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Nursing Role in caring for Palliative patient and families

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<p>Abstract</p> <p>This study intends to explore the nursing roles on caring for the palliative and families. The purpose was to suggest ways to improve on the quality of palliative care to enable dying patients realize a more peaceful, dignified and comfortable life before their death.</p> <p>The used study method was literature review, and the literature was collected by using different databases such as Cinahl, Google Scholar. The articles that were accepted were mainly published between years 2009-2020, but in addition one older article was included as well. Thematic analysis was applied in the analysis and synthesis of data for the twelve selected articles. The full texts of the articles were read through, and data grouped to create themes and sub-themes. The study identified three themes: planning and counselling such as early nursing care plan, education and reassuring and informing the patient. Second is the importance of the communication to the patient and to the families and Lastly, the prevention for further complication.</p> <p>During research, it was discovered that the nursing profession is a profound role. Not that we only cater to the needs of the patient but also to the families. Nursing role start as we received the endorsement of the patient until the dying time, and we have a great role with consoling to the remain families.</p> <p>-</p>		
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1. Introduction

The aim of the professional activities of health care professionals is to promote and maintain health, to prevent illness, to cure those who are ill and to alleviate their suffering. In their professional activities, health care professionals must employ generally accepted, empirically justified methods, in accordance with their training, which should be continually supplemented. Each health care professional must weigh the benefits of their professional activity to the patient and its possible hazards (Finlex, 2015). Integrated people centered health services is a crucial part of Palliative care. Relieving of suffering such as physical, psychological, social and spiritual or the causes of suffering might be cancer or organ failure, drug-resistant tuberculosis or severe burns, end-stage chronic illness or acute trauma, extreme birth prematurity or extreme frailty of old age, palliative care is needed and upheld in all cases of care. (WHO, 2020). Palliative care emphasizes the importance of communication about goals of care and patient preferences. This approach may extend from diagnosis through to treatment and recovery, living with cancer as a chronic illness, advanced cancer and end of life care. (Sydney, 2017).

According to the Suomen Syöpärekisteri 2018, there are 4,934 new cases of breast cancer, 5015 new cases of prostate cancer and 3538 of bowel cancer. 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).

Coronavirus disease 2019 (COVID-19) has brought a tsunami of suffering that is devastating even well resourced countries. The disease has wreaked havoc on health systems and generated immense losses for families, communities, and economies, in addition to the growing death toll. Patients, caregivers, healthcare providers, and health systems can benefit from the extensive knowledge of the palliative care community and by taking heed of long-standing admonitions to improve access to essential medicines, particularly opioids for the relief of breathlessness and pain. During the COVID-19 pandemic, access to essential palliative care at end-of-life, including bereavement support, will be limited in the face of high demands in all countries. There will be increased isolation and suffering for palliative care patients and those who are bereaved. Strict physical distancing regulations to slow disease transmission mean that patients who die from COVID-19 will usually be without loved ones by their side, who in turn will be unable to say goodbye or undertake traditional grieving rituals (Radbruch , Knaul, de Lima, Joncheere & Bhadelia, 2020). The ultimate goal of palliative care is to improve quality of life for both the patient and the family. Hence care is not restricted to the patient alone but also involves the family and relatives (Rome, 2011; Vissers, van den Brand, Jacobs, Groot, Vehldoven, Verhagen, Hasselaar, Engels, 2013).

In this study the palliative care is to be explored from the nurses' role to how to be an effective care giver and rendered best quality of care to terminally ill clients. 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' role and to the families.

2. Background

2.1 Definition

Palliative care definitions, descriptions, and perspectives vary widely in clinical practice and often do not align with perspectives offered by palliative care organizations (Pavlish & Ceronsky, 2009). Palliative care is a method that improves the quality of life of a dying individual and their families facing complication associated with a life-threatening illness, with the prevention and relief of suffering means the early detection and impeccable assessment and treatment of pain and other problems such as physical, psychosocial and spiritual. . Elimination of patients' pain and other symptoms , psychological and social support, nutritional support, and the provision of training needs of the patient is the fundamental objective of palliative care. (WHO 2014;Turan, Mankan & Polat, 2017) Palliative care is a specialty that applies to patients of all ages, but with special needs linked to dying in a very broad sense (Voumard, 2018). More recently, there is increased awareness of the need for palliative care for other chronic diseases or conditions such as HIV/AIDS, congestive heart failure, cerebrovascular disease, neurodegenerative disorders, chronic respiratory diseases, drug-resistant tuberculosis, and diseases of older people. (WHO, 2014). Over the few period of time, other labelled has been used to defined this progressing entity, that includes "care of the dying", "end of life", "terminal care", "holistic care", "continuing care" "total care" ," "pain and symptom management," and

“quality-of-life care”. And added recently “supportive care” and “best supportive care”(Hui et al., 2013).

2.2 Advocacy and collaboration

According to American Nurses Association (ANA), advocacy is a pillar of nursing. Nurses instinctively advocate for their patients, in their workplaces, and in their communities; but legislative and political advocacy is no less important to advancing the profession and patient care. According to Vaartio-Rajalin, Leino-Kilpi¹, Zabalegui, Valverde, Mantecon& Puukka, 2014, the care of others is nursing's most basic tenet, in which patient advocacy is ethically grounded, it pertains to fostering and protecting in order to promote well-being whether in a return to health or facilitating a peaceful death.

Counselling to ensure patients can make educated decisions about their health care needs and protecting and supporting their rights describes the act of patient advocacy. Patient advocacy is specifically important when the patient is disempowered due to cognitive challenges caused by age, illness or treatments. Every level of care should be applied in any cases of the disease and patients could receive them along with therapeutic measures such as chemotherapy, radiotherapy and surgery. Holistic interprofessional care is the goal of Palliative care. (Taleghan et al., 2018).

Patient advocacy is especially important when the patient is disempowered due to cognitive challenges caused by age, illness or treatments, or language problems. Cancer patients are usually near or past middle-age, and cancer itself as an illness, its' medical management and especially the side-effects, as well as the different transitions during the illness trajectory are known to affect cancer patients' cognitive skills and informational expectations. Most

cancer patients do not meet the criteria for cognitive impairment, but they might still experience subtle deterioration in cognitive functioning that can impact their daily living and quality of life. Study found out that cancer patients from different ethnic backgrounds have different knowledge expectations: white patients tended to be more willing to talk about cancer and seek help, whereas certain ethnic minorities tended to be hesitant to talk about cancer or seek help, possibly due to the stigmatized nature of cancer in some cultures . White patients also tend to place the most priority on their own individual experiences and benefits, and they want to have control of their own bodies and lives, whereas in some cultures like Hispanic or Asian, patients tend to emphasize the welfare of the family. relationship (Vaartio-Rajalin, Leino-Kilpi¹, Zabalegui, Valverde, Mantecon& Puukka, 2014).

Providing palliative care, is considered an interprofessional teamwork and attainment. The aims of the care is to be the organization of coordination and mutual understanding between different health care members. The participation and open communication between the health care team members including the social workers, spiritual advisers and other providers of the palliative holistic approach. (Taleghani, 2018) Nurses can also coordinate end-of-life decision-making. Studies have shown that, in general, nurses are involved in end-of-life decision-making but do not make the actual decisions. Researchers are found that nurses were not viewed as integral to the decision-making process. They also reported that although nurses were usually the first to recognize medical futility, the level of their involvement in decisionmaking was related to the physician in charge and the nurse's seniority.(Ganz, 2019) These attributes of empowerment are antecedents of

patient advocacy, such as the patient's activity in communication and collaboration within the patient-nurse relationship (Vaartio-Rajalin, Leino-Kilpi, Zabalegui, Valverde, Mantecon & Puukka, 2014).

Palliative care requires health professionals from different disciplines to work together for the patient and family using a collaborative model of care, which has become very popular in all areas of service delivery. It provides a helpful definition of interprofessional collaboration that assists palliative care nurses, as the patient and family are at the centre of care. Interprofessional collaboration involves paying attention to sharing, partnership, joint working, and power issues. The World Health Organization believes that collaboration occurs when 'multiple health workers from different professional backgrounds work together with patients, families, carers and communities to deliver the highest quality of care'. (McDonald & McCallin, 2010; WHO, 2010).

To achieve the goals of palliative care, all of its 4 dimensions should be covered: somatic, spiritual, social, and psychological. This can only be achieved by the close collaboration of caregivers with a distinct background in a multi- and interdisciplinary team approach. (Vissers, van den Brand, Jacobs, Groot, Veldhoven, Verhagen, Hasselaar, Engels, 2013).

It is also of importance is the need to differentiate between palliative and hospice care, often misunderstood by healthcare providers. As described by the World Health Organization (WHO), it emphasizes a team-based, holistic approach to care of the patient and family through assessment and treatment of physical, psychosocial, or spiritual symptoms and prevention and relief of

suffering. End-of-life and hospice care are a part, but not the whole, of palliative care. (Callahan, Breakwell & Sahayda, 2011)

2.3 Nurse and Patient relationship

According to Mok, Chui 2004 & WHO 2014, Palliative care aims to promote the physical and psychosocial well-being of patients whose disease is no longer responding to curative treatment. In nurse–patient relationships, nursing work is directed at maintenance of the body rather than its restoration. Emotional and psychosocial distress are common as individuals confront the terminal phase of an illness and their impending death. One of the core elements of good palliative care is good nurse–patient relationships. The nurse-patient relationship is considered the foundation of nursing care, in nursing profession. It is the interpersonal process that develops over the time with the patients and nurses. The element of this process includes a beginning or the development of trust, middle/ working phase, and ending/termination phase of the context of caring, sharing and goal orientation. (Hagerty & Patusky, 2003)

Amid the dying process, there is a time limitation and the patient are vulnerable that it made the patient and nurse relationship an interesting field for palliative care exploration. It highlights the important role of nurses in helping terminally ill patients to come to terms with the imminence of death. Such work is highly demanding and often stressful. The nurse–patient relationship goes beyond ‘sitting and listening’ and ‘talking’, in which the patient is the object of clinical attention or a subject manifesting psychosocial

problem. Here, the patient not only wishes to speak, but is also known to the nurse in an intimate and private way. Because of the underlying structural inequality of relations between nurse and patient, it has described the relationship as in some way pastoral. The nurse expresses sympathetic concern, while at the same time the patient reveals the most private aspects of their life; the relationship is not mutual. The patient's right to information and the professional's duty to provide information. Legally, the patient has the right to know and the duty of confidentiality is owed to the patient (Dunne et al., 2004) However, some patients prefer to detach themselves from the situation. In such cases, they do not allow nurses to become involved, which makes care more difficult as nurses are then unable to perceive how patients are feeling. In addition, when nurses take time to talk to patients and meet their needs, they must then contend with other, competing, work demands. In order to take time to talk, nurses may have to re-arrange other work or re-allocate staff. It emphasizes how the nurse-patient relationship is imbued with a moral value, which is an investment that undercuts its status as paid labour. (Mok & Chiu, 2004)

2.4 Ethical Issues

Caring for dying patients presents a range of dangers for instances, not knowing what to say and saying the wrong thing; failing to control patient distress and even feeling inadequate in the support offered to dying patients. The irony, though, is that dying is the only certainty, yet it presents so many difficulties for both patients and health professionals to negotiate. One difficulty is that dying has become part of social death. The idea of social death suggests that how patients die is not the concern of the patient alone, but the wishes of the family of the patient. Some patients are obliged to leave

instructions behind (e.g. last will testaments) so that they remain a part of the living. It is adequate that such wishes are approved out and may even be enforced through courts of law. The belief of that although the dead may no longer be with us, they in fact are still present among us. (Nyatanga, 2015)

The matter of when was the appropriate moment to focus on existential concerns was a contentious issue. For example, a DNR order was important because it publicly declared that the patient could be near death. As such, nurses' requests to physicians for a DNR order created an opportunity for nurses to talk openly to patients and their families about the threat of mortality and to help them prepare for it. Although many patients did have Do Not Resuscitate (DNR) orders, nurses still expressed confusion when deciphering and following them. More specifically, nurses expressed frustration with DNR orders which did not clearly reflect what patients and families wanted during a medical emergency. Nurses had to clarify what DNR orders meant to patients and families or ask the physicians to do this. (Leung, Esplen, Howell, Rodin & Fitch, 2011)

2.5 Psychological and Spiritual of well being

Every nurse can facilitate palliative care. Palliative care principles is the fundamental scope and main goal of professional nursing and all specialize field of nursing practice. With this perspective, palliative care and nursing care are the same. Rendering compassion, client-centered, family-based care as a part of a multidisciplinary team and supervising the physical, psychosocial, and spiritual needs of clients in a culturally substantial background is the essence of nursing (McHugh & Buschman, 2012).

It has been suggested that palliative care should be based on holistic assessments of the patient and carers, and that care should meet the needs identified. This care should comprise a broad range of care actions based on an understanding of the sources of distress that might impact on the patient's sense of dignity (Brown, Johnston & Östlund, 2011). The Department of Health and Social Care in UK developed strategy which approaches to the district nursing that building upon care, compassion, knowledge communication, courage and commitment. These guidelines set out how district nurses should lead and support their teams to deliver care in the home, including to those at the end of their lives. While working in partnership, one of the priorities for the district nurses included ensuring that the right staff with the right skills were in the right place, so that all patients received appropriate care. Recognition of what was important to the patient and their family and respecting their preferences, together with patient-focused proactive and flexible care were identified as key to effective care delivery (Bowers & While, 2019).

In palliative care the spiritual element is recognized as one of the more difficult ones to define. When facing a crisis, persons often turn to their spirituality as a means of coping in what describes as 'a highly individualized search for the connectedness with a transcendent force'. (Ireland 2010). Finding spiritual comfort is about the dignity-sustaining effects of turning toward or finding solace within one's religious or spiritual beliefs. Offering of clergyman, priest or ministers and religious artefacts can be beneficial to the patients and families. (Brown, Johnston, Östlund,2011)

Finally, spirituality provides strength and promotes a patient's comfort concurrently. In Indonesia has notable with its religious and cultural diversity; therefore, spirituality should be an essential aspect of palliative care. (Nuraini, Andrijono, Irawaty, Umar&Gayatri, 2018)

2.6 Involvement of the family

Family support is a fundamental component in palliative care due to its roles in increasing a patient's motivation and progress (Nuraini, Andrijono, Irawaty, Umar & Gayatri, 2018). Nursing care for family mostly consists of emotional support. Family members often discuss their ideas of and moral feelings on the decision to withdraw or withhold treatment with nurses. During care for the patient and his family, nurses have to deal with the relationships that exist between the patient and his family, but also with the relationships the nurse herself has with the patient and his family. Nurse must clearly align their advocacy role with patients. The discussions must include helping family members develop confidence in their abilities to care for patients at home, preparing families for the grieving process, assisting families in accepting patients' expressed preferences, and teaching family's ways to relate to their dying loved ones.

According to Noome , Kolmer, van Leeuwen, Dijkstra & Vloet 2016, A meaningful relationship between nurses and family is needed to establish good nursing care. Working with the family includes getting to know the patient by talking with the family and to reflect on their lives together, while also by being physically present at the patient's bedside. There is a need to strengthen the therapeutic relation between family and professionals, which

included holding the family in high esteem, for example talking with family about themselves, making eye contact and sitting close. It is important to give family enough time to be alone with the patient. It is importance of the acceptance of death by patient and family. The acceptance of death is the idea that a patient and his family do not have any unresolved issues. The family needs to be supported in realistic hope, for example by assuring that the patient and family would continue to be cared for, foreshadowing, compassion, reframing hope, and allowing time to process information during their stay. Family care is an important part of our palliative care. (Pavlish & Ceronsky, 2009)

2.7 Pain management and comfort

Disturbances in physical conditions may affect the emotional state. Pain associated with stress is supported by the results of study that which explains chronic pain acts as a physical and psychosocial stressor that causes faster aging cells characterized by shortening of leukocyte telomere length. Other researchers added pain related to the stress and mood of women who experienced it and can affect the depression and healing of it. (Nuraini, Andrijono, Irawaty, Umar & Gayatri, 2018)

Pain has been identified as the most prevalent symptom in advanced disease and the multidimensional nature of pain whereby the person is affected physically, psychologically, spiritually and socially emphasizes the need for health care professionals to approach the management of pain in a holistic way (Dunne et al, 2004)

Although palliative sedation has been described amply in the medical literature, there is a paucity of information in the nursing literature. According to Bruce, Hendrix & Gentry 2006, Palliative sedation is defined as the monitored use of medications to relieve refractory and unendurable symptoms by inducing varying degrees of unconsciousness—but not death—in patients who, given their disease state, progression, and symptom constellation, are expected to die within hours or days. Researchers defined palliative sedation as a medical procedure to decrease the level of consciousness in order to relieve severe physical distress refractory to standard interventions. Some studies stressed two factors as the core nature of sedation. First, the presence of intractable or severe distress refractory to standard palliative treatment and Secondly, the use of sedative medications with the primary aim of relieving severe symptoms by reduction in consciousness.

With palliative sedation, a patient is sedated to unconsciousness to be freed from refractory symptoms. Refractory symptoms are symptoms that cannot be controlled adequately in a tolerable time frame despite aggressive use of usual therapies and seem unlikely to be controlled adequately by further invasive or non-invasive therapies without excessive or intolerable acute or chronic side effects/complications. (Bruce, 2006)

A study conducted by Pavlish and Ceronsky (2009) interviewed 33 nurses in focus groups and determined that essential educational components were (a) "Palliative care should include the family," (b) "Palliative care is a process or journey over time," and (c) "Palliative care allows patients to focus on goals and quality of life." It that palliative care creates a shift to holistic care and

symptom management with a focus on patient and family preferences. Researchers rank the nurses core competencies for palliative care education. Symptom management and how to talk to patients and families about dying were selected as the top-ranked essential competencies. The conclusion of these three studies revealed similarities among core topics considered to be essential for palliative education and practice (symptom management; comfort, pain, end-of-life, and hospice; family focus and patient and family preferences; and quality of life and psychosocial issues). By identifying these components, programs can begin to standardize the teaching content and practice for palliative care. (Harden, Price, Duffy, Galunas & Rogers, 2017)

3. Aims, Purposes, and Research Question

The aim of this research is to explore the nursing roles on caring with palliative patients based on existing research. The purpose was to suggest ways to improve on the quality of palliative care to enable dying patients realize a more peaceful, dignified, and comfortable life before their death. This study is sought to address a research question: What are the best way for nurses on conducting a palliative care for patient and to the families involvement?

4. Methods and implementation of the study

4.1 Literature review

A literature review is a "comprehensive study and interpretation of literature that addresses a specific topic" "systematically search, critique and combine the literature to demonstrate a gap in the existing research base" while demonstrating "their understanding of both the research and the methods previously used to investigate the area" (Aveyard, 2010).

Literature review is an assessment of a body of research that addresses a research question. The purpose of the literature is to identify what has been known about the area of study field. It also identify questions a body of research that does not answer, that makes the study a need for further investigation of research question (Harvard graduate, 2020).

As outlined by Machi and McEvoy (2012), the process of a literature review consists of six basic steps. First, selection of a topic, followed by searching the literature, then developing an argument, and surveying the literature. Critiquing the literature comes next and finally, writing the review. As the first step, a subject that originated from the interests of the researchers was formulated into a topic of research. As the second step, the literature was searched by managing data, scanning and skimming literature, mapping material and creating subject memoranda that lead to refining the research topic.

Research is the cardinal tool of scientific development. Research is the systematic inquiry into phenomena and relations between and among

phenomena by way of acceptable methodology. Science is the system of theoretical knowledge that results from systematic research. In a practice discipline like nursing, scientific knowledge is assumed to contribute to the betterment of nursing care. The mechanism of such an improvement is through more knowledgeable and better-informed nurses. The assumption is that nursing research develops nursing science, which in turn is available to be used to practice nursing in better ways. (Kirkevold, 1997)

4.2 Conducting Literature review

Conducting a literature review is the usual first step in any research project. The reason we do is to identify what others have found out about the topic that we are interested in, before we start. At the end of a research project, however, the findings often open as many new questions as they answer. This means that thinking about what evidence already exists in the literature helps us to think about what we don't know and therefore what is a useful question. This process is implicit in the word, 're-search'. Research involves searching again (re) through what we know in order to establish a novel research question. It is important to have a novel question, because if someone has already answered the question, it makes our project redundant. Often, when we start a research project we think of a general area of interest. Conducting a literature review therefore ensures that there is a need for our project, that is, to answer previously unanswered questions, and that the question we ask is appropriate according to what we already know. (Rowley, Slack 2004)

5 Steps in Conducting a Literature

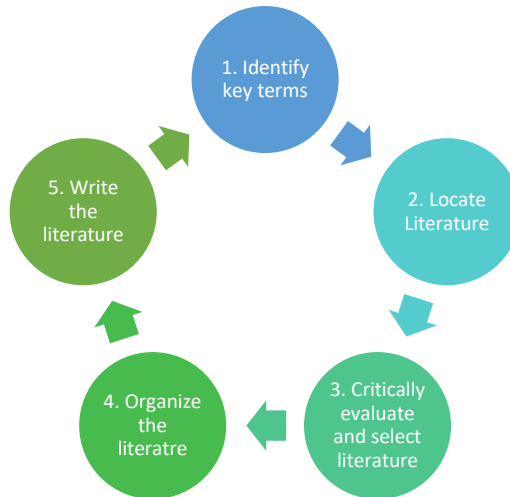


Figure 1. Adapted from University of Bahamas, 2020 (Virginia Balance)

4.3 Article Selection

The two databases that were selected for searching for articles were CINAHL and Google Scholar. The criteria that was given for searching were that the articles had to be original research studies, peer-reviewed, written in English language and were published during the years 2009 to 2020. Figure 2 below shows the inclusion and exclusion criteria

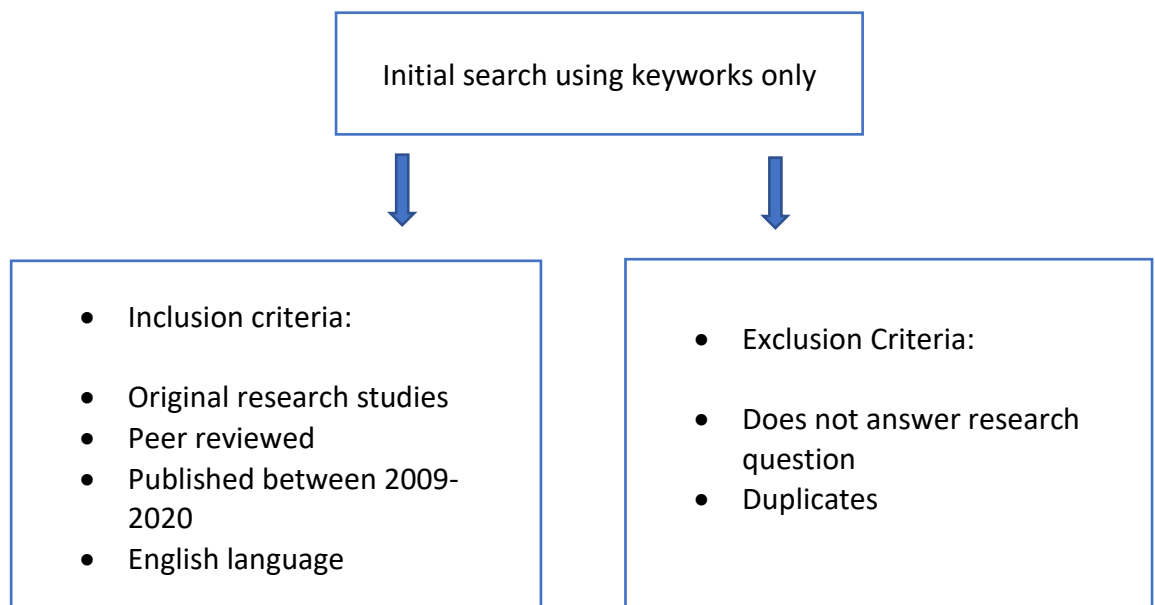
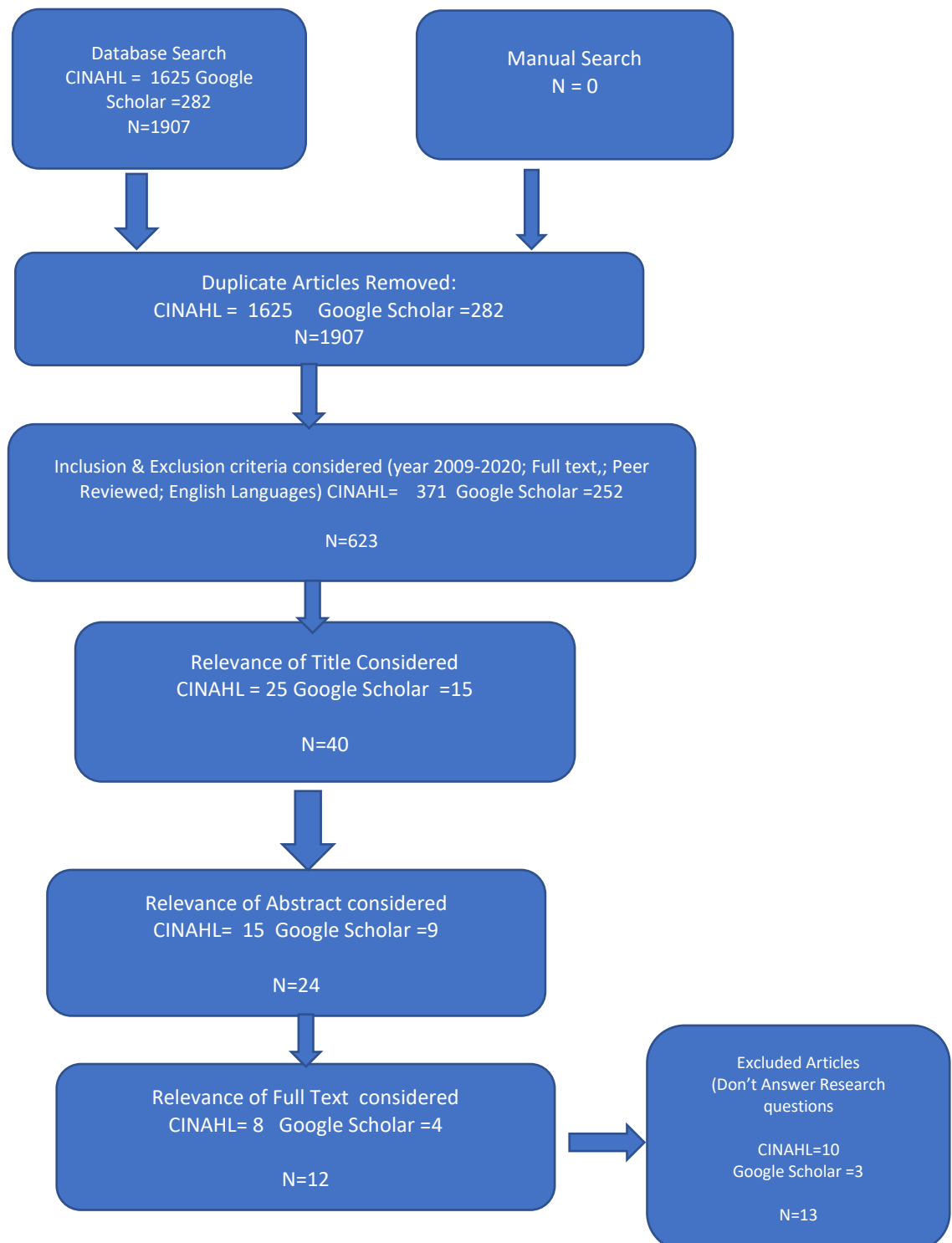


Figure 2. Inclusion and exclusion criteria

The selected articles were preferred to be published quite recently, between the years 2009-2020, but also one older article was included because of its' relevance. This choice was motivated by the fact that nursing palliative care topic is a vast knowledge where there is a constant drive that needed to be updated.



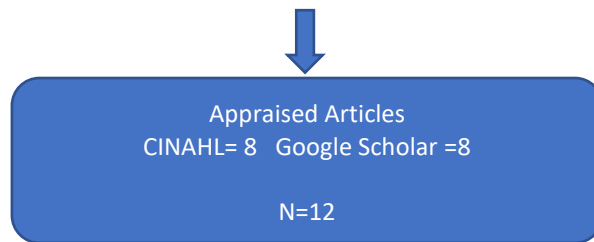


Figure 3 Selection Process

4.4 Data Analysis

When analyzing the data, two things should be considered: relevancy and quality. Whether the article is relevant or not to the study can be simply identified by reading the material and determining whether it answers the research question. Determining the quality of the read articles is the responsibility of the reader. (Aveyard, 2010, 90-91). 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).

Content analysis is commonly used in nursing studies either in the form of inductive or deductive analysis. Moreover, content analysis is an option for qualitative approaches when providing evidence concerning sensitive topics.

Inductive content analysis can be used when no previous studies about the phenomenon in hand exist, or when it's fragmented

5. Results

The results are further presented within three main categories: social support, institutional support and personal coping strategies. Figure 5 illustrates the main categories and their subcategories. The results are further explained in the text.

Research Question	Themes	Subthemes
Nursing Role in Caring for Palliative Patient and Families	Planning and Counselling	<ul style="list-style-type: none"> • Early Nursing care plan • Education • Reassuring and Informing patient
	Communication	<ul style="list-style-type: none"> • Honesty • Attentiveness • Meaningful Relationship
	Prevention for Complication	<ul style="list-style-type: none"> • Bedsores • Decreasing pain • Symptom control

Table 1

5.1 Planning and Counselling

Nurses need a strong foundation of knowledge and access to information to make critical decisions while planning appropriate care to best serve patients and families in crisis (Rolland, 2016). Cancer patients rarely receive palliative care in a timely manner. Ideally, palliative care is initiated at the time that the patient is admitted to the hospital and newly diagnosed with cancer and is continued throughout the medication and/ or intensive treatment through the end-of-life stage. There is evidence that palliative care may reduce morbidity, mortality, and the costs associated with cancer treatment (Nuraini, Andrijono, Irawaty, Umar, Gayatri, 2018)

The health and well-being of a community depended on the skills and knowledge of its dwellers (Rolland,2016). According to Turan, Mankan & Polat (2017), Considering the knowledge of nurses about the meaning and purpose of palliative care; it was determined that nurses define the meaning of the palliative care as "Improving the quality of life of individuals in the terminal stage later it has been transformed to "terminal care", "supportive care", and "terminal stage care" concepts, and deemed equivalent to pain management. Considering the training and knowledge of nurses on the palliative care, more than half of the nurses were found to have no training on the palliative care. It was determined that the knowledgeable nurses had acquired this knowledge during their college education, and more than half of the nurses were found to consider this education rather acceptable, and, it was also found that the training program provided was addressing ethical

issues .According to the studies being conducted, it has been stated that palliative care was not a priority subject in nursing curriculum and work program. The provision of limited, if any, training on the palliative in curricula is the major obstacle in the implementation of palliative care. This negatively affects the quality of life of the patient and family during terminal illness as well as affecting the family after the death of their patient. Supplementations with education, staff resources, and mentoring may help nurses transitioning their role from curative to end-of-life care (Turan, Mankan & Polat 2017; Rolland, 2016).

A study conducted by Handley et al, stated as follows: *I think if we could have more education so that the (care home) staff, I think the staff give ... a wonderful level of care,* (Handley, Goodman, Froggatt , Mathie, Gage, Manthorpe, Barclay , Crang & Iliffe , 2014)

5. 2 Communication

Communication should be regular, proactive, and respect the privacy and confidentiality of the person who is dying and those important to them. Staff must also check the patient and others' understanding, clearly documenting any conversations occurring in relation to treatment goals, plan of care, prognosis and any concerns raised by the patient or those important to them. These conversations should be ongoing, taking into consideration changes in the patient's condition and whether the patient has capacity, (Merlane, 2020)

The perception that palliative care end-of-life care is commonly held by healthcare providers and the public. An effective communication may be

useful in addressing that misconception. The nurse carefully addressed the goals of palliative care within the context of incorporating the patient in decision making to manage the other aspects of her illness and other discomforts. (Kazanowski, & Sheldon, 2013). Many nurses suggested that being honest demonstrates respect and is essential to a trusting and therapeutic relationship with patients and their families. A study conducted by Pavlish et al., (2009), with the nurses stated as follows; one participant stated, *Since I care about them, I try to be honest. When questions arise, I don't dodge the bullet. But I also do it in a kind way and ask them, "Where do you think you are? What are your beliefs on dying? What about afterlife?"* and help them define what it is and address their fears too. Several nurses commented that being honest is a prerequisite to advocating for patient preferences. For example, one nurse said, I will always be truthful, but sometimes it's bits of information, so it's a process over a period. Without abandoning the ideal of honesty, nurses described the importance of remaining within a caring relationship and accepting patients. Many nurses stressed the importance of being honest during end-of-life situations. You have to be truthful without knocking the pins out from underneath them. (Pavlish & Ceronsky,2009)

5.3 Preventing more complication

Improving the quality of life of the individual" (69.8%), "Relieving the individual" concepts, and deemed equivalent to pain management. (Turan, Mankan & Polat, 2017) According to Pereira, Barbosa & Dixie 2017, A research has resulted to presuppose a certain appreciation of the technical-instrumental and pharmacological interventions for symptomatic relief associated with nonpharmacological measures directed at the end of life patient, although reference is made to the provision of comfort care (hygiene

care and skin protection, positioning, feeding) in accordance with the measures practised in this service. To optimise care, the use of technology must coexist with maintenance and comfort care, and it is argued that caring and treating concepts do not compete with one another; rather, they are complementary (Pereira et al., 2017)

Unavoidable pressure ulcer is defined as one that develops even though the provider has evaluated the patient's clinical condition and pressure ulcer risk factors; defined and implemented interventions that are consistent with the patient's needs and goals are formulated with recognized standards of practice; monitored and evaluated the impact of interventions; and revised these approaches as appropriate' Pressure ulcers are fairly common in end-of-life care in Sweden. End-of-life care can be categorised as either general palliative care or specialist palliative care. General palliative care is defined as care given to patients with needs that can be met by staff with a basic knowledge of palliative care. Specialist palliative care is given to patients who have complicated symptoms or specific needs. It is provided by a multi-professional team with specialist knowledge and competence in palliative care. (Carlsson & Gunningberg 2017)

Palliative sedation, the act itself must be good or at least neutral (administering pain medications or sedation); the intention of the act is to produce a good effect by relief of pain although a harmful effect which is death is foreseeable in some cases; the harmful effect of the act must not be the means to the good effect; and the good effect must outweigh or balance the harmful. The principle is to established the terminal condition of the

patient, the urgent need to relieve suffering, and the consent of the patient or healthcare delegation.(Bruce, Hendrix & Gentry, 2006)

6. Discussion

6.1 Discussion of the Main results

The aim of this thesis was to find out the Nursing roles in caring for the palliative Patients and to the Family. Palliative care, as a discipline, aims at improving the quality of life of patients and their families. Patient-centred care is emphasized in palliative care, which means that patients and their families are the unit of care. Nurses should provide individualized care to patients and their families which focuses on their needs, goals and expectations for treatment and care.

Palliative care itself is a symptom care for clients whom disease no longer responds to cure-focused treatment. This care may differ from hospice in the client is not necessarily believed to be imminently dying.

The physiologic needs of people who are dying are related to the slowing of body process and to homeostatic imbalances. Nursing care plan include providing personal hygiene measures, controlling pain and assisting with every nutrition, hydration and elimination and providing comfort.

Pain control is essential to enable clients to maintain some quality in their life and their daily activities, including eating, moving and sleeping. Many drugs have been used to control the pain associated with terminal illness such as

morphine and opioid drugs. Because physician usually prescribe dosage ranges for pain medication, nurses use their own judgement as to the amount and frequency of providing pain relief.

Spiritual support is of a great importance in dealing with death. Although not all clients identify with a specific religious faith or belief, most have a need for meaning in their lives, particularly as they experience a terminal illness.

The nurse has a responsibility to ensure that the client's spiritual needs are attended to, either through direct intervention or by arranging access to individuals who can provide spiritual care. Nurses need to be aware of their own comfort with spirituality issues and be clear about their own ability to interact supportively with the client. Nurses have a responsibility to not to impose their own spiritual belief or religious activity to the client but to respond in the client's background and needs. Communication skills are most important in helping the client to articulate their needs and develop the sense of trust and caring. It is also important for nurses to establish an effective interdisciplinary relation with spiritual support.

The most important aspects of providing support to the family members of a dying client involve using therapeutic communication to facilitate their expression of feelings. When nothing can reverse the inevitable dying process, the nurse can provide compassion, empathy and caring presence. The nurse also serves as a teacher explaining what is happening and what the family can expect. Due to the effects of stress of moving through the grieving process, family members may not accept what they have heard and has the need to repeatedly provide information. The nurse must have to be calm and understand to the patient demeanour.

6.2 Reliability, Validity and Ethical Consideration

This thesis was written in accordance with JAMK project reporting instructions. The instructions outlined the rules and regulations that were required for writing an academic project. Unethical character such as plagiarism and fabrication of information was strictly avoided by ensuring that the articles that were utilized in the writing process were carefully selected and accurately documented in the report.

Collection of the information was carried out only through authorized official access to JAMK library databases such as CINAHL and Google Scholar. The articles that were utilized in the writing of the report were carefully checked to ensure that they were original articles and that the authors were acknowledged

Reliability and validity are ways of demonstrating and communicating the rigour of research processes and the trustworthiness of research findings. If research is to be helpful, it should avoid misleading those who use it

Reliability and Validity

The extent to which results are consistent over time and an accurate representation of the total population under study is referred to as reliability and if the results of a study can be reproduced under a similar methodology, then the research instrument is considered to be reliable. **Validity** determines whether the research truly measures that which it was intended to measure or how truthful the research results are. In other words, does the research instrument allow you to hit "the bull's eye" of your research object.

Researchers generally determine validity by asking a series of questions, and will often look for the answers in the research of others (Golafshani, 2003).

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 Limitations

This study focused on the nursing role in palliative care for only cancer patients, which is there are as well other terminal illnesses. However, the findings of this study are applicable to other terminal illnesses other than cancer since the main focus of palliative care is the same of other illnesses because perhaps when we talk about palliative care, the only thing that comes up to everyone's mind is cancer which also has to be corrected and taught at school for more clear vision.

In added of the limitation, the articles that is used upon the research is limited because the availability of the results in databases. And to that the there has been plenty of research articles that has been conducted but they are conducted way back for many years. Nevertheless, this research can

contribute to the student nurses and nurses towards the improvement of palliative care. It can be used as management and policy makers in formulating strategies that could be used to the health care team members. The research is applicable in all countries as it has no restriction geographically. There has been many interesting articles but they are out-dated and it needs payment for access.

6.4 Conclusion and Recommendation

Death and its aftermath can challenge health professionals on a number of levels. It is important that nurses continue to broaden their repertoire of knowledge and skills regarding palliative care in order to have a deeper understanding of issues surrounding death and dying. (Nyatanga, 2015,99)

Development of communication skills and the ability to 'be there' (presence) can help to show heartfelt support for patients and families. The way patients approach death is going to reflect differences in the bereaved and, as nurses, we should allow families to navigate their grief at their own pace. We cannot put time frames on how and where they should be in their grief, because the chaos often created by death can be hard to resolve. It is important to allow the bereaved to find their own order, since it is their chaos. (Nyatanga, 2015,99; Leung, Esplen Peter Howell, Rodin & Fitch, 2011)

In study, it was determined that the majority of nurses hadn't received training about palliative care, and those who received that training were found to have received this training at the college. In addition, the majority of knowledgeable nurses about palliative care was found to have inadequate knowledge, and had no comprehensive in service training on the palliative care. It was determined that the majority of nurses was college graduate;

however only the minority had received a course on the palliative care in their college education. It was determined that nurses do not have adequate knowledge about palliative care, and unable to distinguish between palliative care and hospice. In addition, nurses should receive professional training in palliative care, taking into account the dynamics and specificities of the emergency department. (Pereira et al., 2017; Turan et al., 2017)

Nurses play a critical role in symptom management for patients, and managing these symptoms at the end of life can be particularly challenging. By virtue of their role in the interdisciplinary care team, nurses are vital to facilitating a good death for these patients and their families. It is critical that nurses continue to advocate for their patients and provide education to other members of the healthcare team who are less knowledgeable about palliative sedation (Bruce, Hendrix & Gentry, 2006). By implementing specific palliative care roles, advancing competence in professional attributes, and collaborating with palliative care specialty teams, oncology nurses can make more significant contributions toward the best possible quality of life for patients and their families. (Pavlish & Ceronsky, 2009)

Primary care nursing roles are already targeted at supporting people with long-term conditions. The predicted increase in the older population who will require quality palliative care. Importantly identifying the opportunity to maximise the nursing role to promote the primary palliative care that is advocated internationally in policy. Developing the palliative care knowledge and skills of nurses should be prioritised to build on their existing skills and strengths in forming relationships with other services and ensuring effective coordination of those services. Further, it seems that care provided to family

mainly consists of giving advice on how to care for the patient; care for family members themselves was only mentioned in a few studies. Therefore, it seems that family does not always receive adequate care yet, which may be helpful in preventing problems like depression, anxiety or post-traumatic stress disorder. (Noome et al., 2015; Raphael, 2014)

Nurses are prepared to be generalists in palliative care. Nurses are able to do further education advancement studies and develop clinical expertise in preparation in palliative care nursing field. It is through the advanced practice nurses and partnership who are able to develop and advocate the palliative care across setting. They are the leaders of palliative care nursing who can influence and support the nurses in providing quality palliative care. Key to the delivery is the assurance for patient that will be receiving the continuity of care. For continuity of care to become a reality for every patient, intra and inter agency relationships must be established which foster a portable plan of care supportive of the patient in every setting. (McHugh et al., 2012; Taleghani et al., 2018).

It is essential to emphasize the community-centered care. It is not the location that dictates care but instead the patient that needed straight care. The main focus of the care is the individual, not the geographical location. The perspective that all nursing rendered care is palliative can allocated health care with nursing take the lead. With the progress of the interprofessional cooperation and the need of using this platform for providing holistic care approach, the framework has been set for providing palliative care as an unquestionable necessity for the health care team members to manage

patients. It is outmost important to report that not all pressure ulcers are avoidable in dying patients, to decrease the delimma of ethical stress.

(Carlsson & Gunningberg, 2017).

To look forward that appropriate care for the palliative care patients and their families will be rendered with thorough planning for creating the necessary infrastructures framework to train expert and skilled resources. Putting up palliative care courses in nursing curriculum, medical, and other health care students as much as needed can be helpful in the advacement in the goals for palliatice care. Henceforth, health care providers and managers of the community health centers must be able to provide the neccessary resources for the purpose and pursuit for empowerment programs to the professional health care team members. Improvement and enhancement of the quality of palliative care services to be needed by the patient.

(McHugh et al., 2012; Taleghani et al., 2018

Family support, good communication with the family, and the provision of operational and environmental support for high-quality end-of-life care is the component of Family centered care.. Nurses should maintain ongoing, open communication with family members, while monitoring their choice of words and the timing of conversations. An important role of the nurse is to comfort the family throughout the bereavement process and provide a supportive environment, both physically and emotionally. Nurses are the primary coordinators of patient and family care. Therefore, they must take an active role in end-of-life care and decision-making, including family conferences.

(Ganz, 2019).

Nurses must help families navigate through the uncertainties of the dying process, remaining cognizant and respectful of individual, family, and cultural differences. Perhaps most importantly, nurses must have access to educational opportunities and emotional support from their colleagues and managers if they are to provide the highest-quality care to critically ill patients and their families (Ganz, 2019; Dunne et al., 2005).

Family members should be encouraged to participate in the physical care of the dying person as much as they wish to. The nurse can suggest they can assist with bathing, speak or read to the client and hold hands. The nurse must not have a specific expectations for family members in participation. Those who feel unable to be with the dying person also require support from the nurse. After the client dies, the family should be encouraged to view the body, because this has been shown to facilitate the grieving process. And perform cultural and spiritual rites as per request from the family remaining.

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Appendices

Appendix 1- Summary of reviewed articles.

	Authors, year, country, title	Purpose /Aim	Research Method	Main results
1	Rolland,2016, USA. Emergency Room Nurses Transitioning from Curative to End-of-Life Care: The Rural Influence	to explore the rural influence on rural ER nurses transitioning from curative to end-of-life care. The goal was to capture areas of need to best support rural nurses caring for dying patients and their families in the rural communities.	A secondary analysis using deductive content analysis	The strongest characteristic of rural nurses was self-reliance. For this reason, adequate support and resources are essential to care for dying patients and their families in rural communities.
2	Handley, Goodman, Frogatt, Mathie, Gage, Manthorpe, Barclay, Crang , Iliffe, 2014. UK. Living and dying: responsibility for end-of-life care in care homes without on-site nursing provision	to describe the expectations and experiences of end-of-life care of older people resident in care homes, and how care home staff and the healthcare practitioners who visited the care home interpreted their role.	a prospective study. A mixed-method design was used	The findings suggest that to support this population, there is a need for a pattern of working between health and care staff that can encourage review and discussion between multiple participants over sustained periods of time.
3	Turan, Mankan Polat, 2017.Turkey. Opinions of Nurses about Palliative Care	it's aimed to determine nurses' level of knowledge about palliative care, increase their sensitivity and awareness, and to perform training activity planning in this regard.	500 nurses who agreed to participate in the research was included in the study. study is a descriptive type research.	the majority of the nurses were not knowledgeable about the palliative care, define palliative care as "improving the quality of life of the individual in the terminal period", and expressed that palliative care covers the services offered to cancer patients in the terminal phase.
4	Pereira, Barbosa, Anjos Dixie, 2018. Portugal. Palliative care for end-of-life patients in a basic emergency service	describe the care provided by the nursing staff of the Western Department of the Basic Emergency Service for end-of-life patients.	retrospective, quantitative, exploratory and descriptive study	.In the recognition of predictive factors of imminent death, the nurses favoured the patient's entry into a comatose state and aggravation of asthenia.
5	Bruce, Hendrix, Gentry, 2006, USA.Palliative Sedation in End-of-Life Care	To explores these principles and some of the challenges associated with providing palliative sedation	Literature Review	Palliative sedation is recognized as a valid treatment approach to the relief of intractable or refractory symptoms and is therefore firmly within the realm of good, supportive palliative care and is not euthanasia.

6	Pavlish, Ceronsky, 2009. USA. Oncology Nurses' Perceptions of Nursing Roles and Professional Attributes in Palliative Care	The aim of this research study was to explore oncology nurses' perspectives of palliative care through narrative analysis of participants' descriptions of life experiences.	conducted nine, one-hour focus group sessions with 33 oncology nurses in three urban medical centers in the idwestern region of the United States.	Findings revealed five primary nursing roles: teaching, caring, coordinating, advocating, and mobilizing. In all five roles, seven professional attributes were described: clinical expertise, honesty, family orientation, perceptive attentiveness, presence, collaboration, and deliberateness.
7	Nuraini, Andrijono, Irawaty, Umar, Gayatri, 2018. Indonesia. Spirituality-Focused Palliative Care to Improve Indonesian Breast Cancer Patient Comfort.	To develop a path model of the relationships between the variables of nursing care (information, emotional support, technical support, and palliative care), patient coping, family support, patient spirituality, and patient comfort expressed through physical and emotional mediators.	This cross-sectional study involved 308 breast cancer patients from 3 referral	Spirituality-focused palliative care is fundamentally importance for breast cancer patients. Nurses play an essential role in providing spirituality-focused palliative care to promote comfort in breast cancer patients in Indonesia.
8	Noome, Beneken genaamd Kolmer, Leeuwen, Dijkstra, Vloet, 2016. Netherlands. The nursing role during end-of-life care in the intensive care unit related to the interaction between patient, family and professional	to explore how intensive care unit (ICU) nurses describe their role during End-of-Life Care (EOLC) in the ICU, related to the interaction between patient, family and professionals (care triad).	Quantitative and qualitative studies	It can be concluded that it is important for ICU nurses to be aware of the existing relationships; however, comparing the literature, care triad does not appear to be reached.
9	Simon, Pralong, Radbruch, Bausewein, Voltz. 2020. Germany. The Palliative Care of Patients With Incurable Cancer	is to ensure universal high-quality palliative care for all patients with incurable cancer in Germany	methodological directives on systematic literature reviews	Non-drug options for the treatment of fatigue and other symptoms include aerobic exercise and psycho-educative methods, particularly cognitive behavioral therapy.
10	Raphael, Waterworth, Gott, 2014. New Zealand. The role of practice nurses in providing palliative and end-of-life care to older patients with long-term conditions	to explore the role of practice nurses in the provision of palliative and end-of-life (EoL) care to older patients with long-term conditions.	qualitative descriptive study	Developing the palliative care knowledge and skills of PNs should be prioritised to build on their existing skills and strengths in forming relationships with other services and ensuring effective coordination of those services,
11	Carlsson, Gunningberg, 2017. UK. Unavoidable pressure ulcers at the	to identify and describe the different ways in which nurses understood unavoidable PUs in late palliative care. A second aim was to explore the	qualitative interview	It is important to communicate that not all pressure ulcers are preventable in dying patients, to lessen the burden of ethical stress for nurses.

	end of life and nurse understanding	expediency of the different levels of understanding.		
12	Kazanowski, Sheldon, 2014, USA. Working Together: Including Palliative Care With Oncology Care	to provide skilled and coordinated care as patients traverse through multiple healthcare settings.	A case study	that research shows that providing information to patients with serious illnesses helps them make decisions and can improve their quality of life. In addition, information gives them more control over their response to the illness and facilitates the planning of their lives.

Appendix 2- Critical Appraisal of the articles (Hawker et al. 2002)

Author	1 abst ract /title	2 Introd uctio n and aims	3 meth ods and data	4 sampli ng	5 Data analysis	6 Ethics and bias	7 Resul ts	8 Transfera bility or generaliz ability	9 Implic ation s and useful ness	total	Commen ts
Rolland, 2016, USA.	3	3	4	4	4	2	4	4	4	32	No commen t
Handle y, Goodm an, Frogatt, Mathie, Gage, Mantho rpe, Barclay, Crang , Iliffe, 2014. UK.	3	4	4	4	4	3	3	3	3	31	
Turan, Mankan Polat, 2017.Tu rkey.	4	4	4	3	4	3	3	3	4	32	
Pereira, Barbosa,	4	4	4	4	4	2	4	3	4	31	

Anjos Dixie, 2018. Portuga l.											
Bruce, Hendrix , Gentry, 2006, USA.	4	4	4	4	3	3	3	4	3	32	
Pavlish, Ceronsk y, 2009.	4	4	4	4	4	4	4	3	3	34	
Nuraini, Andrijo no, Irawaty, Umar, Gayatri, 2018. Indones ia.	4	4	4	3	3	3	3	4	4	32	
Noome, Beneken genaam d Kolmer, Leeuwe n, Dijkstra, Vloet, 2016. Netherl ands.	4	4	4	4	3	4	3	3	3	32	

Simon, Pralong, Radbruc h, Bausew ein, Voltz. 2020.	3	3	3	4	4	1	4	4	4	30	
Raphael , Waterw orth, Gott, 2014. New Zealand .	3	3	4	4	4	3	4	4	4	33	
Carlsson, Gunning berg, 2017. UK.	4	4	4	3	3	2	4	3	4	31	
Kazano wski, Sheldon , 2014, USA.	4	4	3	3	3	1	4	3	3	28	