

# **The role of a nurse in patient-centered approach in palliative care A literature review**

**Winnie Kyamulabi**

**Magdaline Nyairo**

**Elizabeth Kiama**

Degree Thesis  
Degree Programme in Nursing  
2021

DEGREE THESIS	
Arcada University of Applied science	
Degree Programme:	Bachelor's degree in Nursing
Identification number:	24813, 24817, 23000
Author:	Winnie Kyamulabi, Magdaline Nyairo, Elizabeth Kiama
Title:	The role of a nurse in patient centered approach in palliative care- a literature review
Supervisor (Arcada):	Lotta Eronen
Commissioned by:	
<p><b>Abstract:</b></p> <p>The aim of the study was to investigate and discuss patient-centered approach in palliative care. This study explores the benefits of patient centered approach in palliative care, the challenges faced during the implementation and possible solutions to the challenges thereby posing three research questions as i) Importance of patient- centered approach. ii) the challenges nurses face in implementing patient centered palliative care and iii) how these challenges are mitigated?</p> <p>Qualitative literature review was performed to answer the three above research questions. Research was conducted form different online research databases; PubMed, Google scholar, Science Direct and EBSCO. Inclusion and exclusion criteria were applied in which the published period range was from 2000 to date. The research was globally done, and the language of the articles was restricted to English, peer reviewed with full text and free accessibility. Inductive and deductive process of reading through the texts of the 30 chosen articles was used in content analysis.</p> <p>Jean Watson theory of human caring was used to demonstrate the nursing practices applied in the caring process by nurses to mediate compassion and develop helping -trusting relationships to ease suffering in palliative patients and their families. The findings revealed the integral role of nursing care process in palliative care and through nursing competencies patient-centeredness is achieved in part by understanding patients experiences with illness as well as understanding patients holistically resulting better health outcomes and patient satisfaction. However, some of the challenges nurses engaging in palliative care face include lack of advanced competencies, insufficient communication skills to effectively address individual needs in the continuum of care and restrictive policies that limit pain medication administration. The general recommendations in mitigating these challenges include continuous training programmes and advocating for policies that support pharmaceutical and non-pharmaceutical interventions.</p>	
Keywords:	Nurse-patient relationship, nurse competences, palliative care, patient-centered care
Number of pages:	49
Language:	English
Date of acceptance:	

## CONTENTS

<b>1</b>	<b>INTRODUCTION .....</b>	<b>6</b>
<b>2</b>	<b>BACKGROUND .....</b>	<b>8</b>
2.1	Definition and concept.....	8
2.2	The modern hospice.....	8
2.3	Who needs palliative care?.....	11
2.4	Trajectory of illness/ dying.....	11
2.4.1	The Sudden death .....	13
2.4.2	The Terminally ill.....	13
2.4.3	The Organ failure.....	14
2.4.4	The frailty .....	14
<b>3</b>	<b>THEORETICAL FRAMEWORK.....</b>	<b>15</b>
3.1	Conceptual Elements .....	17
3.2	Assumptions. ....	17
3.3	Integrating Watson’s human theory into patient-centered palliative care .....	18
<b>4</b>	<b>AIM AND OBJECTIVE OF THE STUDY .....</b>	<b>21</b>
<b>5</b>	<b>METHODOLOGY .....</b>	<b>22</b>
5.1	Data collection.....	22
5.2	List of Articles Chosen .....	24
5.3	Content analysis.....	27
5.3.1	Reading and coding. ....	28
5.3.2	Listing and categorizing.....	28
5.3.3	Emerging themes and sub-themes from collected categories .....	29
5.4	Research ethics .....	29
<b>6</b>	<b>FINDINGS .....</b>	<b>30</b>
6.1	Importance of patient-centered approach in palliative care .....	30
6.1.1	Nurse’s role .....	31
6.1.2	Patient/family centered .....	32
6.2	Challenges nurses face in providing patient-centered care.....	33

6.2.1	Nurse's Role .....	33
6.2.2	Patient/family centered .....	35
6.3	How nurses mitigate the challenges faced in Patient-centered care .....	36
6.3.1	Nurse's Role .....	36
6.3.2	Patient/Family Centered.....	37
<b>7</b>	<b>DISCUSSION.....</b>	<b>39</b>
7.1	Limitations .....	43
<b>8</b>	<b>CONCLUSION .....</b>	<b>43</b>
	<b>REFERENCES .....</b>	<b>45</b>

**FIGURES**

Figure 1 Theoretical Trajectories of Dying ..... 12

Figure 2 Carative Factors ..... 18

Figure 3 Illustration of the data collection process ..... 23

**TABLES**

Table 1 Inclusion and Exclusion criteria of the study ..... 22

Table 2 illustration of the emerging themes and sub-themes categories ..... 29

# 1 INTRODUCTION

World Health Organization (WHO) noted about 40 million people require palliative care each year, 78% of this figure live in low and middle wage economies, however barely 14% of the people that require palliative care have received it. In response, World Health Assembly resolution, WHA 67.19 agenda item organized the first global resolution on palliative and during this conference.

WHO and member states were mandated with improving accessibility to palliative care as an essential constitute of health systems, with a principal focus on primary health care and community/home-based care (WHO 2019). Consequently, the number of patients with life-threatening illnesses who need palliative care will continue to increase.

These patients may battle with progressive losses, increased disability, and often challenging symptoms. As the illness advance, patient may need to depend upon others for care and worries arise about the value of the past and the future ahead. Besides, thoughts of social isolation and concerns about how their family will cope with their illness and death are almost inevitable.

In palliative care context, there may not always be a second chance to get things right and the work of bereavement support begins not after the patient has died, but at the point of first contact. Hence, it is important to focus on all the possibilities amidst many losses, patient and family pursuit of meaning and sustain their experience of connectedness as they adapt to the challenges around them by ensuring they are consoled by the knowledge that their loved ones are well cared for, and that they themselves have the opportunity to be heard and understood (Fallon & Hanks, 2013, Sherman, D.W, 2010).

The provision of palliative care of high quality includes relieving the patients 'pain 'total pain' and increasing their quality of life, established on the holistic view that suffering is physical, psychosocial and spiritual (WHO, 2000). Consequently, to understand an individual person's care needs, it is important to allow them to identify their own priorities irrespective of similarities in the needs of other clients related to the type of illness in the trajectory.

Palliative care is characterized by personalized holistic models of care delivered cautiously both ethically and therapeutically through comprehensive skilled communication, meticulous assessment, and evolving knowledge. On this account, a multi-

professional approach is emphasized, within which nurses have a critical role, routinely being in continuous close contact with patients. The most important aspect of care the nurse as caregiver brings to the patient is the quality of presence in which, an opportunity and space are generated to discern and address personal issues, pain and suffering experienced by family members through a relationship based on mutual trust and respect between the nurse and the patient (Fallon & Hanks, 2013, Mok & Chiu, 2014).

The goal of this thesis was to establish the importance of patient-centered approach in palliative care. This concept has progressively been regarded as crucial for the delivery of high-quality care by scholars such as Jean Watson and Katie Eriksson, who advocate for *caritas* as an aspect of nursing practice. (Meehan, 2012) states that *caritas* is the nurses' experience and expression of love for patients and others as the benevolent affection of one human person for another that flows through nurses' inner awareness. This study elucidates the significance and impact of these practices on palliative care throughout the phases and trajectories of patients' illnesses. The authors used qualitative literature review to critically analysis the articles. The study explored the importance and challenges that nurses face in implementing patient-centered palliative care. In addition, it sought to find ways to mitigates these challenges.

In a nutshell, the introduction chapter briefly presents the concept of the research study. The background chapter defines palliative care concepts, goals, the philosophy, and the trajectory of illness/dying. The theoretical framework chapter reflects on Jean Watson theory of human caring. The aim and the objective chapter discuss, the goal of the research and research questions used to investigate and discuss the study. The methodology chapter lays out the data collection method used for the study and the content analysis. The results are summarized in findings chapter and in the discussion chapter, the results are clarified in detail and possible recommendations presented. The conclusion chapter summaries the study and presents the limitations and strengths of the study.

## **2 BACKGROUND**

### **2.1 Definition and concept**

The word palliative derives from the Latin pallium, meaning cloak – reflected in the Middle Eastern blessing, ‘may you be wrapped in tenderness, you my brother, as in a cloak’. The original meaning of the word ‘hospice’ was derived from earlier pilgrimages, meaning ‘a resting place for weary travelers’ (Stevens, Jackson& Milligan,2009). According to Hudson, (2014) palliation in the context of palliative care means ‘to cover the person and their family with a protective cloak of care including personalized attention to thoroughly assessed physical, spiritual, psychological, and emotional needs’. Furthermore, Palliative care is defined as interdisciplinary care that aims to improve quality of life for patients living with any serious illness, and their families; ideally, it begins at diagnosis and is provided concordantly with other disease-directed treatments (Kelley& Morrison, 2015).

According to the Global Atlas of Palliative Care,(2020) published by The World Hospice Palliative Care Alliance (WHPCA): worldwide, over 56.8 million people are estimated to require palliative care every year including 31.1 million prior to and 25.7 million near the end of life. The majority (67.1%) are adults over 50 years old and at least 7% are children. The majority (54.2%) are non-decedents who need palliative care prior to their last year of life.

### **2.2 The modern hospice**

Modern palliative care, developed by Balford Mount, from the hospice philosophy is embedded in the hospice philosophy attributed highly to the great work of Cicely Saunders (1918-2005) Doctor, nurse, and social worker as pioneer and founder of St, Christopher’s which is recognized today as the model for the modern hospice movement. (Stevens, Jackson& Milligan 2009)

This philosophy focused on the quality, rather than length of life during the course of a disease (Randall and Downie 2006) and aimed to achieve a better quality of life and bet-



ter conditions for the dying by providing holistic care for patients and their relatives (Stewart et al 1999)

Furthermore, Cicely Saunders devised the Concept of 'total pain' through palliative patient pain experience by interactions and meticulous record keeping concluding that physical, spiritual, and psychological pain can be interwoven this way putting the whole person at the center of care to achieve optimal pain relief (Mehta & Chan 2008). This concept is embedded today in WHO's 2002 definition of palliative care as a global concept to include all patients with life-threatening diseases, rather than cancer alone (Sepúlveda et al. 2002). In 2002, the World Health Organization published a revised definition which stated that '*palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems physical, psychosocial, and spiritual*' (WHO,2002).

The primary components of palliative care focus on the symptom management for example pain, nausea, vomiting, and dyspnea etc. The nurse assesses and treats psychological symptoms like anxiety depression and delirium as physical symptoms bearing in mind psychosocial and spiritual needs of the patient (W.H.O 2016). The treatment improves quality of life of the patient and raise physical and cognitive function throughout the illness through pharmacological or non-pharmacological treatment and considering values and needs of the patient (W.H.O 2016).

The Lancet Commission on Global Access to Palliative Care and Pain Relief report challenged WHO 2002 definition of palliative care, as it drives to ensure that the definition 'encompass health-system advances and low-income settings where medical professionals often have the difficult task of caring for patients without necessary medicines, equipment, or training' (Knaul, 2018).

Following the recommendations of the Lancet commission in formal relation with WHO, the international association of hospices and palliative (IAHPC) defined palliative care as '*the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life. It*

*aims to improve the quality of life of patients, their families, and their caregivers'* (IAHPC,2019).

### **Holistic care**

The various definitions of palliative care are framed around holistic care of persons across all ages and is supported by different organizations namely, WHO 2002 principles of palliative care, IAHPC definition framework, and WHPCA. In addition, holistic care considers the whole person physically, psychologically, socially, and spiritually with the aim of achieving the best possible health outcomes. According to (Ventegodt, Kandel, Ervin & Merrick, 2016), holistic healthcare is a comprehensive care that considers the 'whole' person's needs, the reaction and effect of the illness on the ability to function and attend to individual needs. The ideology behind holistic care motivates for a patient-centered approach in palliative.

### **Patient-centered care**

Therefore, Patient-centered care in healthcare is defined as care provision that is consistent with the values, needs, and desires of patients and is achieved when clinicians involve patients in healthcare discussions and decisions (Mead and Bower,2000).

The WHO guide for programme managers, *Planning and implementing palliative care services*, WHO came up with one of the first global resolution on palliative care for the member states to develop and create access to palliative care for everyone adults, old people, and the children. This has been identified as a fundamental human right. (WHO,2016).

However, the guide for planning and implementing palliative care, points out that Palliative care is not for postponing death, but it focuses on the ethical principles, shared decision making and advanced care to identify patient's and goals for their end-of-life care. Therefore, the needs and the expectations of the patient should not be mixed with those of the caregivers because it can be a dilemma for healthcare givers to determine whose needs are priority (W.H.O,2016). Moreover, according to (O'Neill & Fallon 1997) the focus is to support excellent quality of life and to foster healing that is, a shift in response towards an experience of integrity and wholeness on the continuum of the quality of life.

Finally, palliative care aims to bring “the patient home” with an assumption that it is necessary for the medical ideology not only to attend to the health and wellbeing of the patients but also to assist them in dying and enduring a humane and dignified death. (Dekkers, 2009). Besides, for patients who prefer to die at home, (WHO 2016), bereavement support is an important factor to the patient/family that needs emotional support to come in-terms with a dying family member or complicated grief in requiring treatment. (O’Neill & Fallon 1997).

## **2.3 Who needs palliative care?**

WHO published statistics of patients that would need palliative care stating that a large percentage of adults in need of palliative care have chronic health conditions such as cardiovascular diseases (38.5%), cancer (34%), chronic respiratory diseases (10.3%), AIDS (5.7%) and diabetes (4.6%). In addition, other disease conditions that may need palliative care include kidney failure, chronic liver disease, multiple sclerosis, Parkinson’s disease, rheumatoid arthritis, neurological disease, dementia, congenital anomalies, and drug-resistant tuberculosis’ (WHO,2020).

## **2.4 Trajectory of illness/ dying.**

For better description and analysis to target the patient group and timing of palliative care initiatives have been made to describe palliative care in terms of phases and trajectories of patient’s illnesses. In his book, *Palliative care perspective*, James L. Hallenbeck indicated that the concept of a dying trajectory was first studied by Glaser and Strauss in 1965 in an attempt to understand changes in health condition over a period time as a patient nears death (Hallenbeck, 2003). Therefore, using qualitative research methods, Glaser and Strauss described the trajectories common for sudden unexpected deaths as well as the lingering trajectories, which are often experienced in chronic illness (Teno, Weitzen, Fennell and Mor, 2001).

In connection to the study, Palliative physician Joanne Lynn and June R. concluded that Trajectories of functional decline at the end of life are quite variable. In their article,

*Patterns of Functional Decline at the End of Life*, they expressed Glaser and Strauss trajectories assumptions into a set of functional trajectories in which short-term expected deaths (terminal illness) are portrayed separately from lingering expected deaths (frailty) (Lunney, Lynn, Foley, Lipson, and Guralnik, 2003).

The theoretical trajectories analysis decline of function according to cause of death, duration, and structure of the function. These trajectories have been beneficial in understanding patterns of advanced illness and dying for different disease processes, which in turn have implications for care needed, decision making, and projection (Lunney, Lynn, Foley, Lipson, and Guralnik, 2003).

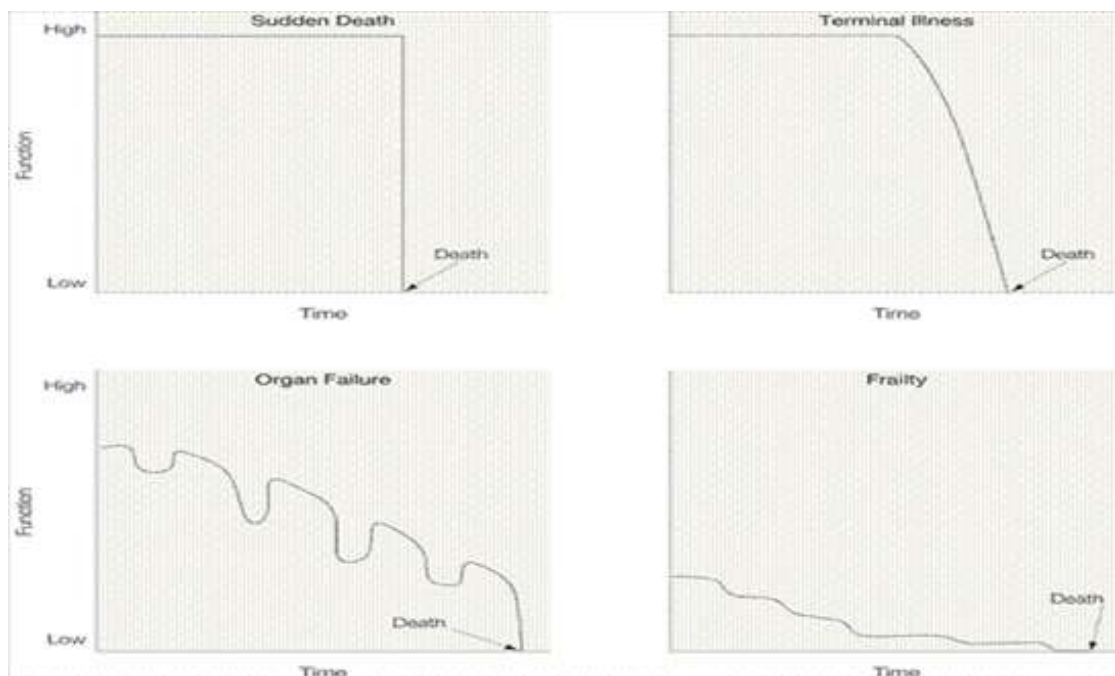


Figure 1 Theoretical Trajectories of Dying (Lunney, Lynn, Foley, Lipson, and Guralnik, 2003), Lynn, Foley, Lipson, and Guralnik, 2003)

### **2.4.1 The Sudden death**

The group consisted of people who progressed from normal function to death with little forewarning, often with little interaction with the health care system (Cohen-Mansfield, Skornick-Bouchbinder and, Brill, 2018). ‘In the Sudden Death Trajectory, the person has no opportunity to prepare or sort out pending personal matters; death is sudden, without notice and loved ones are left in shock. This being the case, hospice or palliative care is not required’ (Ballentine,2018). In addition, according to Skornick-Bouchbinder and Brill (2018).

### **2.4.2 The Terminally ill**

‘It consisted of people who died after a distinct phase of terminal illness. These persons may function relatively well for a long period of time and then experience a rapid decline until death (e.g., in cancer)’ (Cohen-Mansfield, Skornick-Bouchbinder and Brill, 2018). A health condition with a terminal trajectory is absolutely accompanied by advance care planning and palliative care, preferably starting at diagnosis stage (Ballentine,2018). McCuskey assumption estimated that 90% of all cancer deaths had a Terminal Care Period, of average duration 94 days, better functional status was associated with a longer Terminal Care Period (McCusker,1984).

### **2.4.3 The Organ failure**

Primarily included people with a serious and eventually fatal organ system failure, such as congestive heart failure or chronic obstructive pulmonary disease (Cohen-Mansfield, Skornick-Bouchbinder and Brill, 2018). The trajectory reflects acute relapse, active treatment, and improvement, but primarily a steady decline in the organ function. People with this type of trajectory cope with their illness for several years and go through uncertainties. According to Jennifer Moore Ballentine, under the organ failure trajectory, palliative care should preferably be started at the point of diagnosis and continue throughout the progression and crises of the illness.(Hallenbeck,2003).

### **2.4.4 The frailty**

Those with dementia or general frailty have a much lower baseline level of functioning, with a declining but variable downward course towards death (Murtagh, Preston and Higginson, 2004). People with this type of trajectory often live with their illnesses for many years. 'The group included people who suffer from Alzheimer's disease, stroke, Parkinson's, and other types of dementia and long-term diseases which show a slow and gradual decline' (Cohen-Mansfield, Skornick-Bouchbinder and Brill, 2018). Advanced neurological or musculoskeletal health conditions such as Dementia do indeed qualify for long-term palliative care and continues illness management policies (Ballentine,2018).

### 3 THEORETICAL FRAMEWORK

The theoretical framework of this thesis is based on Jean Watson human caring theory since caring is an essential part of nursing care and patient relationships. Therefore, it is an important theory due to its fundamental insight of human caring and describes the meaning of the patient, their health, and nursing. (Braz Evangelista, C. et al. 2020). Besides, nurses should have the expertise to show care in all aspects of nursing and the ability to care helps nurses provide a more holistic type of care thus Watson's theory of caring is a core concept in nursing that helps guide nursing practice. (Rafael,2000) Watson created several concepts regarding human caring, which aligns with what every nurse, learn in basic nursing care (Pajnkihar et al., 2017). Jean Watson is a nursing theorist who formulated the theory of human caring and the 'caritas' processes in further support of this theory (Watson & Woodward,2020) Watson's milieu is in nursing and psychology, consequently, through her practice, she observed the effect of genuine caring on patients and the subsequent health outcomes. She has published many works on the "...philosophy and theory of human caring and the art and science of caring in nursing" (Alligood, 2017).

According to Watson (1997) the core of the Theory of Caring is that "humans cannot be treated as objects and that humans cannot be separated from self, other, nature, and the larger workforce." Her theory encompasses the whole world of nursing; with the emphasis placed on the interpersonal process between the care giver and care recipient. The theory is focused on "the significance of human caring and on the caring-to-caring transpersonal relationship and its healing potential for both the nurse who is caring and the patient who is being cared for" (Watson,2002).

Watson's Caring Science an interdisciplinary approach consists of concepts from the fields of philosophy, ethics, ecology, and mind-body-spirit medicine to describe a caring practice that extends the beyond the patient, the community, the world, and universe (Watson, 2008, Costello, 2018) Furthermore, Watson explains the healing process that cares for the spirit or soul of the patient by being in authentic relation during that space in time (Watson, 2008). Watson, adds that caring for the patient at the end of life, re-

quires compassion, the “capacity to bear, witness, suffer with, and hold dear with in our heart the sorrow and beauties of the world” (Costello, 2018).

Watson assumes that care provided by the nurse is based on human values, which support the human components of care of respecting and promoting of human dignity with an aim of the to patient achieve peace between the mind, body and soul (Aghaei& Vanaki& Mohammadi 2020). Additionally, the nurse has to give competent, compassionate and culturally sensitive care to patients and their families during the diagnosis of serious illnesses (Costello, 2018).

Watson described caring as a fundamental factor in nursing, which itself is described as human science and art. She pointed to a transpersonal caring relationship and a specific type of professional and human-to-human contact. (Pajnkihar, M. et al. 2017). Transpersonal caring relationship is defined by Watson as a particular type of individual care relationship, a union with another person high regard for the whole person and their being in the world. (Alligood, 2014 p 82).

Thereafter developing the theory, Watson took up terminology with the intention that this would contribute to readers’ better understanding of the theory and its conceptual elements. Human care was first defined as a “dynamic human-to-human transaction” lately, it is revised to human caring, referring to “deeper human-to-human involvement and connection of one to another. (Pajnkihar, M. et al. 2017).

Moreover, Jean Watson’s theory describes three of the four metaparadigm concepts in nursing: health, nursing, and person or human being. Health is the peace of the mind, body, and soul, combined with the degree of consistency between the self as perceived and the self as experienced. Nursing is acknowledged by Watson as a philosophical, dynamic, and changeable concept that implies caring and has several meanings. (Braz Evangelista, C. et al. (2020).

Therefore, the nurse is considered as a co-participant of the caring process, helping people find meaning, even in a time of disharmony and suffering, and supporting in the decisions regarding the patient’s condition. The person is defined as a being-in-the-world, spiritual, magnificent, a part of nature, not just matter. The person has three dimensions (mind, body, and soul) influenced by the self (Braz Evangelista, C. et al. 2020).



### 3.1 Conceptual Elements

The theory defines the heart of contemporary nursing as person-centered transpersonal caring, meaning a wholeness of mind, body, and soul. It then advanced between 1975 and 1979 based on her views of nursing, combined and informed by her doctoral studies in educational, clinical, and social psychology. The initial work of Watson evolved dynamically from her initial writings to a more revised view of caritas and caring science as sacred science (Pajnkihar, M. et al. 2017).

Watson further connects her theory to Nightingale's sense of deep commitment and calling to ethic of human care (Alligood, 2014). At the start of her work, Watson used the term carative as an antonym to curative; this was to distinguish nursing from medicine. Lately, the term carative has evolved into caritas a Latin word meaning "to cherish and appreciate, giving special attention to, or loving" (Pajnkihar, M. et al. 2017). In addition, Watson supported the readers understand her theory by briefly listing the main conceptual as relational caring, transpersonal caring, caring-healing consciousness and the 10 carative factors (Pajnkihar, M. et al. 2017).

### 3.2 Assumptions.

Jean Watson's theory major assumptions are further explained in the table below.

<b>Carative Factors</b>	<b>Caritas Processes</b>
1.. "The formation of a humanistic-altruistic system of values"	"Practice of loving-kindness and equanimity within the context of caring consciousness"
2, "The instillation of faith-hope"	"Being authentically present and enabling and sustaining the deep belief system and subjective life-world of self and one being cared for"
3. "The cultivation of sensitivity to oneself and to others"	"Cultivation of one's own spiritual practices and transpersonal self-going beyond the ego self"
4. Development of a helping-trust relationship" became "development of a helping-trusting, human caring relation"	"Developing and sustaining a helping trusting authentic caring relationship"
5. "The promotion and acceptance of the expression of positive and negative feelings"	"Being present to, and supportive of, the expression of positive and negative feelings as a connection with deeper spirit and self and the one-being-cared for"
6. "The systematic use of the scientific problem-solving method for decision making" became "systematic use of a creative problem-solving caring process"	Creative use of self and all ways of knowing as part of the caring process; to engage in the artistry of caring-healing practices"

7.. “The promotion of transpersonal teaching-learning”	“Engaging in genuine teaching-learning experience that attends to unity of being and meaning, attempting to stay within others’ frame of reference”
8. . “The provision of supportive, protective, and (or) corrective mental, physical, societal, and spiritual environment”	“Creating healing environment at all levels (physical as well as nonphysical, subtle environment of energy and consciousness, whereby wholeness, beauty, comfort, dignity, and peace are potentiated)”
9. “The assistance with gratification of human needs”	“Assisting with basic needs, with an intentional caring consciousness, administering ‘human care essentials,’ which potentiate alignment of mind body spirit, wholeness, and unity of being in all aspects of care”
10. “The allowance for existential-phenomenological forces” became “allowance for existential-phenomenological spiritual forces”	“Opening and attending to spiritual-mysterious and existential dimensions of one’s own life-death; soul care for self and the one-being-cared for”

*Figure 2 Carative Factors: the old and the new designation of the ten steps proposed by Watson to deliver transpersonal caring (Braz Evangelista, C. et al. 2020).*

### 3.3 Integrating Jean Watson human caring theory into palliative care that is patient centered.

Watson’s theory of human caring places the (person) patient in the context of the family, the community, and the culture by placing the (person) patient as the focus of the practice rather than technology hence from the person-centeredness approach, the ‘person’ is central. The (person) patient is treated with dignity, respect, and compassion while living with a serious illness. This approach in turn evokes the *caritas* process. The caring nurse assists in the healing process, treats persons as wholes, accepts them now and who they will become later, develops authentic relationships, and assists in humanity development (Watson, 2008).

Therefore, the Caring science behind Watson theory centers nursing around helping the (person) patient achieve a higher degree of harmony in a holistic manner- physical, emotional, social, and spiritual wellbeing. In patient centered palliative care setting, the patient’s, and the nurse’s self- contemplation and self- knowledge can help bring understanding to the significance of the illness, improvement, and sustainable quality of life for the patient and their loved ones.

*'A valued person in and of him or herself to be taken care of, treated with dignity, appreciated, understood and assisted, in general a philosophical view of a person as a fully functional integrated self. He, human is viewed as greater than and different from, the sum of his or her parts' (Ryan, 2005).*

A vital consciousness is created at the moment that care is provided by the nurse and received by the patient (Watson, 1994). Indeed, the formation of a humanistic-altruistic system of values carative factor (Watson, 1979) advocates for preservation of the (person) patient's dignity and harmony during the caring process. According to Jean Watson, Instillation of Faith incorporates humanistic and altruistic values, to advance holistic nursing care and positive health in the patient community. (Alligood, 2017). Therefore, integrating individual culture, faith and traditions in supporting patients with acceptance of the existing health status. (Rosa, Estes and Watson, 2017) felt that the spiritual and cultural aspects of a patient can be explored to promote love and healing as an element of life.

*"It is this love that enables one to remain whole and intact as he or she explores the naturally arising spiritual existential questions like: Who am I really? What is important now? What do I believe? Will I be remembered? Who will remember me? How will I face death? Who will stand with me on this journey into the mysterious, subtle realms of life-death?" (Rosa, Estes and Watson, 2017)*

Therefore, inclusivity of Jean Watson realm of individual spirituality to palliative care is reinforced by many researchers, theorists and institutions such as Elisabeth Kubler-Ross in the 1970's who believed that the fear-based culture of death, dying and restoration of human dignity should be addressed. Another example is, The Conscious Dying Institute which supports a sacred passage that honors life with spiritual guidance. (Payne, Seymour, and Ingleton, 2004) Included spiritual care under chaplaincy and faith advisors in their book *Palliative care nursing: Principles and evidence for practice*.

Furthermore, Watson stated that humanistic caring goes beyond one-sided relationships (Watson, 2011), transpersonal caring relationship articulates the nurse-patient relationship that is developed during encounters. The carative factor of development of a helping-trusting human care relationship (Watson, 1979) allows for perceptive of the other's feelings and consciously becoming involved. Besides, the dimensions of transpersonal

relationships draw from connectivity, interaction, communication and caring oriented from an action. It is expressed through supererogatory acts and the altruistic part that a compassion nurse plays in the process of offering palliative care.

According to Watson, one of the most appropriate instruments to establish and maintain important aid-trust relationships between professional and patient is empathy. The nurse's capacity to feel and understand the patient translates into a transaction that promotes a supportive system, as well as activate the patient in participating in the caring process.

Empathy is stimulated by Watson's Carative factor of assistance with gratification of human needs (Watson,1979) which denotes the essence of a nurse recognizing the bio-physical, psychophysical, psychosocial, and intrapersonal needs of self and patient. Therefore, recognizing the patient's hierarchy of needs and attending to them is an approach that can be used to alleviate distress and improve the quality of life of palliative care patients. For example, arranging a companion for patients whose families may be unable to visit or for patients who do not have families.

Watson's Transpersonal caring relationship describes the nurse's caring consciousness and moral commitment to make an intentional connection with the patient through genuine presence and being centered in the caring moment. In addition, *actions, words, behaviors, cognition, body language, feelings, intuition, thoughts, senses and the energy field contribute to the transpersonal caring connection*' (Alligood, 2017).

According to Payne, Seymour and Ingleton (2004) effective communication and interaction are essential in managing and coping with a terminal illness. Moreover, the Key aspects of communication highlighted by fisher (2002) in palliative care included being skilled at responding to the patients' needs and feelings such as reflecting back, facilitating emotional expression, drawing out, holding strong emotions such as anger and sadness.

## **4 AIM AND OBJECTIVE OF THE STUDY**

The aim of this research is to investigate and discuss patient-centered approach in palliative care. The thesis builds on the knowledge of palliative care which has been described by WHO as under the human right to health (WHO,2020).

The objective of the study will be to examine the importance of patient-centered approach in palliative care. The study will also investigate the challenges that nurses face in implementing patient-centered palliative care and ways to mitigate these challenges. These objectives will be motivated with the nurses' roles and participation in providing patient-centered care.

### **Research Questions**

1. What is the importance of patient centered approach in palliative care?
2. what challenges do nurses face in providing patient- centered care?
3. How do nurses mitigate the challenges?

## 5 METHODOLOGY

In this chapter the authors used qualitative literature review to conduct the study in which articles that addressed the chosen topic were reviewed to investigate the research questions and provide insight to the aim of the study.

### 5.1 Data collection

Literature review was conducted through data retrieved from online databases; PubMed, Google scholar, Science Direct, Arcada Finna and EBSCO. An initial search for full text articles with keywords palliative care, patient-centered, and Nurs\*was done. The published period range was limited from 2000 to date. The search was kept broad for possible overlap of palliative care and ‘end-of-life’ articles. The search employed other keywords e.g., caring, “caring science”, “human caring”, “human caring theory”, “caring theory”, carativ\*, and caritas. There were no restrictions on the country of research, but the language of publication was restricted to English. The final search was achieved by selecting peer reviewed articles along with reviewing the titles and abstracts. This resulted in 30 articles being selected.

*Table Inclusion and Exclusion criteria of the study*

Inclusion criteria	Exclusion criteria
Articles in English	Articles not in English
Articles that have keywords palliative care, patient-centered, caring OR caring science, human caring OR “human caring theory” OR “caring theory”, carativ*, caritas	Articles not relevant to our topic
Articles must be peer reviewed	Articles not peer reviewed
Articles that were available in “full text” and freely available	Articles not freely available
Articles from 2000- to date	Articles older than 2000

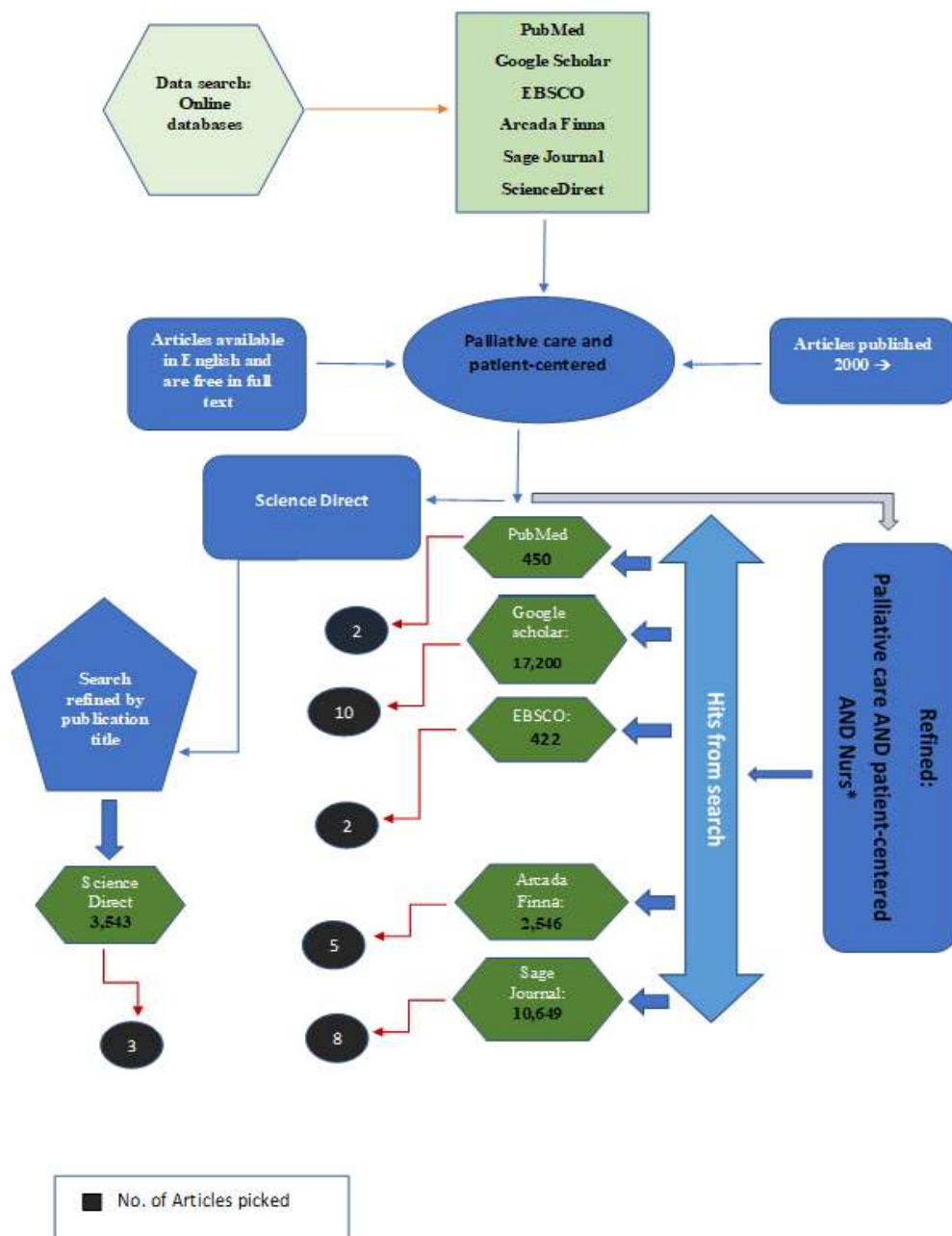


Figure 3 Illustration of the data collection process

## 5.2 List of Articles Chosen

1. Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: The Lancet Commission report. Felicia Marie Knaul, Paul E Farmer, Eric L Krakauer *et al.* 2018. *Lancet Commission*.
2. An analysis of Jean Watson's theory according to Chinn and Kramer's model. Braz Evangelista C, Limeira Lopes ME, Lima da Nóbrega MM, Ferreira de Vasconcelos M, Gomes Viana AC. 2020. *Revista de Enfermagem Referência*.
3. Applying a palliative care approach in residential care: effects on nurse assistants' experiences of care provision and caring climate. Ingela Beck, Ulf Jakodsson and Anna-Karin Edberg. 2014. *Scandinavian Journal of Caring Science*.
4. Barriers and facilitators to the implementation of person-centred care in different healthcare contexts.), Moore, L., Britten, N., Lydahl, D., Naldemirci, Ö., Elam, M. and Wolf, A., 2017. *Scandinavian journal of caring sciences*, 31(4
5. Caring from the heart as belonging—The basis for mediating compassion. Hemberg, J. and Wiklund Gustin, L., 2020. *Nursing open*, 7(2)
6. Collaborative Practice Model: Improving the delivery of bad news'. Bowman, P. N., Slusser, K. and Allen, D. 'Hutch' (2018). *Clinical Journal of Oncology Nursing*, 22(1), pp. 23–27. doi: 10.1188/18.CJON.23-27.
7. Compassion in health care: an empirical model. Sinclair, S., McClement, S., Raffin-Bouchal, S., Hack, T.F., Hagen, N.A., McConnell, S. and Chochinov, H.M., 2016. *Journal of pain and symptom management*, 51(2)
8. Compassion fatigue in palliative care nursing: a concept analysis. Cross, L.A., 2019. *Journal of Hospice and Palliative Nursing*, 21(1)
9. Dignity-conserving care actions in palliative care: an integrative review of Swedish research', Harstäde, CW, Blomberg, K, Benzein, E & Östlund, U 2018. *Scandinavian Journal of Caring Sciences*, 32(1), pp. 8–23. doi: 10.1111/scs.12433.



10. Elephant in the Room Project: Improving Caring Efficacy through Effective and Compassionate Communication with Palliative Care Patients. Denise K. Betcher. March/April 2010. MEDSURG Nursing (Jannetti Publications, Inc) Vol. 19/No. 2
11. Education, implementation, and policy barriers to greater integration of palliative care: A literature review. Aldridge, M., Hasselaar, J., Garralda, E., van der Eerden, M., Stevenson, D., McKendrick, K., Centeno, C. and Meier, D., 2015. *Palliative Medicine*, 30(3)
12. Ensuring dignity at the end of life: a personal perspective. Hurtley, Rosemary 2015. *Nursing & Residential Care*, vol. 17, no. 7 viewed 17 February 2021, <<http://search.ebscohost.com.ezproxy.arcada.fi:2048/login.aspx?direct=true&db=c8h&AN=109804349&site=ehost-live>>.
13. Family caregiver views on patient-centred care at the end of life. Kevin Brazil PhD, Daryl Bainbridge PhD, Jenny Ploeg PhD, Paul Krueger PhD, Alan Taniguchi MD and Denise Marshall MD. Scand J Caring Sci; 2012. *Scandinavian journal of caring science*. 26
14. Fit For Practice. Analysis & Evaluation of Watson's theory of human Caring. Majda Pajnikihar, RN; PhD1, Hugh P. McKenna, RN; PhD; FAAN2, Gregor Štiglic, PhD1, and Dominika Vrbnjak, RN. 2017. *Nursing Science Quarterly*. Vol.30(3) 243-253.
15. From Theory to Practice Caring Science According to Watson and Brewer. Pamela N. Clarke. 4 October 2009. *Nursing Science Quarterly* Volume 22 Scholarly Dialogue
16. Global Atlas of palliative care 2<sup>nd</sup> Edition, Worldwide Hospice Palliative Care Alliance (WHPCA). London, UK 2020. Published in WHO <https://www.who.int/ncds/management/palliative-care/palliative-care-atlas/en/>
17. How do nurses in palliative care perceive the concept of self-image?. Jeppsson, M. and Thomé, B., 2014. *Scandinavian Journal of Caring Sciences*, 29(3)

18. Identifying the barriers and enablers to palliative care nurses' recognition and assessment of delirium symptoms: a qualitative study. Hosie, A., Lobb, E., Agar, M., Davidson, P.M. and Phillips, J., 2014. *Journal of pain and symptom management* 48(5).
19. Integrating Palliative Care into Oncology: A Way Forward. Ramchandran, K., Tribett, E., Dietrich, B. and Von Roenn, J., 2015. *Cancer Control* 22(4)
20. *Jean Watson's theory of human caring*. Watson, J. and Woodward, T.K., 2020. *SAGE Publications Limited*.
21. Nurse–patient relationships in palliative care. Mok, E. and Chiu, P.C., 2004. *Journal of advanced Nursing*, 48(5)
22. Oncology nurses' communication challenges with patients and families: a qualitative study. Banerjee, S.C., Manna, R., Coyle, N., Shen, M.J., Pehrson, C., Zaider, T., Hammonds, S., Krueger, C.A., Parker, P.A. and Bylund, C.L., 2016. *Nurse education in practice*, 16(1)
23. Palliative care nursing: Principles and evidence for practice. Payne S., Seymour J., and Ingleton C., 2004. *Open university press*. Berkshire, England.
24. Palliative Care Communication: Outcomes from COMFORT™ 8480; a train-the-trainer course for providers. Elaine Wittenberg, PhD, Joy Goldsmith, PhD, Betty Ferrell, PhD, FAAN, CHPN, Haley Buller, MSHSC, Yesenia Mendoza, MA, and Sandra L. Ragan, Ph. 2020. *Clinical Journal of Oncology Nursing*, 24(1), pp. E1–E6. doi: 10.1188/20.CJON.E1-E6.
25. Palliative care nursing: Quality care to the end of life. Springer Publishing Company. Sherman, D.W., 2010.
26. Scoping review of patient-centered care approaches in healthcare. Constand, M., MacDermid, J., Dal Bello-Haas, V. and Law, M., 2014. *BMC Health Services Research*, 14(1).
27. The philosophy of palliative care: critique and reconstruction. Randall, F., Downie, R.S. and Downie, R.S. 2006. *Oxford University Press*

28. Watson's Caritas Processes® as a Framework for Spiritual End of Life Care for Oncology Patients. Margaret Costello, PhD, RN School of Nursing and Health Science, Simmons College, Boston, Massachusetts, USA. 2018. *International Journal of Caring Sciences*.
29. 6 Watson's Human Caring Theory-Based Palliative Care: Mir Hossein Aghaej, Zohreh Vanaki, Eesa Mohammad. 2020 : *A Discussion Paper. International Journal of Cancer Management*. In Press. 10.5812/ijcm.103027.
30. What are the barriers to care integration for those at the advanced stages of dementia living in care homes in the UK? Health care professional perspective. Kupeli, N., Leavey, G., Harrington, J., Lord, K., King, M., Nazareth, I., Moore, K., Sampson, E. and Jones, L., 2016. *Dementia*, 17(2)

### 5.3 Content analysis

Content analysis method was used to analyze the qualitative data and interpret its meaning, through a systematized process involving classification, evaluation, and unbiased verification (Schreier, 2012, Elo et al. 2014). Content analysis is very helpful to examine communication patterns and it is preferred because it is non-invasive nature, and it ensures credibility, dependability, conformability, transferability, and authenticity of the qualitative data at hand. (Graneheim & Lundman 2004). The method involved an inductive and deductive process of reading through the texts of the chosen literature review in order to obtain an understanding and deduce meanings.

Firstly, the authors read through all the selected thirty (30) articles in which the inclusion and exclusion criteria had been applied taking into account the meaning of manifest as 'what the text say' and latent as 'what the text is talking about'. Meaning units refer to words, sentences or paragraphs that are related and connected in both content and context. (Graneheim & Lundman 2004). In addition, a code represented the labels of the meaning unit. In the reading process that followed, all the meaning units were highlighted and coded according to the manifest content of the text. These codes were based

on their direct relationship to the keywords used in the research. For easier identification, the keywords were highlighted with colored markers for easier coding.

### **5.3.1 Reading and coding.**

The articles were read frequently, and brief notes made on the margins when interesting or relevant information that answers the research questions was found. In the process, notes were made, marked, and labelled using codes. The codes correlated to the key words that were used in the research study which were further divided into categories. Each category was thoroughly read through so that it fitted and was relevant to each research question.

### **5.3.2 Listing and categorizing**

The process of labelling and organizing data to identify different themes and the relationships is done during the data analysis. Relevant codes which are words or short phrases are placed into appropriate categories. Emerging sub themes are split into categories that help organize codes based on how they relate to one another. The articles are reviewed separately to prevent the influence other articles may have on the researcher's understanding and interpretation of the data.

### 5.3.3 Emerging themes and sub-themes from collected categories

Table 2 illustration of the emerging themes and sub-themes categories

Theme	Importance of patient-centered palliative care		Challenges/barriers nurses face in implementing patient-centered palliative care		Mitigation of the challenges	
Major categories	Nurse's role	Patient/family centered	Nurse's role	Patient/family centered	Nurse's role	Patient/family centered
Minor categories	Caring communication	Pain management	Communication	Communication	Skills and knowledge	Communication awareness
Unit of analysis	5,7,9,10,12,18,20,21,22,23,24,25,26,29	1,16,18,23	1,10,14,15,16,17,23,26,28,29	1,11,16,18,23	1,11,16,18,19,23	1,4,7,10,13,15,16,18,19,22,23
	2,5,6,7,10,12,13,14,15,16,17,18,20,21,25,28		7,5,10,12,15,17,18,20,21,23,25,28,29	4,5,7,8,12,16,15,17,18,21,24,25,27,30	3,4,5,6,7,8,10,14,15,17,18,21,22,23,24,25,27,28	7,4,9,18,21,22,23,25
			10,12,18,20,21,22,23,25,26,28,29	4,5,6,7,8,18,21,23,25,27,28,29,30	4,5,7,8,10,11,12,15,16,17,18,21,22,23,25,27,28,29	4,10,15,16,17,19,23,25
					4,16,21,22,23,25	
					7,4,18,21,22,23,25	
					1,4,7,16,17,18,23	

### 5.4 Research ethics

The Finnish National Board on Research Integrity TENK, appointed by the Ministry of Education and Culture (Tenk, n.d), promotes the responsible conduct of research, prevents research misconduct, promotes discussion, and spreads information on research integrity in Finland. This has been done by devising guidelines for good scientific practice, handling misconduct and fraud in science with the aim of promoting good scientific practice to prevent research misconduct in all public organizations carrying out re-

search, such as universities, research institutes and polytechnics (Tenk, n.d). The authors used the standard and instructions that have been laid down by Arcada University of Applied Science and the ethics rules that guide scientific writing to avoid research misconducts when conducting this research study using literature review.

The authors used the Arcada University of applied Sciences' Thesis Template version of 2018 as the writing guide for the study. Will follow the guideline as recommended by Arcada. The thesis template aids in the arrangement of work, citation and referencing of the articles used. This will enable the researchers clearly present the work and the reader properly follow the findings.

To develop good quality production through the concept of reliability and authenticity of the study the researchers will be keen to eliminate bias from own experiences that may affect the interpretation of results due to their pre-understanding of the phenomena through previous experience.

## **6 FINDINGS**

The findings show the content analysis of the 30 articles reviewed for the study. A quality check of the chosen articles was done within the authors and two major themes were agreed upon as 1. nurse's role and 2. patient/family centered. The findings have been analysed in the order of the research questions.

### **6.1 Importance of patient-centered approach in palliative care**

The findings revealed that patient-centered approach in palliative care is respectful of and responsive to individual patient preferences, needs and values and that through caring, which is central to nursing practice, the role of the nurse in palliative care is integral in pain management. Besides, with effective communication and compassion mediation amongst other carative factors a nurse-patient relationship based on mutual trust and respect is established in which the holistic needs of the patient are met. This aims to improve quality of life of patient and family members in support of WHO definition of palliative care as mentioned earlier in the study.

### 6.1.1 Nurse's role

The findings identified that, Caring occurs when the nurse has knowledge about the core concepts of Jean Watson theory of human caring, the carative factors and caritas processes that facilitate hearing, honour, and wholeness (2,14,28,29) hence these resources became a resource for 'personalized' care (10,15,16,17). It was noted that Patient-centered care honours the patient as a 'whole human being' (10), treats the patient with dignity, respect (16), and recognises human vulnerability enabling the nurse's preparation in deliverance of the bad news, comforting the family and putting culture into consideration (6) as well as addressing the dignity-related concerns (9). The study further identified that spiritual care highlights the role of compassion presence, (28) thus nurses mediate compassion by encountering the patient with humility and love by being in the moment and bearing responsibility for the patient leading to a caring communion that alleviates suffering. (5,7,20). In addition, it was further noted that through relationship of trust nurses demonstrate holistic approach to caring (21) and the patient's needs are met when there is a good caring relationship between the nurse and the patient (3) and involvement of the family members in the care plan. (12).

The findings revealed that Pain management was seen as the pillar of palliative care (1) and it spared the patient avoidable pain while enabling them to die with dignity (1,16). In further support the findings established that Medication such as acetaminophen (paracetamol), Nonsteroidal anti-inflammatory drugs (e.g., Ibuprofen) and opioids; as well as non-medication methods are used in alleviating physical and psychological pain (1,16,23) and the nurse's role is to administer the pain reliever while considering each patient's and family needs (1,16,23). Furthermore, the nurse spends more time with the patient than any other health professional and was thus in an ideal position to constantly assess and evaluate the effectiveness of their pain treatments and assess common side effects for comprehensive pain management (18,23,25). The study found that communication was an essential component in palliative care (10,23,26) that helps patients verbalize their fears and concerns (10,23). Furthermore it was noted that effective communication entails respect for the patient (13) and Comfort communication improves patient-centered communication in care (24). In support of the finding, the study further found that through effective communication with the patient the nurse was able to interpret non-verbal indicators of pain/stress in facial expression manner (12,24) thus, it

was the responsibility of the nurse to communicate empathetically for the overall well-being of the patient(22,25).In addition, the articles discuss the importance of effective communication between the patients and healthcare professionals in order to essentially manage their diagnosis and cope with the disease (10,23,26).

### **6.1.2 Patient/family centered**

The study established that Person centered care with effective communication was regarded as quality care by patient and family members (7) thus supports nurse patient relationship through which patients confide to the nurse and receive comfort in a caring communion alleviating suffering and improving quality of life (21,22,25). Furthermore, Effective communication between the nurse and the patient allowed for a better understanding of the patient's needs and conveyed information specific to their individual care besides, patients want to know their diagnosis, prognosis, possible treatment options and relevant side-effects hence a proper nurse- patient relationship was noted to allow communication and the nurse was able understand the patient's feelings and offer support (1,10,23,26,29).

In addition, the study identified that Cultural and spiritual competencies of the nurse offer patient an atmosphere where individual needs were recognized giving hope and preserving their dignity (25). It was further noted that Patient-centered care enables the patient to disclose the spiritual needs (29) and the greater the spiritual needs of the patient are addressed; the more satisfaction and quality care was achieved (28). The authors noted that Patient satisfaction came with an understanding of the patient's perspective (26,15) which meant obtaining a picture of who the patient (self-identity) was of central importance in his or her life (17,23). It was further found that Patients wanted and expected nurses to be open (10) about their prognoses, treatment options, and values and goals (17,23,10,15).

The study further established that spiritual well- being of a patient improves quality of life (28) therefore, nurses, guided by Jean Watson's theory, are concerned with the patient's health, illness and allow healing to take place (14) Therefore, recognizing spiritual and cultural factors related to patient health was important in development of a successful care plan supporting self-actualization and worth (21,25) thus the nurse



evaluates the patients' needs constantly and empower them in making care plan decisions (12,29). It was further suggested that Improved outcomes can be expected when health services are designed to include reflective approach of the patient and family for the purposes of health improvement, risk management and early detection of illness (10,17,23,26). Also recognition of human vulnerability, sensitivity to patient's life story and identity-promoting care that supports the patient's self-image, and satisfaction with care was noted (15,16,17,23).

## **6.2 Challenges nurses face in providing patient-centered care.**

The research findings identified poor pain management, nurses' incompetence and inadequate communication as the key elements that nurses face in implementing patient-centered care in palliative care. Also, the patient's culture, communication, and ignorance of palliative care limit patients to receive quality palliative care.

### **6.2.1 Nurse's Role**

The research revealed that lack of effective communication prohibits patient centered care. Communication skills both verbal and non-verbal hinder empathetic communication (22). It is desirable to have health care professionals who are able to communicate at deeper levels with their patients if this is what the patients wish, insufficient communication skills to maintain those comfortable and non-threatening conversations between a nurse and a patient can be challenging (23). In a patient centered dialogue when nurses encounter patient with communication disorder (4), they are restricted by time to discuss and assess the spiritual needs of the patient, they feel they are unprepared to provide spiritual care (28). Due to daily routine exposure of nurses to suffering and death they are predisposed to compassion fatigue limiting their capability to offer compassionate care (8) and handle family emotions during the delivery of bad news (6). Also, Poor, or delayed communication among team members impedes the quality of care given to patients (23,30).

The findings from the research identified that nurses receive little to no education about palliative nursing (24), therefore, they are not always comfortable articulating the caring work they do, and some have difficulties adopting multidimensional aspects into

their caring context (15,17) such as assessing self-concept/self-image (17), being in position to address the patient's concerns and wishes and do not share other options in case any(13).In assessments where structured interviews as questionnaires are required, the nurses feel limited to ask free questions to motivate the patient narrative(27).

The inadequate skills, limited knowledge, and lack of experience by some nurses especially the novice is likely be an impediment to compassion mediation (5,7). Furthermore, the findings pointed out that limited education hinder the delivery of individualized care resulting in poor symptom recognition and management (16,30). Also, Scepticism and stereotypes can knowingly or unknowingly influence behaviour resulting to lack of commitment reverting to disease management (4). It is suggested that nurses appear demotivated in providing personalised and compassionate care due to lack of advance care planning within primary and secondary care that has resulted in uncoordinated, fragmented care, incomplete pain assessment (12,18,25,30) and commercially driven care that turns to a culture of minimalistic provision of care aimed at meeting basic needs and neglecting other dimensions (30).

Additionally, the study noted that nurses face a challenge alleviating pain in patient centered care. In the pain management process, one of the emphasized recommendations is that of immediate-release of morphine be made available both in oral and injectable dose for any patient with moderate-to-severe pain (1,23), however the growing gaps between needs and availability makes it an enormous problem worldwide (16) and a barrier to effective palliative care (1,16).

The study furthermore revealed that the nurse's role of essentially administering pain relievers and alleviating suffering is overshadowed by overly strict regulation, limitations on available forms of medication particularly oral opioids, lack of supply and distribution systems, advocacy efforts around substance control and regulatory barriers (1,11), limitations on who can prescribe or administer, fear of law enforcement intervention into medical use (1,16). Efforts to prevent non-medical use of internationally controlled substances, such as morphine and other opioid analgesics, have hampered and crippled access to opioids for palliative care (1,16).

### **6.2.2 Patient/family centered**

The findings indicated that communication/language barrier in patients result to misinterpretation and needless physical, emotional distress (22,25), frequent fatigue and may have cognitive impairment or other symptoms that may impede their ability to contribute at the level the patient would wish (23). The research further noted that such patients are unwilling to talk about their struggles resulting into sentiments of depression, anger, pain, and helplessness (21).

Due to a prevalent but unwarranted fear of non-medical use and addiction to opioids and opioid-induced side-effects, both among health-care providers, regulators and among patients and their families, has led to insufficient medical use (1,23,). The study noted.

The Unbalanced laws and excessive regulation perpetuate a negative feedback loop of poor access that mainly affects poor people, this leads to underestimates of needs, which in turn affects the amounts of opioids that are produced or imported for medical use; meaning the end user 'the patient' is eventually affected (16).

Furthermore, the study identified in some cases, patients fear illness progression and related side effects due to limited knowledge resulting to patient decline to abide by the treatment or report pain at all. (25) They also find it difficult to accept changes in the cognitive function due to delirium (18) and even changes in the physical appearance as they are strongly connected with the identity (17,).

Additionally, Culture was observed to be a challenge in patient-centered care. Nurse-patient relationship of trust can be obstructed by religion and spirituality differences (25). Psychologically, most people fear and avoid anything relating to death (16). It is suggested that there is often a belief that even acknowledging the possibility that one may die soon is harmful and thus many cultures have expressly prohibited informing patients of their diagnosis and prognosis when life-threatening (16). Patient reflective strategy of self-comparison is quite a risky strategy if patients compare themselves with someone with the same illness who is deteriorating or dying causing emotional insecurity (23).

## **6.3 How nurses mitigate the challenges faced in Patient-centered care**

The results of the research focused on ways to mitigate the challenges nurses face while providing patient-centered palliative care. The findings pointed out strategies that can be used to tackle challenges in pain management, communication, competences and caring. The sub themes were divided into the nurse's role and Patient/family centered.

### **6.3.1 Nurse's Role**

The authors addressed pertinent components that are pillars to pain management in light of high burden of pain, symptoms, spiritual and psychological distress in palliative care patients; the nurse's involvement in early identification, assessment, continuous support, consideration, and provision of pharmacological and non-pharmacological interventions to patient needs from the point of diagnosis through survivorship and end of life is significant (11,16,19,23). Based on the results, there is global support for access to pain relievers through effective policy making in national health systems and International collective actions that ensure all people, including poor people, have access to pain relief for life-threatening and life-limiting health conditions and end-of-life care (1,16). Furthermore, encouragement of activism of patients in the care journey is fundamental to positive outcomes and management of pain (1,19,11). Suggestion of intermediate training, as well as specialist palliative care training for nurses that routinely work with patients with more complex symptom management is needed (16,11). There is an increasing body of research demonstrating that inpatient palliative care lowers costs by preventing symptom crises, for example severe pain management that requires nurse's intervention, and matching treatments to patient goals thereby reducing misutilization (11).

Palliative care nurses require effective communication skills to offer supportive care to patient and their families (18,25). To mitigate the challenges of communication, the authors drew attention to Watson's theory (14,15) that builds nurse-patient relationship and allows the goal of caring and healing to take place. It is implied that high levels of communication among the nurses deliver effective goals of caring (24) and the optimal delivery of bad news occurs when all teams are prepared (6) and are in a supportive en-

vironment (3). The findings connected practicing mindfulness, addressing personal biases and the physical presence of the nurse to effective communication both verbal and nonverbal. Moreover, the nurse-patient relationship formed during interaction, brings out a better understanding of the spiritual and basic needs of the patient, as well as stimulates the patient's narrative for the continuity of care in the course of the illness trajectory (4,8,22,28). It also is reported that in this kind of relationship, the patient perceives the nurse as having a compassionate bedside manner when they demonstrate warmth and caring while trying to understand the patients' fears, values, and goals (10,15). In this sense, person-centred care offers a perspective that considers the social interactions as fundamental promoters of the patient's self-identity (15,17).

Findings show an increasing attention and commitment to developing and practicing human caring as an ethical, philosophical, as well as theoretical model for nursing and beyond (10,15,17). Introduction and continuous training in areas such as communication skills, compassion in healthcare, deepening understanding of the importance of our human connectedness towards healing, mindful of the nurse's intentions for heart-centered caring relationships are urged in improving patient outcomes (4,15,17,23). Therefore, training programmes empower nurses with the skills to communicate empathy (7) assess communication needs of the patient and family members and practice how to communicate in difficult and challenging moments (22). It is suggested that sufficient knowledge in the nursing profession emerges from nursing theories (29) from which nurses acquire education and training, nurses learn the spiritual and basic needs of the patient. Additionally, incorporation of teaching models in mediating compassion during clinical nursing education programs is advocated for in empowering nurses to provide patient-centered care (12,28). Although, theoretical nursing models can be off-putting, the context can be translated into practices that are more accessible to nurses and in turn open up to new possibilities in patient-centered care (15,17).

### **6.3.2 Patient/Family Centered**

The study finds that the nurses understanding of 'Who I am' in a multidimension of identity, self-assessment, social function, and self-knowledge (17) emerge to be important in ensuring that the patient obtain the positive benefits of patient-centred care without emphasizing the patient's potential future deterioration (23). The nurse nurtures

a compassionate nurse-patient relationship that offers human service to sustain and preserve human dignity and humanity; to sustain caring in instances where it is threatened (10,15,25) The nurses introduce stimulating techniques for instance role playing, and interdisciplinary approach such as chaplaincy to help overcome anxieties related to discussion of terminal illness and support the spiritual aspects (10,19,23). Nurses demonstrate cultural competencies through developed trust and maintain a feeling of hope with patients and their families that is realistic and not false (4,23,25).

According to the author, although nurses possess social communication skills that can provide the basis for building other interpersonal and communication skills, literature and training can be explored in responding to the patients' needs and feelings such as reflecting back and emotional expression (23). Nurses Engage in verbal, nonverbal and written communication (7,) and avoid use of medical terms for clear understanding by patient and family members (22) with the aim of developing a therapeutic relationship (25). Therapeutic communication by nurses' prompt patients to focus on their struggles and fears (21).

It is noted that the nurse's role in educating the patient about preventative attitude towards pain and non-pharmacological interventions for pain relief is important in patient-centred care (23, 16,19). Nurses participate in patient education on importance of pain management (18) and health promotion in creating awareness of illness trajectory to the patient and family members while addressing knowledge gaps on possible side effects (25). Even though there might be a difference in opinion between the nurse, the patient, and the family; the patient remains the central point from which decisions regarding care are made (13)

Furthermore, the findings pointed towards nurse's understanding of a patient's experience of pain and suffering and valuing the collaborative multidisciplinary teamwork in assessment and relieving pain are essential in achieving better quality care (15,16,19,23). It is implied that patients and families also need extensive training on how to manage personal care, body mechanics, expected symptoms and how to manage and imminent death (16). The nurse can apply a deep caring-healing relationship that addresses suffering, life threats and challenges that result in heart-centred compassionate care (10,15). Nurses who are literate with caring relationships are capable of having

loving, heart-centered compassionate, kind, and sensitively meaningful, personal caring connections with an increasingly enlightened humanity (15,17)

## 7 DISCUSSION

The aim of the study was to establish the importance of patient-centered approach in palliative care while taking into consideration the nurse's role. The study explored the challenges the nurses face when providing patient-centered palliative and the steps taken to mitigate those challenges. The authors found the findings were consistent with Jean Watson framework that caring for the patient at the end of life, requires compassion, the capacity to bear witness, to suffer with, and hold dear with in our heart the sorrow and beauties of the world (Costello, 2018). In view of the results chapter, nurses are expected to provide competent, compassionate, and culturally sensitive palliative care to patients and their families throughout the illness trajectory. It was noted that, the ultimate relationship in palliative care that was between the patient and nurse existed in real world of space and time. These elements of space and time formed the actual environment that created a setting that promoted communication at the personal and collective levels and was not constricted to the measures of the physical realm. With this ideology in mind, palliative care framework requires the nurse and the patient work mutually together and at a time and place of this connection coverage which results in creating an appropriate harmony and balance that helps to satisfy the needs.

As presented in the results, nurses are portrayed as an integral component of palliative care that nurture those human-to-human connection that is so important in routine interactions. The nurse's capacity to feel and understand the patient through caring connection involving *actions, words, behaviors, cognition, body language, feelings, intuition, thoughts, senses, the energy field*, transforms into a platform that fosters a supportive system, as well as motivate the patient in participating in the caring process (Alligood, 2017). Watson emphasises that focus on caring, and caring healing relationships, emerges from within the discipline of nursing and the practice of professional nursing (15). Nurses facilitate compassion by acting from their 'inner ethos' and encounter the patient with humility and love by being in the moment and bearing responsibility for the patient leading to a caring communion that alleviates suffering (5,7,20). These caring

practises promote patient-centered palliative care that is holistic and culturally congruent.

The results of the articles reviewed corroborated the Watson's transpersonal caring relationship that describes the nurse's caring perception and moral responsibility to make a purposeful connection with the patient through genuine presence and by being centered in the caring moment. In the findings, support is availed to allow patients in palliative care live fully throughout the care period until death, as well as facilitate effective communication between the care team, patient and their family; brings a better understanding of the care goals, patient's needs and convey information specific to their individual care (IAHPC,2019). It was noted that caring communication lays a surface for development of appropriate nurse- patient relationship that allows for an understanding of the patient's feelings and provision for support. The nurse engages in supportive patient practices that borne strategies such as reflective approaches which include meditation on patient's life story, self-identify and self-fulfilment. The importance of these supportive patient practices being health improvement, risk management and early detection of illness. Retroactively, the patient expects the nurses to be honest about their diagnoses, treatment options, and goals. The nurse-patient relationship also paves way for therapeutic communication between the nurse, patients and particularly families by providing appropriate and reliable information in terms of diagnosis and treatment as well as help in understanding the purpose of care plan and goal and for making further decisions ((Mok & Chiu 2004).

In delivery of patient-centered palliative care, it is important that nurse have the right competences. Nurses' competences are characterized by knowledge, key skills, nurse's behaviours, and favourable character. It is interesting to note that the articles reviewed placed palliative care education into three important levels: basic palliative care training for all health care professionals; intermediate training for those routinely working with patients with life threatening illnesses; and specialist palliative care training for patients with more complex symptom management needs and palliative care teachers and researchers. Case in point; pain management. The nurse relies heavily on individual competences and communication skills to spares the patient from avoidable pain and suffering.



The nurse functions in a significant way to ensure the patient understands the effectiveness of pain management. The nurse employs patient-centered pain management strategies and interventions which encompass early identification, assessment, continuous support, consideration, and provision of pharmacological and non-pharmacological interventions in addressing distress in palliative care. In this regard, the nurse takes into consideration the patient needs and judiciously uses medication and application of non-medication to enhance the patient's quality of life and make the control of pain an attainable goal. Communication and pain management is focused to an individual patient at a time and the nurse remains in an ideal position to constantly assess and evaluate the effectiveness of their pain treatments.

The nurse is responsible for conveying information between the patients and healthcare professionals to facilitate management of their diagnosis and coping with the disease (10,23,26). The nurse is also responsible for establishing proper nurse- patient relationship that allow effective communication habits that support the patient and bring understanding of their feelings. For example, (Fisher,2002) identified being skilled at responding to the patients' needs and feelings such as reflecting, facilitating emotional expression, drawing out, holding strong emotions such as anger and sadness among the main elements of communication. In addition, the results indicated that it was the responsibility of the nurse to communicate empathetically for the overall well-being of the patient (22,25). The concept of family-centered care and holistic care delivery such as considering beliefs, spirituality, feelings, and experiences are critical determinants of palliative care planning and effectiveness are assisted with effective communication practices. Effective communication entails respect for the patient and comfort communication improved patient-centered communication in care (24). The philosophy of palliative care is to provide further care with maintenance of quality of life, dignified humanity in which comfort measure comes as a first priority for patients struggling with life threatening and long-term illnesses (Stevens, Jackson& Milligan 2009).

The findings however reported challenges in patient-centered palliative care beginning with incompetence in the nursing field extending to patient as a barrier whereby, most people fear and avoid anything relating to death (16). According to the article reviewed, some nurses lack the competences or rather, they do not know what to examine or do when presented with certain situations. For example, some nurses have insufficient knowledge when dealing with fear that stems from cultural and spiritual beliefs. challenges originate from the patient's fear of embarrassment due to side effects or decline in cognitive function. In addition, some patient reflective techniques such as self-comparison can impede and become risky in the care journey. For example, if a patient compares themselves with another patient with a similar illness but with a rapidly declining illness trajectory (23). The most challenging aspect for nurses is to manage difficult conversations that come with negative emotional control when delivering sensitive information or bad news with patients and their families in palliative care and end of life (22).

In pain management policies were a major obstacle in care delivery. The most prominent being insufficient or unavailability of pain medication that is frustrated by stricture policies and regulation, insufficient distribution systems and advocacy efforts surrounding substance control and regulatory. The fact that access to such an affordable, essential, and effective intervention is denied to most patients in low-income and middle-income countries and in particular to poor people—is a medical, public health, and moral failing and a travesty of justice (1). Indeed, the findings determined that this challenge dissociates itself from the basic needs of the patient through absence of pain medication to alleviate pain and suffering. It deprives the patient of comfort and denies the nurse the opportunity to assist the patient to achieve their physical and emotional needs as suggested by Watson's carative factor of assistance with gratification of human needs (Braz Evangelista, C. et al. 2020). In view of the findings, limitations on who can prescribe and administer the medication affects the overall outcomes of pain management.

The way forward for patient-centered palliative care is a major increase in the workforce and continuous training. The training programs should allow for incorporation of theoretical frameworks into practice; education that deepens the understanding of the importance of our human connectedness towards healing. Apart from the advancement in competences, aspects that hinder appropriate care should be addressed. These in-

cludes encouragement of policies and guidelines that support safe administration of opioid, analgesics and other controlled medicines that do not generate unjustifiable restrictive barriers for patients (1,16). Beneficial strategies can be put in place to diminish the risk of pain medication misuse and improve quality of care; ultimately equipping the nurse to effectively address patient's varying degrees of pain. Another way to deal with the challenges is to perform community education and awareness campaigns about palliative care during the time the services are established. And also train patients and their families on how to do self-care, the symptoms to expect when diagnosed with any illness, how the signs/symptoms can be managed and informed of the body changes/ physical appearances as the result of the illness (17,18).

## **7.1 Limitations**

The study was restricted to sources that was freely available online only. Moreover, the coronavirus pandemic situation impeded direct contact between the authors, extended restrictions on availability of library services and empirical scholarly works.

## **8 CONCLUSION**

The aim of the study was to investigate(i) the importance of patient-centered approach in palliative care, (ii)the challenges nurses face in implementing patient centered palliative care and(iii) How these challenges are mitigated.

Patients with palliative care needs require support with their physical, emotional, spiritual, and social needs hence patient-centered care helps them receive more appropriate care and feel entirely cared for as a human being. Besides, it comes along with other benefits to patients and healthcare Centers overall. Patient-centered care also embodies a shift in the conventional roles of patients and their families from one of passive to team member thus making it a quality of personal, professional, and organizational relationships. In this regard, efforts to promote patient-centered care should consider family-centeredness (patients and their families), clinicians, and health systems. Therefore, facilitating patients to be more active in discussions during consultations transforms eras of health professionals-dominated dialogues to those that engage patients as active contributors.

The study established that nurses play a significant role in palliative care however, while implementing patient -centered care they face challenges. These challenges were noted to emanate from lack of caring competences where nurses are uncomfortable to articulate caring resulting to impediments in adopting an intricate aspect into the caring concept. However, it was pointed out that nurses can overcome these challenges through education and continuous training in the palliative care field focusing on aspects such as caring competences, communication skills, pain management, compassion and applying transpersonal relationship, spirituality, and ease patient's suffering.

## REFERENCES

- Aghaei, Mir & Vanaki, Zohreh & Mohammadi, Eesa. 2020. Watson's Human Caring Theory-Based Palliative Care: A Discussion Paper. *International Journal of Cancer Management*
- Aldridge, M.D., Hasselaar, J., Garralda, E., van der Eerden, M., Stevenson, D., McKendrick, K., Centeno, C. and Meier, D.E., 2016. Education, implementation, and policy barriers to greater integration of palliative care: a literature review. *Palliative medicine*, 30(3), pp.224-239.
- Alligood Marha Raile, 2014. Nursing Theorists and Their Work. USA, 8th ed. *Mosby, an imprint of Elsevier Inc.* Accessed 04.2.2021
- Alligood Martha Raile, 2017. Nursing Theorists and Their Work. E-Book. USA: *Elsevier Health Sciences*
- Ballentine, J M., 2018. The Five Trajectories: Supporting Patients During Serious Illness. *CSU Shiley Institute for Palliative Care*. <https://csupalliativecare.org/wp-content/uploads/Five-Trajectories-eBook-02.21.2018.pdf> Accessed 02/02/2021 Accessed 02/02/2021
- Banerjee, S.C., Manna, R., Coyle, N., Shen, M.J., Pehrson, C., Zaider, T., Hammonds, S., Krueger, C.A., Parker, P.A. and Bylund, C.L., 2016. Oncology nurses' communication challenges with patients and families: a qualitative study. *Nurse education in practice*, 16(1), pp.193-201.
- Beck, I., Jakobsson, U. and Edberg, A., 2014. Applying a palliative care approach in residential care: effects on nurse assistants' experiences of care provision and caring climate. *Scandinavian Journal of Caring Sciences*, 28(4), pp.830-841.
- Bowman, P., Slusser, K. and Allen, D., 2018. Collaborative Practice Model: Improving the Delivery of Bad News. *Clinical Journal of Oncology Nursing*, 22(1), pp.23-27.
- Braz Evangelista, C. *et al.*, 2020. An analysis of Jean Watson's theory according to Chinn and Kramer's model, *Revista de Enfermagem Referência*, (4), pp. 1–6. doi: 10.12707/RV20045.
- Brazil, K., Bainbridge, D., Ploeg, J., Krueger, P., Taniguchi, A. and Marshall, D., 2011. Family caregiver views on patient-centred care at the end of life. *Scandinavian Journal of Caring Sciences*, 26(3), pp.513-518.
- Brown, A. and Clark, J., 2015. A Parent's Journey: Incorporating Principles of Palliative Care into Practice for Children with Chronic Neurologic Diseases. *Seminars in Pediatric Neurology*, 22(3), pp.159-165.
- Clarke, P.N., Watson, J. and Brewer, B.B., 2009. From theory to practice: Caring science according to Watson and Brewer. *Nursing Science Quarterly*, 22(4), pp.339-345.
- Cohen-Mansfield, J., Skornick-Bouchbinder M., Brill S., 2018, Trajectories of End of Life: A Systematic Review, *The Journals of Gerontology: Series B*, Volume 73 *The Journals of Gerontology: Series B*, Vol. 73
- Constand, M., MacDermid, J., Dal Bello-Haas, V. and Law, M., 2014. Scoping review of patient-centered care approaches in healthcare. *BMC Health Services Research*, 14(1).

Costello, M., 2018. Watson's Caritas Processes® as a Framework for Spiritual End of Life Care for Oncology Patients, *International Journal of Caring Sciences*, 11(2), pp. 639–644. Available at:

<http://search.ebscohost.com.ezproxy.arcada.fi:2048/login.aspx?direct=true&db=c8h&AN=131851601&site=ehost-live> (Accessed: 3 February 2021).

Cross, L.A., 2019. Compassion fatigue in palliative care nursing: a concept analysis. *Journal of Hospice and Palliative Nursing*, 21(1), p.21.

Dekkers, W., 2009. On the notion of home and the goals of palliative care. *TheorMed Bioeth* 30, 335 <https://doi.org/10.1007/s11017-009-9121-5>.

Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K. and Kyngäs, H., 2014. Qualitative content analysis: A focus on trustworthiness. *SAGE open*, 4(1), p.2158244014522633.

Fallon, M. and Hanks, G. eds., 2013. *ABC of palliative care*. John Wiley & Sons.

Finnish National Board on Research Integrity TENK, n.d. <https://tenk.fi/en/tenk> accessed 20/02/2021

Fisher, M. 2002. Emotional pain and eliciting concerns, in J. Penson and R.A. Fisher (eds) *Palliative Care for People with Cancer*. Malta

Graneheim, U.H. and Lundman B., 2004. Qualitative Content Analysis in Nursing Re-search: Concepts, Procedures and Measures to Achieve Trustworthiness. *Nurse Education Today*, 24 (2004), pp. 105-112.

Hallenbeck, J., 2003. Palliative care perspectives. *University Press*. New York

Harstade, C., Blomberg, K., Benzein, E. and Östlund, U., 2021. *Dignity-conserving care actions in palliative care: an integrative review of Swedish research*.

Hemberg, J. and Wiklund Gustin, L., 2020. Caring from the heart as belonging—The basis for mediating compassion. *Nursing open*

Hosie, A., Lobb, E., Agar, M., Davidson, P.M. and Phillips, J., 2014. Identifying the barriers and enablers to palliative care nurses' recognition and assessment of delirium symptoms: a qualitative study. *Journal of pain and symptom management*, 48(5), pp.815-830.

Hudson, R., 2014. Palliative Care for the Older Person: Cloak or Cover-up? *Journal of Religion, Spirituality & Aging*, 26(2-3)

Hurtley, R., 2015. Ensuring dignity at the end of life: a personal perspective. *Nursing and Residential Care*, 17(7), pp.380-384.

International Association of Hospice and Palliative Care (IAHPC), 2019. *Consensus-Based Definition of Palliative Care*. <https://hospicecare.com/what-we-do/projects/consensus-based-definition-of-palliative-care/definition/> Accessed 29/01/2021

Jeppsson, M. and Thomé, B., 2015. How do nurses in palliative care perceive the concept of self-image?. *Scandinavian journal of caring sciences*, 29(3), pp.454-461.

Kelley, A.S. and Morrison, R.S., 2015. Palliative care for the seriously ill. *New England Journal of Medicine*.

Knaul, F. M., *et al.* 2018. Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: The Lancet Commission report. *The Lancet (British edition)*.

Kupeli, N., Leavey, G., Harrington, J., Lord, K., King, M., Nazareth, I., Moore, K., Sampson, E. and Jones, L., 2016. What are the barriers to care integration for those at the advanced stages of dementia living in care homes in the UK? Health care professional perspective. *Dementia*, 17(2), pp.164-179.

Lunney JR, Lynn J, Foley DJ, Lipson S, Guralnik JM. 2003. Patterns of Functional Decline at the End of Life. *JAMA*. 2 JM. 2003. Patterns of Functional Decline at the End of Life. *JAMA*. 2

Lynch, M., Dahlin, C., Hultman, T. and Coakley, E.E., 2011. Palliative care nursing: defining the discipline? *Journal of Hospice & Palliative Nursing*.

McCusker, J., 1984. The terminal period of cancer: definition and descriptive epidemiology. *J Chron Dis* 1984;1984

Mead, N. and Bower, P., 2000. Patient-centredness: a conceptual framework and review of the empirical literature. *Social science & medicine*, 51(7), pp.1087-1110.

Meehan, T., 2012. The Careful Nursing philosophy and professional practice model. *Journal of Clinical Nursing*, 21(19pt20), pp.2905-2916

Mehta, A. and Chan, L.S., 2008. Understanding of the concept of "total pain": a prerequisite for pain control. *Journal of Hospice & Palliative Nursing*

Mok, E. and Chiu, P.C., 2004. Nurse–patient relationships in palliative care. *Journal of advanced Nursing*, 48(5), pp.475-483.

Moore, L., Britten, N., Lydahl, D., Naldemirci, Ö., Elam, M. and Wolf, A., 2017. Barriers and facilitators to the implementation of person-centred care in different healthcare contexts. *Scandinavian journal of caring sciences*, 31(4), pp.662-673.

Murtagh F., Preston M., and Higginson I., 2004. Patterns of dying: palliative care for non-malignant disease. *Clinical medicine* Vol. 4

O'Neill, Bill & Fallon, Marie, 1997. ABC of Palliative Care: Principles of Palliative Care and Pain Control. *BMJ (Clinical research ed)*. 315. 801-4. 10.1136/bmj.315.7111.801

Pajnkihar, M. *et al.*, 2017. Fit for Practice: Analysis and Evaluation of Watson's Theory of Human Caring, *Nursing Science Quarterly*, 30(3), pp. 243–252. doi: [10.1177/0894318417708409](https://doi.org/10.1177/0894318417708409).

Payne S., Seymour J., and Ingleton C., 2004. Palliative care nursing: Principles and evidence for practice. *Open university press*. Berkshire, England.

Rafael, A.R.F., 2000. Watson's philosophy, science, and theory of human caring as a conceptual framework for guiding community health nursing practice. *Advances in nursing science*, 23(2), pp.34-49.

Ramchandran, K., Tribett, E., Dietrich, B. and Von Roenn, J., 2015. Integrating palliative care into oncology: a way forward. *Cancer Control*, 22(4), pp.386-395.

Randall, F., Downie, R.S. and Downie, R.S., 2006. *The philosophy of palliative care: critique and reconstruction*. Oxford University Press

Rosa W., Estes T., Watson J., 2017. Caring Science Conscious Dying: An Emerging Metaparadigm. *Nursing Science Quarterly*. Vol. 30

Ryan, L., 2005. The journey to integrate Watson's Caring theory with clinical practice. *International Journal of Human Caring* 9(3), 26-30.

Saunders, C., 2000. The evolution of palliative care. *Patient education and counseling*

Schreier, M., 2012. Qualitative content analysis in practice. Thousand Oaks, CA: Sage.

Sepúlveda, C., Marlin, A., Yoshida, T. and Ullrich, A., 2002. Palliative care: The World Health Organization's global perspective. *Journal of pain and symptom management*

Sherman, D.W., 2010. *Palliative care nursing: Quality care to the end of life*. Springer Publishing Company.

Sinclair, S., McClement, S., Raffin-Bouchal, S., Hack, T.F., Hagen, N.A., McConnell, S. and Chochinov, H.M., 2016. Compassion in health care: an empirical model. *Journal of pain and symptom management*,

Stevens, E., Jackson, S. and Milligan, S. eds., 2009. *Palliative nursing: Across the spectrum of care*. John Wiley & Sons.

Stewart, A.L., Teno, J., Patrick, D.L. and Lynn, J., 1999. The concept of quality of life of dying persons in the context of health care. *Journal of pain and symptom management*.

Teno, J., Weitzen, S., Fennell, M. and Mor, V., 2001. Dying Trajectory in the Last Year of Life: Does Cancer Trajectory Fit Other Diseases?. *Journal of Palliative Medicine*, 4(4), pp.457-464. Mor, V., 2001.

Ventegodt S., Kandel I., Ervin D.A., Merrick J., 2016. Concepts of Holistic Care. In: Rubin I.L., Merrick J., Greydanus D.E., Patel D.R. (eds) *Health Care for People with Intellectual and Developmental Disabilities across the Lifespan*. Springer International Publishing Switzerland 2016

Watson J., 2008. *Nursing: The philosophy and science of caring* (revised edition). Caring in nursing classics: An essential resource.

Watson J., 2011. *Human caring science*. Jones & Bartlett Publishers. USA

Watson, J. 1994. *Applying the art and science of human caring*. New York: National League for Nursing Press

Watson, J. and Woodward, T.K., 2020. *Jean Watson's theory of human caring*.



Watson, J., 1997. The theory of human caring: Retrospective and prospective. *Nursing science quarterly*, 10(1)

Wittenberg, E., Goldsmith, J., Ferrell, B., Buller, H., Mendoza, Y. and Ragan, S., 2021. Palliative Care Communication: Outcomes From COMFORT, *a Train-the-Trainer Course for Providers*.

World Health Organization, 1990. Cancer pain relief and palliative care: report of a WHO expert committee [meeting held in Geneva from 3 to 10 July 1989]. *World Health Organization*.

World Health Organization, 2002. National Cancer Control Programs: Policies and Managerial Guidelines. *World Health Organization*. 2nd ed. Geneva.

World Health Organization, 2016. Planning and implementing palliative care services: *a guide for programme managers*

World Health Organization, 2020. Palliative care. <https://www.who.int/news-room/fact-sheets/detail/palliative-care> Accessed 29.01.2021.

Worldwide Hospice Palliative Care Alliance (WHPCA), 2020. Global Atlas of Palliative Care. 2020 2nd Ed.