

# Experiences of Nurses Providing Palliative Care for Dying Adult Cancer Patients

**Literature Review** 

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#### **Abstract**

The aim of this literature review was to study nurses' experiences providing palliative care to dying adult cancer patients and their families. The purpose was to suggest ways to improve on the quality of palliative care to enable dying cancer patients realize a more peaceful, dignified and comfortable life before their death.

Articles for use in the study were obtained from CINAHL, PubMed and Elsevier Science Direct. Selection of articles was conducted based on a predetermined inclusion and exclusion criteria as well as relevance by title, abstract and full text.

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: nurses' challenges in provision of palliative care, positive and negative impact of family on patient's care and treatment and open, trust, faith, acceptance and compassionate communication skills of a nurse.

During research, it was discovered that the quality of palliative care is compromised by the challenges faced by nurses during practice. The study therefore suggested ways to minimize on nurses' challenges while at the same time maximizing on supportive behaviour.

Key words / tags (Subjects)

Cancer, Palliative care, Oncology Nurses, Cancer Patient and Family

Miscellaneous

# Contents

1	Introduction	3
2	Care and Treatment for Dying Cancer Patients	4
	2.1 End-of-Life Care for Cancer Patients	4
	2.1.1 Pain Management, Emotional and Spiritual Support	6
	2.1.2 Obstacles and Supportive Behaviour	7
	2.1.3 Ethical Issues in Palliative Care	10
	2.2 Palliative Care	12
	2.3 Clinical Oncology	13
	2.4 Nurses' Role and Their Perceptions	13
3	Aim, Purpose and Research Question	18
4	Methodology	19
	4.1 Literature Review	19
	4.2 Scientific Article Selection Process	20
	4.3 Data Extraction and Synthesis of Data	22
5	Results	26
6	Discussion	33
	6.1 Discussion of Main Results	33
	6.2 Implications to Nursing Practice and Healthcare	35
	6.3 Ethical Considerations	36
	6.4 Validity and reliability	38
	6.5 Recommendations	39
R	eferences	43
A	ppendices	0
	Appendix 1. Summary of the Selected Articles	0
	Appendix 2: Summary of Critical Appraisal Scores	0

# **Figures**

Figure 1 Number of Cancer Cases and Deaths Worldwide in 2012	.22
Tables	
Table 1 Keywords and their combinations	. 20
Table 2 Inclusion and Exclusion Criteria	.21
Table 3 Phenomenology of the study	.32

# 1 Introduction

Every patient facing the inevitability of death from a life-limiting disease or injury deserves a peaceful and dignified death. This can be achieved through palliative and hospice care. Nurses have been identified as central to palliative care, providing holistic, practical, 'hands-on' care, symptom management, emotional support and co-ordinating services for patients and families. The nursing role has also been recognised in studies that have examined palliative care services and in studies that have considered the views of patients and families on the experience of dying. (Dunne, Sullivan, & Kernohan 2005, 373.)

According to Naimeh and colleagues, for oncology nurses, an understanding of other nurses' perception of palliative care would provide an opportunity to improve their own care (Naimeh, Borimnejad, Mardani, & Tahmasebi 2014, 69). The decision to focus on palliative care for cancer patients in this study was due to the tremendous rise in cancer deaths in recent years. In the UK alone, one in four people dies from Cancer and it is estimated that more than 15 million people worldwide will experience cancer in 2020 (Naimeh et al 2014, 69).

It was concluded that there was a gap in knowledge on this research topic. This is because earlier studies on this topic were already getting outdated due to changes and developments in healthcare system. For instance, no studies had adequately researched on ethical dilemmas encountered by nurses in provision of palliative care to dying cancer patients. The aim of this study was to bridge this gap in literature by conducting a literature review study on the experiences of nurses offering palliative care to cancer patients. The purpose of the research was to suggest ways to improve the quality of palliative care for cancer patients to enable terminally ill patients live a peaceful and comfortable life until the time of their death.

# 2 Care and Treatment for Dying Cancer Patients 2.1 End-of-Life Care for Cancer Patients

The need for compassionate and effective end-of-life care (EOLC) grows more critical as the number of people predicted to get cancer is expected to increase in every region of the world (Bray, Jemal, Grey, Ferlay, & Forman, 2012.) Cancer is the second most common cause of death in the United States and around the world, surpassed only by deaths from heart disease. With so many cancer-related deaths, nurses are providing end-of-life care for patients with cancer daily. (Beckstrand, Moore, Callister, & Bond 2009, 446.) The World Health Organization (WHO) and Centre for Disease Control and Prevention (CDC) conducted a global cancer research in 2012. Per the Global Cancer Statistics (2012), 14.1 million new cancer cases were diagnosed. 8.2 million people died from cancer and this is expected to rise to 15 million by 2020. This information is illustrated by the bar graph below.

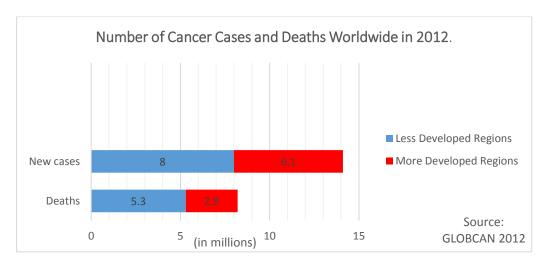


Figure 1 Number of Cancer Cases and Deaths Worldwide in 2012.

Timeliness of initiating end-of-life care (EOLC) is difficult to manage in critical illness, and subsequent delays challenge the quality of dying. High technology care in critical care (intensive care) can seem paradoxical when patients are dying, which lead to uncertain circumstances around when and how to enact EOLC. The added complexity of a cancer diagnosis contributes to difficulties in EOLC practices. (Pattison, Carr, Turnock, & Dolan 2013, 1442.)

While cancer EOLC is regarded as a beacon of good practice, which creates expectations around management of decision-making and EOLC, symptom management deficits persist. However, it is not known whether dying, critically ill cancer patients experience good EOLC. (Natalie et al. 2013, 1443.) These factors have been promoted as a significant and defining example of good nursing practice such as proactive holistic palliative care, encompassing social, psychological, physical and supportive care (McHugh et al. 2013, 72).

During the observation of dying adults hospitalized in the United States in 1995, investigators found major shortfalls of more than 9,000 patients (SUPPORT Principal Investigators, 1995). The SUPPORT study showed lack of communication of patients' desires for EOLC to their healthcare team and shortcomings in frequency of aggressive treatment and other characteristics of death in hospitals, such as do-not-resuscitate (DNR) orders being written within two days of the patient dying or family members reporting that half the time of their hospital stay their dying family members experienced moderate to severe pain. (Beckstrand et al. 2012, 399.) In response to the SUPPORT study, the World Health Organization (2002) issued a statement which could improve patients' quality of life and help them be as active as possible until their time of death. Patients with terminal illnesses and their caregivers deserve supportive and reliable care (Beckstrand et al 2009, 446.)

Other studies have attempted to identify obstacles and supportive behaviours and other interventions to increase the quality of EOLC in the United States and globally such as Emergency nurses' perceptions of size, frequency, and magnitude of obstacles and supportive behaviours in end-of-life care (Beckstrand, Smith, Heaston, & Bond, 2008), Critical care nurses' suggestions

for improving end-of-life care (Beckstrand, Callister, & Kirchhoff, 2006), help for patients in discussing EOL issues with physicians (Clayton, Butow, Tattersall, Devine, Simpson, Aggarwal, 2007), Improving palliative care in cancer (Coyne, Paice, Ferrell, Malloy, Virani, & Fennimore, 2007), patient and family perceptions of EOL care (Heyland, Dodek, Rocker, Groll, Gafni, Pichora, & Lam, 2006), Quality end-of-life care: A global perspective. BMC Palliative Care (Singer & Bowman, 2002), the quality of a good death is determined by the observations of patients, families, and providers (Steinhauser, Clipp, McNeilly, Christakis, McIntyre, & Tulsky, 2000), quality of medical care at EOL (Yabroff, Mandelblatt, & Ingham, 2004). Although these studies add to the body of knowledge regarding EOLC, more data are needed regarding nurses' perceptions of obstacles and supportive behaviours in EOLC. (Beckstrand et al. 2012, 399.)

## 2.1.1 Pain Management, Emotional and Spiritual Support

Pain is a basic symptom of cancer occurring in 50-70% of all cancer patients (Wiese, Löfflr, & Vormelker, 2010). It may result from the primary tumour, metastasis, radiation, chemotherapy, surgery, or comorbidity (Modesto-Lowe, Girard, & Chaplin, 2012). When a patient is suffering from cancer pain it is paramount to consider not only biochemical factors but also psychosocial influences (Mori, Elsayem, Reddy, Bruera, & Fadul, 2012). Of all the physical and emotional symptoms of cancer, pain is often identified as the most distressing (Modesto-Lowe, Girard, & Chaplin, 2012.) Cancer pain negatively affects patients' quality of life, and palliative care for such pain is essential. There is an urgent worldwide humanitarian need for palliative care for people with cancer (Human Rights Watch, 2011). Palliative care addresses psychosocial requirements including the treatment of pain. The quality of palliative care for patients with cancer pain can be improved through nursing

collaboration. An understanding of other nurses' perceptions of palliative pain care would provide an opportunity for oncology nurses to improve their own care and would assist in developing an effective pain management plan. (Naimeh et al. 2014, 69.)

According to Dunne and colleagues, findings demonstrated how nurses experienced difficulties when dealing with patients' symptoms during the palliative stage of illness. They identified pain as being the single most complex symptom during the palliative stage of illness. (Dunne et al.2005, 375.) Management of physical pain occurs not only through provision of relieving drugs but also through actions such as talking to patients. Nurses believe that talking to patients provokes them to express their feelings and helps to relieve their physical pain. (Naimeh et al. 2014, 72.)

Nurses also recognised that opioids can provide essential relief for patients, however while talking to their patients they always pointed out the potential side effects and attempted resorting to other alternatives of relieving pain such as psychological empowerment. Nurses also point out that psychological empowerment through supportive behaviour and distress reduction helps relieve patients' pain. Distress reduction involves understanding patients' aggressiveness and being a good listener. (Naimeh et al. 2014, 72.)

# 2.1.2 Obstacles and Supportive Behaviour

By studying obstacles that stand in the way of providing optimal EOL care, nursing educators and managers will be better able to educate and support bedside oncology nurses in delivering end-of-life care. Moreover, nurses can use the information obtained from the study to work together with the

interdisciplinary team to change and improve EOL care for dying patients with cancer and their families. (Beckstrand et al. 2009, 447.)

Obstacles encountered by nurses in end-of-life care include: Angry and anxious family members, Families not accepting what the physician tells them about patient's poor prognosis, Being called away from patients and families to help with a new admit or to help other nurses care for their patients, Families being overly optimistic despite patient's poor prognosis, Patients' families not wanting patients to be overly sedated because of too many medication doses, Families and friends who continually call the nurse wanting an update on patients' conditions rather than calling the designated family member for information, Intrafamily fighting about whether to continue or stop aggressive treatment. (Beckstrand et al. 2009, 447.)

Employing life-sustaining measures at families' requests even though patients signed advanced directives requesting no such treatment, Not enough time to provide quality end-of-life care because nurses are consumed with activities that are trying to save patients' lives, Lack of education and training regarding end-of-life care and family grieving, Poor design of units that do not allow for privacy of dying patients or grieving family members, Dealing with cultural differences families employ in grieving for dying family members, Families, for whatever reason, are not with patients when they die, Pressure to limit family grieving after patients die to accommodate a new admit to that room. (Beckstrand et al. 2009, 447.)

According to Waldrop (2007), the most common psychological and emotional responses to grief were predominantly intense sadness and anger. Oncology

nurses must not only work with individual families to understand dying patients' situations, they must do so as families are in a heightened state of anxiety, depression, nervousness, restlessness, and fear, leading to difficulty remembering, concentrating, and completing tasks. (Waldrop 2007, 197.)

Supportive behaviour in the end-of-life care involved the following: Allowing family members adequate time to be alone with patients after death, Having social work or palliative care staff as part of the patient care team, Having family members accept that patients are dying, Having the physicians involved agree about the direction of patients' care, Providing a peaceful bedside scene after patients die, Having experienced nurses model end-of-life care for new nurses, Having palliative care nurses establish rapport with patients and their families before death of patients, Teaching families how to act around dying patients such as saying to them, "She can still hear, it is okay to talk to her.", Having one family member be the designated contact person for all other family members regarding patient information, Having enough time to educate families about their loved ones' expected process of dying. (Beckstrand et al. 2009, 451.)

A unit designed so that families have a place to go to grieve in private away from patients' rooms, Having a unit schedule that allows for continuity of care for dying patients by the same nurses, Having family members thank you or in some other way show appreciation for your care of patients who die, Allowing families unlimited access to dying patients even if it at times conflicts with nursing care, Having educational in-service classes on how to talk to and take care of dying patients, Having fellow nurses put their arms around you, hug you, pat you on the back, or give some other kind of brief physical support after patients die, After patients die, having support staff members compile all the

necessary paperwork for you that must be signed by families before they leave the unit, Having the physician meet in person with the families after patients die to offer support, Having a support person outside of the work setting who will listen to you after patients die, Nurses drawing on their own previous experience in end-of-life care with either patients or family members, Having fellow nurses take care of other patients while you get away from the unit for a few moments after patients die, and Having families physically care for dying patients. Conclusively, EOL care can be improved by working to decrease the highest-rated barriers and by continuing to support the highest-rated supportive behaviours. (Beckstrand et al. 2009, 451.)

#### 2.1.3 Ethical Issues in Palliative Care

Ethical dilemmas put nurses and other healthcare professionals in complex situations since they are faced with contradicting conditions that are to be met at the same time. One of the ethical dilemmas in palliative care for cancer patients is disclosure of information. In the palliative care setting, it becomes even more controversial since the patient is in the final trajectory of illness and facing death. If the patient is seeking information and it is withheld, the patient can be denied the right to deal with 'unfinished business', say 'good-bye' or prepare in whatever way is appropriate for his own death. (Dunne et al. 2005, 377.)

Nurses often find themselves at the centre of conflict involving physicians, patients, and family members on the use of aggressive treatment. This is because they are forced to continue aggressive treatment that is deemed futile thus denying patient the benefits of palliative care. Nurses are often put to task whenever confronted with patients whose cultural beliefs contradict medical treatment. In one case, a mother refused to continue care for a child because she believed that poor patients would be denied care so that organs could be

harvested for rich patients. (Ferrell 2006, 928.) According to Chiu and colleagues (2000), ethical dilemmas palliative care in Taiwan included: truth telling, place of care and therapeutic strategy (patient or the family could not accept the goal of treatment being directed towards care rather than cure), hydration and nutrition, blood transfusion, alternative treatment, terminal sedation, and the use of medication in symptom management (Chiu, Hu, Cheng, Chen 2000, 354).

The issue of spirituality is also of interest to discern theological tenets related to the ethical concern of futile care. Some nurses described families' or patients' spirituality as religious traditions that prohibited them from discontinuing life support. Some other patients or families believed in miracles from God thus prohibiting nurses from making decisions to discontinue medical treatment. Some instances also revealed that nurses' own spirituality influenced their responses to clinical situations. (Ferrell 2006, 928.)

According to Kinzbrunner (1995), ethical dilemmas that face physicians in the US referring patients to hospice programs involves clinicians to predict accurately a patient prognosis of 6 months or less, and to what extent hospice programs and clinicians are obligated to deliver patients with complete information about their illness, as the Medicare Hospice Benefit requires that patients sign an informed consent in order to elect the hospice benefit. There are several ethical dilemmas that affect day-to-day patient care and treatment in palliative care programs such as physician concern over the use of morphine because of possible respiratory despair in the progressive cancer patient, the question of offering enteral/parenteral nutritional support to patients who refuse to eat near the end of life, the question of providing parenteral fluids to patients who cannot take fluids during the terminal phases of their illness and

the methodology for quality of life research in palliative care. (Kinzbrunner 1995, 36.)

#### 2.2 Palliative Care

The World Health Organization (2016), describes palliative care as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, across the avoidance and relief of suffering/distress by means of early rapport and flawless assessment and treatment of pain and other problems either physical, psychosocial and spiritual. Philosophically, palliative care is a broad construct defining a continuum that serves patients and families from the time of diagnosis with a chronic or acute progressive illness throughout the entire course of the disease.

Although the similarities between hospice and palliative care are important, it is the differences between them that enable realization of the full value of this approach to caring for patients. Hospice professional focus on caring for patients with a clearly limited life expectancy and who have made an informed decision to discontinue curative care. In contrast, palliative care professionals working outside of hospice programs provide their expertise to patients who wish to continue to benefit from curative and life-prolonging therapies. (Meier and Brawley 2011, 2.)

Throughout the developed world, the philosophy of palliative care is now reasonably well accepted as an approach of caring for patients who are facing the inevitability of death from life-limiting disease. The model for the delivery of palliative care and place of death for patients is largely influenced by the health care system that exists in a country. (Dunne, Sullivan, & Kernohan 2005, 372.) Nurses consistently identify palliative care as an area of practice where

they would like to spend more time with patients and families. It has been argued that one reason for popularity in palliative care is that it allows nurses to do real nursing. (McHugh, Pateman, & Luker 2013, 72.)

## 2.3 Clinical Oncology

Lee and colleagues (2016, 1), define oncology as the field of medicine that is devoted to cancer. Clinical oncology consists of three primary disciplines: medical oncology (the treatment of cancer with medicine, including chemotherapy), surgical oncology i.e., the surgical aspects of cancer including staging, biopsy and surgical resection of tumours and finally, radiation oncology (the treatment of cancer with therapeutic radiation). (Lee, Marks, & Shiel 2016, 1.) A cancer patient is a person who has been diagnosed with any form of cancer and is receiving treatment for the disease. Cancer is an abnormal growth of cells which tend to proliferate in an uncontrolled way and in some cases to metastasize (spread).

Cancer is a broad term that encompasses more than a hundred different and distinctive diseases. Cancer can involve any tissue of the body and have many different forms in each body area. Most cancers are named for the type of cell or organ in which they start. The frequency of a specific cancer may depend on gender. Prostate cancer is common for men whereas breast cancer is common for women. Cancer may also be called malignancy, a malignant tumour, or a neoplasm (literally a new growth). (Lee et al. 2016, 1.)

# 2.4 Nurses' Role and Their Perceptions

A nurse is professional who has undertaken nursing education at a recognised learning institution and has been licenced to practice. According to American Nurses Association (2012), nursing is the protection, promotion and optimization of health and abilities, prevention of illnesses and injury,

facilitation of recovery, improvement of suffering through the diagnosis and treatment of human reaction, and support in the care of individuals, families, groups, communities and populations. Nurses' interpretations about the nature of their role in palliative care services are often shaped by the context of the workplaces that focus on the treatment of the symptoms (Huang et al. 2009, 3422).

Over the last ten years, nurses' roles have changed, moving away from the delivery of personal social care to that of patient evaluators. Their role has prolonged in terms of becoming nurse prescribers; having a function as care managers; providing a positive involvement to palliative care and working in new ways, such as in self-managed teams (McHugh et al. 2013, 72).

A qualitative study of 33 hospital oncology nurses by Pavlish and Ceronsky (2009) identified five key nursing roles in providing palliative care at EOLC (teaching, caring, coordinating, advocating and mobilizing), which all had communication as a common theme. The roles of teaching, caring, and mobilizing essential communication specially between nurse and the patient and family, whereas the roles of directing and supporting required communication with all members of the healthcare team. (Beckstrand et al 2012, 398.)

The experiences of nurses caring for cancer patients and their families are complex and intricate. Nurses have varying degrees of relief in communicating with patients and families and often concede feeling challenged by discussions, especially when spreading disease and forthcoming death are involved. (Daines, Stilos, Moura, Fitch, McAndrew, Gill, Wright 2013, 593.) This

demonstrates a need for more support and education towards skill development to help nurses counter such challenge. Nurses experience difficulties dealing with patients' symptoms during the palliative stage of illness. This is because pain, both physical and emotional, is quite involving as other professionals such as doctors, and pharmacists must come in to help in treatment of cancer pain. Nurses also identify other symptoms such as fatigue and breathlessness quite difficult to cope with. The district nurse's ability to achieve maximum symptom control in general for patients was also affected by the influence of the general practitioner (GP), involvement of the specialist palliative care team (SPCT), out of hours GP cooperatives and out of hour's community pharmacy arrangements. (Dunne et al. 2005, 375.)

Effective communication among healthcare professionals has not been good either. Occasionally, there is no designated person to take overall responsibility for coordinating the care of the family unit. Many district nurses find difficulty communicating effectively with dying patients. Nurses also find it difficult to deal with emotional reactions of the family unit such as anger since the emotional state of an individual has an impact on how information is processed. When confronted with angry patients and family members, nurses tend to distance themselves from the angry outburst. This is because nurses may interpret this form of anger as a personal criticism of themselves. (Dunne et al. 2005, 376.)

Disclosure of information in this setting made nurses feel uncomfortable especially because the patient to whom the information pertains is in the final trajectory of his illness and facing death. Legally, patients have the right to know and to have confidentiality. Family members may not allow the nurse to share the true information to the patient about his condition and this puts the

nurse in dilemma. Nurses also feel inadequate and helpless dealing with children and adolescents in the family about the ongoing care of their parent and as such nurses easily opt to exclude them from any conversation about the condition of their parent. Nurses find the emotional involvement difficult to deal with. (Dunne et al. 2005, 377.) Further exploration about cancer nurses' experiences in the context of significant ambiguity or during transitions to palliative end-of-life care will enhance nurses' capacity to talk about death in ways that support patients and their families to control and limit their distress the end of life (Leung et al. 2012, 2176.)

Nurses' proximity to patients situates them to 'see' and engage with patients' existential distress; however, nurses still appear to be challenged about how to address this kind of distress (Leung, Esplen, Peter, Howell, Rodin, & Fitch 2012, 2176.) Patients' attention or the way treatment is given, are optimized and evaluated to ensure the approach closely mirrors clinical practice. To accomplish this and guarantee honesty of the intervention, process evaluation is supported by many researchers as a predominantly useful approach to assess the process of complex intervention against the planned criteria of a quality intervention. (Chan, Richardson, & Richardson 2012, 235.)

Previous research related to the experiences of nurses offering palliative care for dying cancer patients in the last ten years include; Factors influencing oncology nurses' approaches to accommodating cultural needs in palliative care (Huang, Yates & Prior, 2009), Iranian nurses' perceptions of palliative care for patients with cancer pain (Naimeh, Borimnejad, Mardani, & Tahmasebi, 2014), Oncology nurses' perceptions of obstacles and supportive behaviours at the end of life (Beckstrand, Moore, Callister, & Bond, 2009), Oncology nurses' personal understandings about palliative care (Mahon, & McAuley, 2010), and,

Palliative care for patients with cancer: district nurses' experiences (Dunne, Sullivan, & Kernohan, 2005). Based on the existing literature, it was evident that the previous research was getting outdated due to the many changes and developments in healthcare over time. This study sought to uncover the ethical dilemmas in palliative care as previous studies had failed to give satisfactory information on this. This study aimed to fill this gap in literature by understanding the experiences of nurses offering palliative care for cancer patients and their families.

# 3 Aim, Purpose and Research Question

The aim of this research was to conduct a study on nurses' experience providing palliative care for dying cancer patients and their families based on existing research. The purpose was to suggest ways to improve the quality of palliative care for cancer patients based on the results of the study. This study sought to address one research question: What are nurses' perception of palliative care for dying cancer patients?

# 4 Methodology

#### 4.1 Literature Review

This study was based on a literature review of selected articles. Methods of conducting review of the health care literature have been used since the 1970s in an effort to synthesize finding from discrete primary studies and to increase the generalizability of the phenomenon (Jackson 1980). Harvard Graduate School Gutman Library (2016), defines literature review as an assessment of a body of research that addresses a research question whose purpose is to identify what is already known about an area of study. Moreover, it identifies questions a body of research does not answer as well as make a case for why further study of research questions is important to a field. Broome (1993) added, literature review summarizes past literature to provide a more comprehensive understanding for a particular phenomenon or health care problem (Broom 1993, 231).

The process involved in literature review includes: framing a research question, searching through pieces of literature, analysing search results, synthesizing the research literature and compiling an assessment of the literature (Whittemore & Knafl 2005). According to Aromataris and Pearson (2014), some of the reasons for conducting literature reviews include; presenting general knowledge about a topic, showing the history of the development of knowledge about a topic, identifying where evidence may be lacking, contradictory or inclusive, establishing whether there is a consensus or debate on a topic, identifying characteristics or relationships between key concepts from existing studies relevant to the topic, or justifying why a problem is worthy of further study (Aromataris and Pearson 2014, 53).

Literature reviews have always been a means of summarizing and presenting overviews of knowledge, current and historical, derived from a body of literature (Aromataris and Pearson, 2014, 53). Numerous studies on this research topic already exist thus the authors of this piece of literature chose to conduct a literature review to condense the findings of evidence-based articles related to this research topic to condense their results and establish common themes. Integrative review approach allows the inclusion of diverse methodologies and has the potential to play a greater role in evidenced-based practise for nursing. The integrative review contributes to the presentation of varied perspective of nurses providing palliative care for cancer patients. (Kirkevold 1997, Estabrooks 1998, Evans & Pearson 2001.)

#### 4.2 Scientific Article Selection Process

Articles for use in this research were obtained from CINAHL (Ebsco), PubMed and Elsevier Science Direct. The key words used in the search for articles were: palliative care, nurses' experiences, cancer patients and their synonyms as shown in the table below.

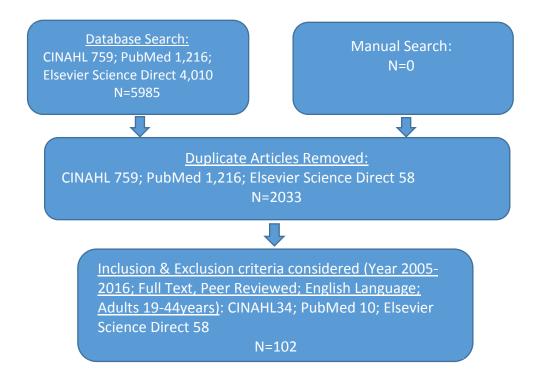
Keywords:		Results	
	CINAHL	PubMed	Elsevier
			Science
			Direct
"Palliative care" or "end-of-life care" or	759	1,216	4,010
"hospice care "or "geriatric care"			
AND			
"Nurses' experience" or "perspective" or			
"view" or "attitude"			
AND			
"Cancer patients" or "oncology patients"			
or "patients with cancer"			

Table 1 Keywords, their synonyms and their combinations

Selection of articles for use in this research was based on a predetermined inclusion and exclusion criteria as shown in table 1 below as well as relevance by title, abstract and full text.

Inclusion Criteria	Exclusion Criteria
Language of publication in English	Literature review articles
The articles are scientific-based and	Duplicate studies
may include theses (masters or	
doctoral)	
Articles published between years	Other illnesses other than cancer
2005 and 2016	
The articles are peer reviewed	Other patients other than adults
	(19-44yrs)
Articles have a full text access	
Articles related to research topic	
Articles answer the research question	

Table 2 Inclusion and Exclusion Criteria



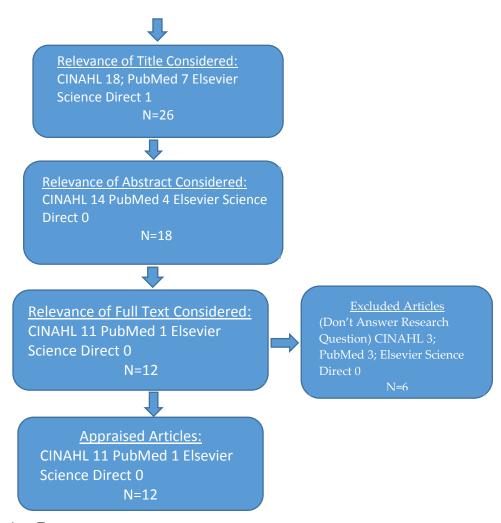


Figure 2 Selection Process

# 4.3 Data Extraction and Synthesis of Data

The articles (N=12) used in this study (also in appendix) were published in the years 2005(1), 2007(1), 2008(1), 2009(2), 2011(1), 2012(1), 2014(3) and 2015(2). The countries where the articles were published are: United Kingdom(n=1), United States of America(n=4), China(n=1), Iran(n=1), Brazil(n=4) and Singapore(n=1). The data collection methods used in the appraised articles (N=12) were; qualitative (n=7), and quantitative (n=5). The data analysis methods used for the selected articles were: Phenomenological approach (n=2), grounded theory (n=1), content analysis (n=2), thematic analysis (n=1), descriptive correlational survey (n=1), SPSS 11,5 (n=1), Cross-sectional survey (n=1), mailed survey (n=1), qualitative approach (n=1), and narrative analysis (n=1)

Critical appraisal was undertaken for the selected articles to determine their viability. According to Hawker, Payne, Kerr, Hardey & Powell (2002), critical appraisal of retrieved article is done in three stages; assessment of relevance, data extraction and scoring for methodological rigor. In the assessment stage, record detail and to determine whether each paper in the database should be "Accepted" for further assessment or "Rejected." Data extraction enables to record full details of the articles under review and to specific about how each of them addressed our research questions. (Hawker, Payne, Kerr, Hardey & Powell 2002, 1298-1291.) Our study is not an empirical study so, scoring for methodological rigor process involves an assessment of the methodological of the accepted empirical studies so that they could be graded according to the reliability of the results (Oxman, 1994, 648).

Hawker and colleagues (2009) appraise the quality of each article on a score of 1 to 4. Good=4; Fair=3; Poor=2; Very Poor=1 (poor quality). The checklist used for appraisal of articles assesses 9 areas of an article. These areas are: abstract and title, introduction and aims, method and data, sampling, data analysis, ethics and bias, results, transferability or generalizability, and implications and usefulness (how important the findings are to policy and practice). (Hawker, Payne, Kerr, Hardey & Powell 2002, 1284-1299.) Appraisal of the articles used for this research is illustrated in appendix 1 and 2. The minimum score for any article to be considered for use in the research was 18, considering that 18 is half of the score for any articles and the maximum is 36. The authors of this paper conducted appraisals of the selected articles separately and average scores tallied.

Thematic analysis was applied in the analysis and synthesis of data in this research. Braun and Clarke (2006, 79) define thematic analysis as a method for

identifying, analysing and reporting patterns within data. The University of Auckland, School of Philosophy, (2006) indicates that the purpose of thematic analysis is to identify patterns of meaning across a dataset that provide an answer to your research question being addressed. It allows for rich detailed and complex description of data and is the most suitable data analysis method for novice researchers who are unfamiliar with the more complex methods of data analysis and synthesis.

University of Auckland, School of Philosophy (2016) point out that patterns are identified through rigorous process of data familiarisation, data coding, and theme development and revision. Besides, thematic analysis allows for flexibility in the researcher's choice of theoretical framework. The methods should be as transparent as possible in order increase the strength of one's findings and to allow the reader understand how the conclusions were arrived at. (University of Auckland, 2006.)

Thematic analysis can be an essentialist or realist method, which reports experiences, meanings and reality of participants, or it can be constructionist method, which examines the way in which events, realities, meanings, experiences and so on are the effects of a variety of speeches operating within society. It can also be a 'contextualise' way, sitting between the two poles of essentialism and constructionism, and categorized by theories such as critical realism. (Willig 1999, 37.) According to Braun and Clarke (2006, 79), thematic analysis follows six steps to ensure clarity and rigour in the process of data analysis and synthesis. These are: familiarizing oneself with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing a report of each theme with vivid examples. (Braun and Clarke, 2006, 79.) University of Auckland, School of Philosophy (2016) indicates

that one of the advantages of thematic analysis is that it is theoretically-flexible.

 Familiarizing oneself with the data by reading through • Also entails transcribing verbal data. **Reading Data** • Organize items describing similar topics into categories • Can be done using colored pens, highlighters, post-it notes **Generating Initial** or computers software (NVivo) Codes • Involves forming themes from the related codes. • Can be done using mind maps, tables or flash cards Searching for Results in a collection of themes and sub-themes Themes • Entails merging similar themes or breaking broad themes to form sub-themes. Reviewing • Data relating to each theme is re-examined for accuracy. Themes Themes are named based on the essence they capture. • The underlying meaning of each theme is taken into consideration. Defining & • Give reader a clue about the theme Naming Themes

Producing a Report

• A coherent, logical, non-repetitive and concise report that is interesting to the audience is written detailing each of the themes with illustrations and vivid examples.

Figure 3 The Process of Analysing data using Thematic Analysis

# **5 Results**

Analysis and synthesis of data from the selected articles for use in this study resulted in three main themes: nurses' challenges during care for patients and their families; positive and negative impact of family on patient's care and treatment; and open, trust, faith, acceptance and compassionate communication skills of a nurse.

Research Question	Themes	Sub-themes	
	Nurses' challenges	-Obstacles & difficulties	
	during care for	-Role mix	
	patients and their	-Cultural issues	
	families	-Inadequate nursing training.	
Nurses'	Positive and	-Accurate information to make	
experiences in	negative impact of	informed decisions.	
	family on patient's	-Ability/ inability to care for	
palliative care of	care and treatment	patient.	
cancer patients.		-Emotional outbursts (anger,	
		anxiety, distress)	
	Open, trust, faith,	-Compassionate communication	
	acceptance and	with dying patients.	
	compassionate	-Open communication with	
	communication	colleagues.	
	skills of a nurse.	-Communication of trust,	
		acceptance and faith with	
		patients' families.	

Table 3 Themes and sub-themes from selected articles

# Nurses' challenges during care for patients and their families

Nurses in a palliative care unit encounter numerous challenges on day-to-day basis. The challenges may arise from their patients, patients' families, physicians, and even from their colleagues. Obstacles regarding patients' families included family not accepting prognosis. Family and friends who continually call the nurse. Families not understanding consequences of aggressive treatment. Family not wanting the patient to be overly sedated. Dealing with anxious, overly optimistic, distraught, or angry family members. (Beckstrand, Collette, Callister, and Luthy 2012, 403.) They also feel inadequate and helpless in dealing with children and adolescents in the family and thus tended to exclude them from conversations and ongoing care of their parent. They felt the emotional involvement difficult to deal with. (Dunne, Sullivan and Kernohan 2005, 377.)

Nurses, too, develop emotions of feeling weakened, powerless, helpless, hopeless, frustrated, angry, distressed or guilty that they have failed patients (Ferrell 2006, 928). Nursing team professionals may be affected by the suffering of patients and their families hence patient's feelings affect to their own emotions. This may compromise the nursing care routines causing serious difficulties for the professionals such as depression. (Waleska, Silva, Pareira, Marcos, Marins, & Sauthier 2014, 73.) Such situations cause discomfort and distress which can cause detachment of the patient and family (Daronco, Rosanelli, Loro, Kolankiewicz 2014, 662.)

Attending to a dying patient can be one of the most nervous moment for a nurse. Studies indicate that more experienced nurses view death from a neutral or more positive perspective than the less experienced nurses. (Lange, Thom, & Kline 2008, 959.) Working with the dying and the bereaved can make nurses painfully aware of the losses in their own lives (Yin, Xia, Yi, & Chia 2007, 19.)

They also displayed a more positive attitude in caring for dying patients. Caring for dying patients requires viewing death from a neutral or escape perspective. This results in improved patient outcomes and satisfaction of patient, family and nurse providing the EOL care. (Lange, Thom, & Kline 2008, 959.) Eye contact is essential for the approach and establishing a bond and trust with patients (Daronco et al. 2014, 661).

Difficulties encountered by nurses in palliative care may include lack of preparation to cope with situations that reflect the complexity of human kind and death, lack of material and human resources, the absence of appropriate physical structure, so as to favour high quality individualized and humanized care (da Silva, de Santanda, Santos, Cirilo, Barrocas, & Moreira 2015, 462.) Caring for a person with no possibility of cure requires technical knowledge and expression of affection (Daronco et al. 2014, 659).

Culture is comprised of practised values, beliefs, forms of knowledge and ways of life that have been systematically structured and institutionalised (Huang et al. 2009, 3421). Accommodating and integrating various cultures into treatment can be difficult for nurses. Nevertheless, nurses must take into consideration the cultural beliefs of their patients during care and treatment. It is important that nurses understand culture and cultural mores, philosophy of cultural care, rely on their previous experiences with people from cultures different to their own and organisational approaches to culture and cultural care. (Huang, Yates, & Prior 2009, 3424.)

# Positive and negative impact of family on patient's care and treatment

Family members are part of the circle of care and attention, the instance that supports the maintenance of patient and that is directly involved in the care process (Daronco et al. 2014, 661). Nurses consider family members' presence essential, independently of whether they may represent a greater demand for work (da Silva and da Silva Lama 2014, 16).

EOL care satisfaction is associated closely with how the family perceive quality of communication from healthcare team. Families want timely and accurate information to make informed decisions. (Beckstrand et al. 2012, 399.) Family members must take the role of carer as many of them want to spend whatever time is left caring for their loved one (Dunne et al. 2005, 377). When family members do not receive proper orientations then inserted in the context of palliative care, their presence negatively affects care for the patient, as their lack of knowledge and emotional breakdown can cause anxiety, conflicts and a feeling of helplessness (da Silva and da Silva Lama 2014, 17).

Family members' interest in giving care contributes to the survey of patient information and represents an opportunity for training in view of the possibility of homecare. Participating relatives are allies of the nursing team, providing information or support in care actions, which changes the dynamics of teamwork in the distribution of staff members. Presence of family members may have negative interferences though such as family members refusing to participate in the care, deny the incurable disease, have knowledge deficit about palliative care, have no aptitude for care, have no emotional balance, having no time available, and, or being elderly or suffering from other illnesses. (da Silva, & da Silva Lima 2014, 15-19.)

Such negative attitudes represent challenges for the nurse and other team members who need to act effectively to clarify doubts and encourage positive attitude. Strategy to develop family members' skills for home care should be encouraged as one of the main difficulties is the feeling of helplessness in the experience of cancer. The nurses should aim to identify family members' needs and to attend to them. This helps establish a partnership based on a relationship of trust. (da Silva, & da Silva Lima 2014, 15-19.)

# Open, trust, faith, acceptance and compassionate communication skills of a nurse.

Palliative care is designed to give patients peaceful and dignified death. For this goal to be achieved there must be effective communication between the nurse in charge of the patient and other stakeholders such as the patient receiving care, the patient's family, colleagues, the physician and any others persons of interest such as the clergy or authorities. However, the communication process is intricate and the sensitive nature of the communication cannot be ignored (Dunne, Sullivan and Kernohan 2005, 376).

Nurses feel that if they can meet the patient from as early as when diagnosis is made then if a problem arises during later stages of the disease then they will have known the patient and family well thus will find an easy way to discuss patient's situation with them. Nurses propose that there should be one designated person responsible for the overall care of the patient. That way it becomes easier to make a follow up and update on the progress in care of the patient and all persons involved. (Dunne et al. 2005, 376-377.) A broader understanding of the situation is needed, with a view to avoiding unfounded prejudgements, as most cases relate to complex life histories, with developments in all spheres, i.e. emotional, spiritual and cultural (da Silva and da Silva Lama 2014, 17).

Findings illustrated that nurses, for whatever reason, had difficulty communicating effectively with dying patients because they feel awkward talking to patients who are dying as some nurses cannot contain the emotional stress of seeing dying patients. Nurses also find difficulty dealing with the

emotional reactions of the family. Nurses tend to distance themselves from angry outburst as most of them interpret anger as a personal criticism of themselves. (Dunne et al. 2005, 376-377.) Traditionally, patients' preferences regarding EOL have been communicated via advanced directives which have not always been effectively communicated to healthcare team. Life-sustaining treatment seeks to clarify and solidify wishes already expressed in a living will. (Beckstrand et al. 2012, 405.)

Nurses also find difficulty disclosing information to dying patients. Sometimes nurses find themselves in dilemma in situations where the patient and family both give controversial information. In palliative care, nurses may find difficulty telling the truth. The family may collude with the nurse to hide the truth from the patient, whereas the patient may at times demand to know the truth. In such situations, nurses must be aware of the risks of telling the truth as well as the harm that can be done by lying to the patient. (Dunne et al. 2005, 376-377.)

#### What is already known about this topic

- Nurses have an important role in the provision of palliative care to patients with life limiting illnesses.
- Palliative care nurses perceive their role as minimising pain and suffering of terminally-ill patients through symptom management and holistic nursing approach.

#### What this research adds

- The quality of palliative care for dying cancer patients can be improved by offering maximum support to nurses in their delivery of care by assessing their concerns and finding solutions to difficult encounters during practice.
- Family has great influence on the approach of care for the patient and as such deserve to receive accurate information so as to make right decisions.

- Communication between healthcare professionals, patients and their families should be enhanced to create elevate trust and respect between the nurses and patients alongside their families.
- Ethical issues in palliative care need to be taken into consideration to protect nurses from dilemmas that could compromise on the quality of palliative care for the patient.

Table 3 Contributions of the study to the existing literature

#### 6 Discussion

#### 6.1 Discussion of Main Results

#### **Analysis**

Previous studies conducted to address this research topic have made tremendous input towards creating a safer and more comfortable environment for patients with life limiting illnesses. Results obtained in the study were from selected articles (N=12). However, all other articles used in the introduction and background of the study indicated similar findings as the selected articles. All articles emphasized on the need to address the persisting challenges in palliative care so as to have an improved care. There was no contrasting information obtained from all other articles on palliative care for cancer patients. This study sought to add to the already existing knowledge the essence of assessing nurses' concerns so that they feel secure at work and have greater satisfaction of their work.

The study identified three themes: nurses' challenges in provision of palliative care, positive and negative impact of family on patient's care and treatment and open, trust, faith, acceptance and compassionate communication skills of a nurse. These themes were familiar and mentioned across all the articles used in the study. Data collected from qualitative (n=7) and quantitative (n=5) indicated that nurses' challenges always came first whenever asked about their experiences or perceptions. They would also point out the aspect of communication during care and the aspect of family in care of patients among other issues that vary among individuals such as ethics in palliative care.

#### Limitations

This study focused on the experiences of nurses providing palliative care for only cancer patients while excluding other terminal illnesses. However, the findings of this study are transferrable to other terminal illnesses other than cancer since the objective of palliative care is same for all other diseases i.e. giving a comfortable and dignified life to patients in their final phase of the illness. The decision to limit the study on nurse's experiences while excluding other participants in palliative care portrays a result that is not all-inclusive hence the full picture of palliative care is not depicted.

Additionally, articles for use in this research were limited to the available information databases while excluding other pay-to-access databases. This is because the study received no funding and as such any incurrences in cost were avoided. Nevertheless, the findings of this study will contribute in a great way towards improving palliative care for dying patients. They may be used by the management and policy makers in formulating policies that could guide the palliative care team. Findings of this research are applicable in any context or country as the research was under no geographic restrictions.

#### Conclusions

Analysis of data from selected articles of this research led to the conclusion that nurses' input in palliative care is valueless. Nurses' experiences on palliative care indicate that it indeed demanding not only for the care givers but also for the family. Offering the necessary support to nurses contributes greatly towards realizing improved quality of palliative care. The communication web for all participants in palliative care needs to be boosted. Open communication helps to minimize on confusion, misunderstanding and role mix. Family should feel appreciated for their input during care and should be motivated so that they can contribute more in care of patients. Ethical issues in palliative care need to be taught widely and exhaustively to nurses with respect to any changes over time so that nurses are updated and capable of mitigating challenges resulting from ethical dilemmas.

## 6.2 Implications to Nursing Practice and Healthcare

The quality of palliative care offered to patients determines their quality of life and their eventual death. Nurses play an integral role in offering care to terminally ill patients and as such a study on their experiences helps a lot in determining the nature of care through formation of appropriate policies and guidelines to improve on the quality of palliative care. It is crucial that nurses' concerns during work practice are fully addressed so that they can have more job satisfaction and reduced stress hence they become more effective in their practice. This points to the responsibility of the management in healthcare to create a safe working environment for nurses and other professionals so as to enable them realize the goals of their care practice.

Nurses need to bond well with patients and their families right from the time prognosis is made to avoid or minimize conflicts during care. Among the positive aspects, the nurses indicate as contributions to the valuation of the relatives' presence in the context, the following stood out: commitment, participation in care, orientation with regard to palliative care, good relationship with the hospitalized patient, as well as with the nursing team (da Silva, and da Silva Lama 2014, 16). This implies that the influence of family in care should be emphasized at school and during their practice so that nurses can fully comprehend.

Open communication is essential as it strives to build a relationship of trust between the nurse and the patients and their families. The importance of communication should be emphasized to all nurses so that they get to understand fully. Nurses need adequate knowledge on the possible dilemmas to expect in palliative care and how to react so as not to jeopardize the care of their patients. Medical futility and the moral distress experienced by nurses are likely to remain important concerns amidst the technological advances in care

and many cultural and emotional issues surrounding decision making (Ferrell 2006, 929). Patients' culture has to always be factored during care plans. Respect, cultural awareness and sensitivity are recognised as important attributes in providing cultural care (Huang et al. 2009, 3424). This calls for a review of their curriculum to suit the present challenges at the work practice. It is the opinion of the authors of this paper that the quality of palliative care can be improved should the aforementioned factors taken into consideration and implemented accordingly.

#### 6.3 Ethical Considerations

#### **Research Misconduct**

Researchers are always reminded to abstain from any form of research misconduct during research such as fabrication, falsification, plagiarism and bias of information. U.S. Department of Human and Health Services, Office of Research Integrity (2016) defines research misconduct as fabrication, falsification, or plagiarism in proposing, performing or reviewing research, or in reporting research results. Fabrication entails concocting data or results and recording or reporting them (Horner and Minifie 2011, 348). Falsification is defined by the Office of Research Integrity (2016) as manipulating research materials, equipment or processes, or altering data or results such that the research is inaccurately represented. Plagiarism is defined by the Office of Research Integrity (2016) as the use of another person's ideas, processes, results, or words without giving appropriate credit. The results and recommendations published in research work are heavily relied upon by many people who believe the information as whole truths. This could be catastrophic if the information availed to the public by a research is false or could cause potential harm.

#### Risk of Bias

Bias in research may not be eliminated, however, the awareness of which enables the researcher to implement strategies throughout the research process that will minimize the risk of research bias as much as possible hence better reliability and validity of research findings. (Malone, Nicholl, and Tracy 2014, 279.) Some of the unavoidable bias in this research include selection bias, language bias, availability bias and cost bias. Articles selected for use in this research were obtained from information databases accessible to students of Jamk. Databases to which permission is not granted for access could not be used to obtain articles. This in part contributes to unavoidable selection bias. Language bias in this research resulted from the fact that articles used in this research were strictly in English as this is the only language common to both the supervisors and researchers of this study. Availability bias exists in this research since only articles with full text were used. All other articles without full text were omitted. This research is not funded. Researchers bear the full responsibility to come up with credible information using articles from the available information databases. This subjects the research to cost bias as relevant articles from pay-to-access databases were left out.

### **Integrity**

It is in the spirit of allegiance to abide by the set ethical considerations and minimisation of risk of bias that this research was conducted to be of relevance to the healthcare sector. The results published in this research are a true representation of information condensed from the selected articles for use in this research. All text that has been used in this article and does not originate from the authors of this literature has been properly referenced (both in-text citation and list of references) and due credit given to the original authors of the information. Articles used to generate results for this literature review are current (2005-2016) and scientific evidence-based. Assurance is hereby given to

readers that the information herein is safe and credible. All necessary ethical issues regarding research work were taken into consideration to produce reliable information.

## 6.4 Validity and reliability

The information used in the research was obtained from CINAHL information database, PubMed as well as Elsevier Science Direct. These three databases give credible and scientific evidence based information. CINAHL (Ebsco) is an online information database in Jamk's website: www.jamk.fi. The database is made accessible to the students as source of information for their studies. Moreover, so as PubMed and Elsevier Science Direct are also an information database made available on the internet courtesy of Jamk corporation, student have access to during research. The information in this research was obtained from current evidence-based scientific articles ranging from years 2005 to 2016. The selection of articles for use in this research was done based on a predetermined inclusion and exclusion criteria. The criteria have been stated in section 4,2 of this article. This implies that the information herein is not only valid but also reliable. The area of study, that is, palliative care in cancer patients has been and still is of tremendous importance in healthcare. Palliative care has been offered over the years, not only for cancer but also many other diseases, and continues to date.

The aim of the study was to come up with ways to improve the quality of palliative care for dying cancer patients. The information availed by this research is suitable and valid for use by healthcare students, teachers and healthcare professionals as it has been well researched and thought out.

#### 6.5 Recommendations

The findings of this study indicate that palliative care is indeed a daunting task not only for the healthcare professionals but also the affected family. The study suggests that effective palliative care is achievable if nurses' challenges are minimised and more supportive behaviour accorded them. An effective palliative care ensures a more comfortable and dignified death for terminally ill patients. The focus of palliative care is the multidisciplinary work with taking attitudes to the reality of human finitude, seeking to meet the human being as a whole to be in the final stages of life (Daronco et al. 2014, 658).

Culture plays a major role in patients' perception of the whole treatment process. Nurses should be trained to be accommodative of all cultures and to integrate into care plan to gain trust and respect from the patients and family. Healthcare providers must re-examine their own values and assumptions to meet the challenges emerging from cultural diversity (Huang et al. 2009, 3424). Being disrespectful to a patient's culture not only ruins the nurse-patient relationship but also hinders the treatment and recovery of the patient. Some nurses described culture as a norm that would dictate the ways people lived, the decisions people made, as well as people's perceptions, attitudes, behaviours, values, and belief systems (Huang et al. 2009, 3423).

Alleviating the suffering of patients in the final stage of life is necessary (Daronco et al. 2014, 660). Palliative care for patients with cancer pain is based on the needs of the patient, and should involve more than attention only to physical pains (Naimeh et al. 73). Nurses ability to effectively relieve cancer patients from pain is a great relief. Besides use of opioids, nurses need to be able to relieve patients from emotional and psychological pain. This is achievable through open communication with patients and being a listener to them. The

care of the pain and suffering is essential in order to restore the dignity of the human being (Daronco et al. 2014, 660).

There is need to review the nursing curriculum so that they are well equipped intellectually to handle palliative care in respect to technological advances and changing cultures experienced with current generation require more skill and attention to effectively attend to patients as well as their families. It is necessary that nurses have knowledge and training about implementation of this modality of care (Daronco et al. 2014, 657-658). The goals of implementing an educational programme regarding care of dying patients aim to foster more positive attitude in younger and less experienced nurses by giving them a strong background in palliative care and coping skills, thus equipping them with higher competence in palliative care, and getting them understand and get used to EOL scenarios they will encounter in the oncology population (Lange et al. 2008, 959).

The death of patients can raise negative feelings and suffering to the healthcare professionals. Professionals are advised not to show such emotions (Daronco et al. 2014, 662). This may compromise their care of immediate subsequent terminal patients. Nurses also need to have the stamina to offer emotional support to grieving and anxious family members as this is part of their role. It is considered important that professionals who care for patients beyond therapeutic possibilities receive emotional support to better cope with their anxieties and limitations in care practice (Daronco et al. 2014, 662).

Communication is an extremely important tool in the care process, especially when it comes to terminal patients, to strengthen the bond between patient/ professional, encourage the patient to verbalize anxieties, worries and doubts about the clinical situation, to give opportunity to the patient/ family to

verbalize preferences in attendance and help them in decision making (Daronco et al. 2014, 661). According to Boyd and colleagues, missed opportunities for discussions on end-of-life with patients and their families should be eliminated so that care decisions can be based on better wider consultation. Nurses should be enabled to have a stronger voice. Effective strategies promote EOL discussions leading to appropriate but less aggressive care. (Boyd, Merkh, Rutledge, & Randall 2011, 237.)

The encouragement of family members' presence during admission of a patient to hospital aims to help the patient feel safe and comfortable da Silva and da Silva Lama 2014, 16). A right attitude will help in delivery of effective palliative care. It is, however, important that nurses respect the views of their patients while trying to clarify areas of misunderstanding. Considering family member's participation in palliative care, based on how nurses perceive their presence, the person's behaviour changes in support of the professionals allowing them to identify adaptive or inefficient responses (da Silva and da Silva Lama 2014, 17).

Patients receiving palliative care require a considerably huge amount of attention from the care givers and family as well. Nurses not only attend to the symptom management but offer holistic care to both the patient and family. The family is treated as a patient because of the emotional distress they go through caring for a terminally ill patient who is in final trajectory of an illness. Palliative care nurses are required to be adequately trained on care for dying patients and their families.

Nurses need emotional support from colleagues and other healthcare professionals involved to overcome the distress during care for dying patients.

This can be in the form of hugs or words of encouragement as well as being relieved shortly before taking on the next patient.

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# Appendices

## **Appendix 1. Summary of the Selected Articles**

No.	Author(s),	Title	Aim(s) and Purpose	Participant,	Data collection	Key	Critical
	Year,			Sample size	and Analysis	results	Appraisal
	Country						(Hawker
							et al. 2002,
							1284-1289).
01	Dunne, K.,	Palliative care	Exploring district	25 female	Unstructured	The	32
	Sullivan, K.,	for patients	nurses' experiences of	district	tape recorded	Communic	
	& Kernohan,	with cancer:	providing palliative care	nurses	interviews,	ation web;	
	G. 2005. UK	district nurses'	for patients with cancer		Husserlian	The family	
		experiences.	and their families.		phenomenologi	as an	
					cal approach.	element of	
						care;	
						challenges	
						of the	
						district	
						nurse in	

						symptom	
						manageme	
						nt and the	
						personal	
						cost of	
						caring.	
02	Boyd, D.,	Nurses'	To characterize	31 oncology	Nurses	Missed	29
	Merkh, K.,	perceptions	oncology nurses'	nurses	completed the	opportunit	
	Rutledge	and	attitude towards care at		adapted version	ies may	
	D.D.,	experiences	the end of life (EOL) and		of the Curing	reflect	
	Randall, V.	with end of life	their experiences in		for Terminally	nurses'	
	2011.	communication	caring for terminally ill		Ill Patients	attitude.	
	St. Joseph	and care.	patients, hospice		Nursing Survey.	Lack of	
	Hospital,		discussion with patients			patients	
	Orange, CA.		and families, and the			and family	
	USA.		use of palliative care			member	
			practices			acceptance	
						was the	

						most	
						important	
						barrier to	
						discussion	
						of hospice.	
03	Huang, Y.L.,	Factors	Explore the social	7 oncology	Semi-structured	Nurses'	27
	Yates, P.,	influencing	construction of cultural	nurses	interview and	would	
	Prior, D.	oncology	issues in palliative care		grounded	accommod	
	2009.	nurses'	amongst oncology		theory data	ate cultural	
	Taiwan &	approaches to	nurses		analysis	need.	
	China.	accommodatin			techniques.	Factors	
		g culture needs				include	
		in palliative				nurses'	
		care.				views and	
						understan	
						dings of	
						culture	
						and	

			cultural	
			mores,	
			their	
			philosoph	
			y of	
			cultural	
			care,	
			nurses'	
			previous	
			experience	
			s with	
			people	
			from other	
			cultures	
			and	
			organisatio	
			n	
			approache	

						s to culture	
						and	
						cultural	
						care.	
04	Seyedfatemi,	Iranian nurses'	To identify Iranian	15 nurses	Semi-structured	Palliative	31
	N.,	perceptions of	nurses' perceptions of	with	interviews.	care for	
	Borimnejad,	palliative care	palliative care for	bachelor	Transcripts of	patients	
	L., Mardani,	for patients	patients with cancer	degrees	the interview	with	
	H.M., &	with cancer	pain.		underwent	cancer	
	Tahmasebi,	pain.			content analysis.	pain must	
	M. 2014.					include	
	Iran.					psychologi	
						cal	
						empower	
						ment,	
						support,	
						and	
						communic	

						ation as	
						well as	
						physical	
						pain relief.	
05	Daronco, V.	Palliative care	Recognizing the	5 nursing	Qualitative,	Through of	26
	F., Schmid	to cancer	perceptions of a nursing	staff	Descriptive and	nursing	
	P. R., Cleci	patient;	team regarding	workers	Exploratory	technique,	
	L., Loro,	perception of a	palliative care to cancer	participated	Study.	conversati	
	M.M.,	nursing team	patients and identify the			ons with	
	Bernat, K., &		care implemented.			patient,	
	Adriane C.					listens to	
	2015.					patient,	
	Brazil.					attention	
						to family,	
						emotional	
						support.	
						These	
						cares	

						targeted to	
						provide	
						quality of	
						life,	
						comfort,	
						pain	
						control	
						and	
						dignified	
						death.	
06	Da Silva, M.	Participation of	To understand the	17 nurses	Descriptive and	The results	25
	M., & Da	family in	perspective of nurses		quantitative	contribute	
	Silva L.L.	hospital-based	about participation of		research.	to promote	
	2014.	palliative care;	family in palliative		Element of Roy	the family	
	Brazil.	perspective of	cancer care and to		Adaptation	adaptation	
		nurses	analyse the nursing		Model used for	and	
			strategies to meet their		the	integrity,	
			needs.		interpretation of	in order to	

		the data. Two	balance the
		categories of	dependent
		thematic	and
		analysis	independe
			nt
			behaviours
			, aiming
			for quality
			of life
			comfort.
			Further
			studies are
			needed
			due to the
			challenges
			of the
			specialty.

07	Waleska,	Nursing team	To understand the	21 nurses	The technique	Comfort	33
	C.B., da	perception of	perception of nursing	from a	of open	measures	
	Silva, P.,	oncological	team members of the	private	interviews was	constitute	
	Andrade,	palliative care:	palliative care in	cancer care	used.	the	
	R.M.C.R.,	a	oncology from the	institution.		foundation	
	Silva, E.R.P.,	phenomenologi	phenomenological			s for	
	Marcos,	cal study	perspective of Mauric-			excellent,	
	A.S., da		Ponty. To indicate the			humanize	
	Fonseca,		implications of this			d care.	
	A.M.M., &		perception for nursing			Value the	
	Marta, S.		practice.			humanity	
	2014.					of patients	
	Brazil					through	
						actions	
						aimed at	
						the	
						humanizat	
						ion of	

						health	
						practices.	
08	Backstrand,	Oncology	To determine the impact	1005	A 69-item	Quality	35
	R.L.,	nurses'	of obstacles and	oncology	mailing survey	care,	
	Collette, J.,	obstacle and	supportive behaviours	nurses who		facility to	
	Callister, L.,	supportive	in end-of-life (EOL) care	has		give	
	Luthy, K.E.	behaviour in	as perceived by	provided		nurses	
	2012.	end of life care;	hospital-based oncology	EOL care.		more time	
	USA.	providing vital	nurses.			to support	
		family care.				the patient	
						and	
						family.	

09	Lange, M.,	Assessing	To assess how nurses	355	Descriptive	Increased	25
	Thomas, B.,	nurses' attitude	employed in a	impatient	quantitative.	education,	
	Kline, N.E.	towards death	comprehensive cancer	and	Voluntary and	training,	
	2008.	and caring for	feel about death and	outpatient	anonymous	and	
	New York,	dying patients	caring for dying patients	oncology	completion of	exposure	
	USA.	in a	and examine any	nurses.	Frommelt	to	
		comprehensive	relationships between		Attitude	providing	
		cancer centre	their attitudes and		Towards Dying	and coping	
			demographic factors.		(FATCOD), the	effectively	
					Death Attitude	with end-	
					Profile Reversed	of-life care.	
					(DAP-R) and a		
					demographic		
					questionnaire.		

10	Yin, O.S.,	Nurses'	Explore the attitudes of	122	Structured	Shows that	35
	Xia, Z., Yi,	perceptions	nurses towards the	registered	questionnaire.	future in-	
	X., Chia,	towards caring	dying patients in the	nurses.	Using SPSS 11.5.	house	
	D.T.	for dying	medical oncology ward		the association	training	
	2007.	patients in	and general surgical		between	plans	
	Singapore.	oncology ward	ward.		demographic	could be	
		and surgical			variable and the	initiated to	
		ward.			various level of	provide a	
					nurses' personal	greater	
					emotions were	understan	
					assessed using	ding about	
					CH-	the care for	
					Square/Fisher's	dying	
					Exact test.	patients.	
11	Pavlish, C.,	Oncology	To explore oncology	33 oncology	Research	Teaching,	23
	Ceronsky, L.	nurses'	nurses' perspectives of	nurses in	inductively	caring,	
	2009.	perceptions of	palliative care through	three	coded research	coordinati	
	USA	nursing role	narrative analysis of		text within each	ng,	

		and	participants' description	medical	focus group	advocating	
		professional	of life experience. Study	centres.	sessions using	, clinical	
		attributes in	nurses' perception of		Atlas.ti 5.2	expertise,	
		palliative care	their role in palliative		software and	honesty,	
			care offers an		apply	family	
			opportunity to examine		categorical-	orientation	
			and improve clinical		content	,	
			practice.		narrative	perceptive	
					analysis	attentivene	
						ss,	
						presence,	
						collaborati	
						on and	
						deliberaten	
						ess.	
12	da Silva,	Palliative care	To identify the	13 nurses	Interview and	Lack of	34
	M.M., de	in highly	difficulties faced up to		applying of	knowledge	
	Santanda,	complex	provide care for people		thematic	in	

N.G.M.,	oncology care:	hospitalized in the	analysis to the	palliative	
Santos,	perceptions of	context of palliative care	data.	care, the	
M.C.,	nurses.	in high complexity	Qualitative	necessary	
Barrocas,		oncology care centre at	approach was	creation of	
J.D.C.D.L.R.,		Rio de Janeiro State	used.	differentiat	
& Morelra,		according to nurses'		ed beds,	
M.C.		perception, and discuss		creation of	
2015.		strategies to better		institution	
Brazil.		quality nursing care in		al network.	
		this context.			

**Appendix 2: Summary of Critical Appraisal Scores** 

	Francis' Score	Rogers' Score	Average
Article 1	34	30	32
Article 2	29	29	29
Article 3	26	28	27
Article 4	30	32	31
Article 5	26	26	26
Article 6	25	25	25
Article 7	34	32	33
Article 8	36	34	35
Article 9	25	25	25
Article 10	34	36	35
Article 11	23	23	23
Article 12	35	33	34
Average	29,75	29,41	29,58