belief that a discussion will cause emotional distress for patients and families, and nurses time limitations. Jung et al., (2021) found that family members were dissatisfied with educational and emotional assistance regarding death and the circumstances after death, indicating a lack of professional programs to assist hospice patients and their family members in preparing for death.

A study by Jung et al., (2021), found that family members who care for hospice patients may feel unpleasant emotions related to dying, such as worry, anguish, and dread of the hereafter. Studies have shown that mourning family members who are having more negative thoughts of death were connected with having more difficulties adapting to life following the death of a family member. The research shows that in assisting family members caring for hospice patients in adjusting to life following the patients' deaths and supporting their psychological well-being, it is vital to first understand the family members' attitudes toward death. Studies also have found that families who planned for death and took death counseling were less surprised by grief than those who did not.

According to Anderson et al., (2019) research a variety of techniques used by healthcare providers might facilitate good communication with family members near the end of life. The patient's decline should be highlighted to help with understanding and decision-making. Other important strategies include emphasizing continuing care by describing comfort care, tailoring information to individual understanding and readiness to discuss dying, being honest and clear to avoid false hope, and providing information repeatedly and in small doses. Jung et al., (2021) say care that is offered to patients and families should be in dept and holistic.

6 ETHICALITY AND RELIABILITY

According to the European Code of Conduct for research integrity (2017), research integrity is a set of basic rules that guide good research practices. They tell researchers how to do their work and how to deal with the practical, moral, and intellectual problems that come up in research. The principles of good research practices are reliability, honesty, respect, and accountability.

Kyngäs et al. (2020, p. 55), explain that researchers have a responsibility to prevent plagiarism. Plagiarism is one of the most significant ethical concerns that must be addressed while producing a literature review. Since it is based on the works of other people, plagiarism is a possibility. Because of this, the researcher needs to maintain an ethical attitude toward the work of other people and her or his work. This can be accomplished by providing appropriate acknowledgment and citation, as recommended by the written instruction provided by the university. In addition, quotations were utilized, and a bibliography was compiled to guarantee that the information that was used was appropriately cited.

The use of trustworthy databases and other sources, in addition to the use of trustworthy sources, helped to ensure that the literature review was credible. In addition, criteria were established, such as the age of the research publications being no more than ten years old, the availability of the complete text, and an analysis of the source material references.

7 CONCLUSION & DISCUSSION

The conclusion in our research has been what we were expecting, even though the subject is very important and there is a lot of information that can be found about palliative care and support to family members, the reality is that it seems very challenging for nurses to understand the importance of supporting people going through the process of losing a family member or has recently lost a loved one.

The information we were able to gather in our research pointed out the problems and solutions when it comes to understanding the emotions that people have when they go through the stages of diagnosis to passing away. It shows us that although we are all individuals and different from each other in the way we deal with this kind of situation, nurses have a key role in helping, supporting, and understanding to make patients and patients' family members feel that the care is not only taken as just another job.

All the studies and lessons that we found tell us the right thing to do but it is also nurses' responsibility to give the personal human touch to the care we give as nurses not only in palliative care but in all the areas we are assigned to. In general, the subjects of end-of-life care are very sensitive, some students do not even want to talk about it and this is where the lessons on how to help and how to do our job in a professional yet with an empathic approach are not learned the right way.

There are a lot of things we can do to improve our care and to make sure our patients feel that we care about them, palliative care nurses should provide an integrative and multidisciplinary treatment approach that helps patients maintain physical, mental, and emotional health and take the time to understand the needs of each patient to provide a customized treatment plan that provides lasting relief.

Also, one of the most crucial elements of providing high-quality treatment is effective communication. By being aware of the many communications needs that patients and those close to them may have, the nurse will provide help to both, which is our goal when we talk about care as a whole.

In other words as nurses we have to remember that in our job we have the chance to help and support people not only physically but also mentally and spiritually, our patients will always remember the way we made them feel in despite of their might forget our names, that is why we need to give our best in every situation because we can make patients feel better even before they are given medication and we can make the difference in how family members cope with the loss of a loved one.

We want to conclude by mentioning that this kind of subject should be talked about more in a nurse's education. It is clear that although we all know that nurses have a crucial role in helping patients discuss death and their final wishes, they must have the support they need to do so. And the very first step in learning about it, these subjects should not be a tabu in our preparation and studies.

Thank you for your interest in this subject and hopefully our work will be contributing to a better understanding of the importance of nurses in a dying patient's family.

BIBLIOGRAPHY

Davies, Elizabeth & Higginson, Irene J. (2004). *Better palliative care for older people*. World Health Organization. Regional Office for Europe. https://apps.who.int/iris/handle/10665/107563

Content analysis. (2023, January 10). Columbia Public Health |. https://www.publichealth.columbia.edu/research/population-health-methods/content-analysis

Coyle, N. (2016). Social aspects of care. Oxford University Press.

- Da Cruz Matos, J., & Da Silva Borges, M. (2018). The family as a member of palliative care assistance. *Revista de Enfermagem UFPE*, 12(9), 2399. https://doi.org/10.5205/1981-8963-v12i9a234575p2399-2406-2018
- Davis, J., Mengersen, K., Bennett, S., & Mazerolle, L. (2014). Viewing systematic reviews and meta-analysis in social research through different lenses. *Springer-Plus*, *3*(1). https://doi.org/10.1186/2193-1801-3-511
- Ferrell, B.R., & Paice, J.A. (2019). *Oxford Textbook of palliative nursing* (5th ed.). Oxford University Press.
- Kaakinen, J. R., Coehlo, D. P., Steele, R., & Robinson, M. (2018). *Family health care nursing: Theory, practice, and research.* F.A. Davis.
- Kaakinen, J.R., Coehlo, D.P., Steele, R., Tabacco, A., & Hanson, S.M.H. (2015). *Family Health Care Nursing: Theory, Practice, and Research*. F.A. Davis Company.
- Kyngäs, H., Mikkonen, K., & Kääriäinen, M. (2020). *The application of content analysis in nursing science research.* Springer Nature.
- McNiel, A., & Gabbay, P. (2018). Understanding and supporting bereaved children: A practical guide for professionals. Springer Publishing Company.
- Rossi, M., & Ortiz, L. (2013). End-of-life care: Ethical issues, practices, and challenges. Nova Science Pub.
- Subject and course guides: Quantitative and qualitative research: *What is qualitative research*? (2022, November 2). Subject and Course Guides at University of Texas at Arlington. <u>https://libguides.uta.edu/quantitative_and_qualitative_research/qual</u>

The European code of conduct for research integrity. (2017, March 24). ALLEA | All European Academies. https://allea.org/code-of-conduct/

WHO. (2020, August 5). Palliative care. World Health Organization (WHO). https://www.who.int/news-room/fact-sheets/detail/palliative-care

BIBLIOGRAPHY FOR LITERATURE REVIEW

- Achora, S., & Labrague, L.J. (2019). An integrative review on knowledge and attitudes of nurses towards palliative care. *Journal of Hospice & Palliative Nursing*, 21(1), 29-37. https://doi.org/10.1097/njh.0000000000000481
- Anderson, R.J., Bloch, S., Armstrong, M., Stone, P.C., & Low, J.T. (2019). Communication between healthcare professionals and relatives of patients approaching the end-oflife: A systematic review of qualitative evidence. *Palliative Medicine*, 33(8), 926-941. https://doi.org/10.1177/0269216319852007
- Angelo, J.K., Egan, R., & Reid, K. (2013). Essential knowledge for family caregivers: A qualitative study. *International Journal of Palliative Nursing*, 19(8), 383-388. <u>https://doi.org/10.12968/ijpn.2013.19.8.383</u>
- Bloomer, M.J., Poon, P., Runacres, F., & Hutchinson, A.M. (2021). Facilitating family needs and support at the end of life in the hospital: A descriptive study. *Palliative Medicine*, 36(3), 549-554. https://doi.org/10.1177/02692163211066431
- ChiplaskeyN, L. M., & Ed. (n.d.). End-of-Life-Care: Are nurses educationally prepared? *RN Journal*. https://rn-journal.com/journal-of-nursing/end-of-life-care-are-nurses-educationally-prepared
- Da Cruz Matos, J., & Da Silva Borges, M. (2018). The family as a member of palliative care assistance. *Revista de Enfermagem UFPE*, *12*(9), 2399. https://doi.org/10.5205/1981-8963-v12i9a234575p2399-2406-2018
- Duke, S., Campling, N., May, C., Lund, S., Lunt, N., & Richardson, A. (2020). Co-construction of the family-focused support conversation: A participatory learning and action research study to implement support for family members whose relatives are being discharged for end-of-life care at home or in a nursing home. *BMC palliative care*, 19(1), 146. <u>https://doi.org/10.21203/rs.3.rs-21155/v1</u>
- Gunilla, E., & Saveman, B. (2013). Health-promoting conversations about hope and suffering with couples in palliative care. *International Journal of Palliative Nursing*, 14(9), 439-445. https://doi.org/10.12968/ijpn.2008.14.9.31124
- Hökkä, M., Lehto, J.T., Kyngäs, H., & Pölkki, T. (2022). Finnish nursing students' perceptions of the development needs in palliative care education and factors influencing learning in undergraduate nursing studies - a qualitative study. *BMC Palliative Care*, 21(1). https://doi.org/10.1186/s12904-022-00915-6

Jung, Y., Yeom, H., & Lee, N. (2021). The effects of counseling about death and dying on perceptions, preparedness, and anxiety regarding death among family caregivers caring for hospice patients: A pilot study. *The Korean Journal of Hospice and Palliative Care*, 24(1), 46-55. <u>https://doi.org/10.14475/jhpc.2021.24.1.46</u>