



**TO SUPPORT THE MENTAL WELLBEING  
OF PATIENTS IN PALLIATIVE CARE**

**A Literature Study**

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<p>Abstract:</p> <p>Mental wellbeing at the end of life is an inherently personal experience that affects patients and the family differently. Coping with the pain, grief and anxiety brought about by a life limiting illness is not only physically draining but it also affects the patient's mental wellbeing. Palliative care, is a patient/family centered care that focuses on optimizing quality of life before death. To effectively improve the mental wellbeing of patients, it utilizes holistic provision of psychosocial support, quality and competent management of symptoms, prevention and relief of suffering. The aim of this review is to elicit knowledge and understanding of current nursing interventions that promote mental wellbeing of patients in palliative care and to provide answers to the following research questions; (1) What is the connection between mental wellbeing and palliative care? And (2) what interventions are central for promoting mental wellbeing of patients in palliative care? The End of Life Theory was used in this thesis to explore the connection between mental wellbeing and the nursing interventions central to mental wellbeing promotion in palliative care. The method used to analyze the data was literature review, using inductive content analysis as the method of analyzing the data. In the analysis fifteen articles were reviewed. Results of the study indicate that there is a connection between mental wellbeing and palliative care, and treating a palliative patient using a holistic approach helps improve not only the mental wellbeing but also the overall wellbeing of the dying patient. Nursing interventions central to palliative care include monitoring and administering pain relief, allowing patients and families in the decision making process, and providing emotional support.</p>	
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<p>Tiivistelmä:</p> <p>Henkisen hyvinvoinnin lopussa elämä onluonnostaan henkilökohtainen kokemus, joka vaikuttaa potilaiden japerheen eri tavalla. Selviytyminenkipua, surua ja ahdistusta tuomatelämä rajoittamalla sairaus ei ole vain fyysisesti tyhjennys, mutta se vaikuttaa myöspotilaan psyykkistä hyvinvointia. Palliatiivinen hoito onpotilaan / perheen keskittyyä hoitoa, joka keskittyy optimointiin elämänlaatua ennen kuolemaa. Tehokkaasti parantaahenkistä hyvinvointia potilaiden, se hyödyntää kokonaisvaltaisesti psykososiaalisen tuen, laatu ja toimivaltaisten oireiden hoitoon, ehkäisyyn ja helpotus kärsimystä. Katsauksen tavoitteena on saada aikaan tietoa ja ymmärrystä nykyinen hoitotyön edistävät henkistä hyvinvointia potilaita lievittävä hoito ja antaa vastauksiaseuraaviin tutkimuskysymyksiin; (1) Mikä onyhteys henkiseen hyvinvointiin ja lievittävä hoito? Ja (2) mitä interventiot ovat keskeisiä mielenterveyden edistämiseen hyvinvoinnin potilaiden palliatiivinen hoito? End of Life Teoria käytettiin tässä työssä tutkiayhteys henkiseen hyvinvointiin jahoitotyön keskeinen henkisen hyvinvoinnin edistäminen lievittävää hoitoa. Käytetty menetelmä analysoida tietoja oli kirjallisuuskatsauksen , induktiivisella sisällön analyysinmenetelmä analysoidatietoja. Analyysissä viisitoista artikkelia uudelleen. Tutkimuksen tulokset osoittavat, että on olemassayhteys henkiseen hyvinvointiin ja lievittävä hoito ja hoitoonlievittävä potilaan kokonaisvaltaista lähestymistapaa, auttaa parantamaan paitsihenkisen hyvinvoinnin , mutta myösyleistä hyvinvointia kuolevan potilaan. Hoitotyön keskeinen palliatiivinen hoito kuuluvat seuranta- ja hallinnoinnista kivunlievitystä, joka mahdollistaa potilaiden ja perheidenpäätoöksenteossa, ja tarjoaa henkistä tukea.</p>	
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### 3 INTRODUCTION

Even under the best of circumstances, facing one's own mortality is very difficult. Diagnosis of a terminal illness commences a challenging and often stressful time. Coping with the pain, grief, and anxiety that comes from a terminal illness is not only physically overwhelming but it also affects the mental wellbeing of the patient. Ferrell et al., (1995) observed that, depression, suffering, dependency/lack of independence, anxiety/fear, loneliness, decreased self-esteem/self-respect, guilt/anger, adjustment to the illness/prognosis, satisfaction with care, denial, are psychological effects that have an impact on the mental wellbeing of patients in palliative care.

About a hundred years ago, the occurrence of death was typically sudden; the risk factors were at birth, infections and accidents, sudden death is not as common today. Approaching end of life majority of the patients develop a life threatening, progressive illness for example cancer, heart diseases that decrease activity until death (Murray et al., 2005).

Access to public health, improving lifestyles, and timely interventions has given the human being longer life, with long life comes chronic illnesses (Lynn and Forlini 2001). The resulting effect is people are living longer from the time of diagnosis to death. This has raised the burden on individual patients, caregivers, families and health care delivery systems. Palliative care addresses people suffering from chronic and serious ailments such as cancer, cardiac diseases such as congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), kidney failure, Alzheimer's, Parkinson's, amyotrophic lateral sclerosis (ALS) and many more (Glare and Virik, 2001).

Whereas the physical challenges of a terminal illness are undeniably clear, the emotional and mental disturbance often lurks below the surface and is easy to go unaddressed in a patient undergoing palliative care. Clearly, the impact of a terminal disease diagnosis on the mental and emotional wellbeing is devastating and often characterized by anxiety, shock, disbelief, anger, difficulties in undertaking activities of daily living, and depression. At each transitional phase of the disease a similar response occurs that is commencing treatment, recurrence, failure to find treatment, disease progression and finally imminent death (Pasacreta and Pickett 1998).

Interest in mental wellbeing of patients under palliative care developed after interacting with patients at Vitas Hospice in Southern California. Motivation for choosing this topic was as a result of working closely with a patient who was on hospice. He specifically identified his mental wellbeing as the most neglected area of care. This review explores nursing interventions that support and promote the mental wellbeing of patients under palliative care.

Several studies Sanson-Fisher et al., (2000), Soothill et al., (2001) argue that patients in palliative care with an advanced stage of illness have high levels of psychosocial needs that are not properly addressed including mental and social wellbeing needs. Professional caregivers emphasize focus on physical problems and to a less extent on mental wellbeing and other psychosocial needs. They also appear to be selective in patients' needs receptiveness which implies that the psychological problems and emotional needs are not adequately addressed (Sanson-Fisher et al 2000; Fallowfield et al, 2001).

Patients diagnosed with terminal illness like cancer often report that nurses providing care do not understand their psychosocial needs and in particular their mental wellbeing, they do not consider psychosocial support an integral part of their care and are unaware of psychosocial health care resources. They fail to adequately treat, evaluate or offer referral for depression or other ramifications of stress resulting from the illness in patients and their families (Maly et al 2005).

## **4 BACKGROUND**

All over the world, changing demographic trends for example increased life expectancy for people living with life-limiting diseases, an ageing population, and the after-effects of disease on a patient's social, physical and mental wellbeing means that the demand for holistic, evidence based, high quality palliative care is expected to increase. (Williams et al, 2010).

There is a rapid increase in the number of hospice and palliative care programs in recent years; this is in response to increase in number of people living with debilitating and life-threatening illness and injury (Pantilat and Billings 2003).



Ferlay and Boniol et al., (2007) noted that in Europe only, it is estimated that 3.2 million individuals are newly diagnosed with cancer, it's also estimated that 1.7 million deaths occur annually. In 2003, The World Health Organization (WHO) estimated that there will be a 24% increase (over 2.1 million) in the number of people dying each year from cancer by 2020 (WHO 2003).

The rising cost of health care worldwide resulting in cuts to palliative care resources, staff members, and services translates to palliative care nurses not spending adequate time with patients resulting to neglect in key areas such as mental and social wellbeing. This often leads to depression. Palliative care patients with cancer in its advanced stages for example are vulnerable to a plethora of psychological and mental wellbeing problems such as depression and anxiety (Lloyd-Williams et al (2004).

According to Smith et al., (2003) anxiety and depression have symptoms that can add unnecessary suffering to the patient. They also significantly impact the physical, psychological wellbeing and social aspects of quality of life of palliative care patients.

Breitbart et al., (2000) observes that increasing anxiety and depression in palliative care patients leads to deterioration of their mental wellbeing to a point they are not able to understand aspects of their care and illness. Depression and hopelessness are predictors of a desire for hastened death among the terminally ill patients. Singer et al., (1999) argues that “ even mild to moderate distress can result in difficulties in finding closure and saying goodbye at the end of life, and this affects the wellbeing of the patient and family members and their ability to cope during a patient's illness and after his or her death”.

## **4.1 Palliative care**

According to World Health Organization (WHO 2006), palliative care is an approach that improves the quality of life of patients and families facing the problems 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. Palliative care:

- Provides relief from pain and other symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten nor postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- Will enhance quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Palliative care is the active, holistic care of patients with advanced progressive illness and their families. Care is focused on the total patient encompassing body, mind and spirit. Throughout the continuum of the disease, palliative care recognizes and addresses the needs of the patient and necessitates access to information, patient autonomy, and choice. Some of these needs may be emotional, psychological, cultural, intellectual, spiritual, social and or physical. It is both a highly structured care delivery system and a philosophy of care. This care optimizes quality of life by anticipating, preventing, alleviating suffering (WHO 2002).

Palliative care can be given as the main focus of care or alongside life prolonging interventions. This care begins the moment an individual is diagnosed with a life-threatening disease and continues until a reversal is attained or death occurs. Its provision is indicated throughout the trajectory of the illness and should not be restricted to the end-of-life phase. Underlying the philosophy of a palliative approach is a positive and open attitude towards death and dying. This philos-

ophy points out that the individual patient's own concept of what is good mental wellbeing should direct all interventions of the palliative care team (Pantilat and Billings 2003).

Providing palliative care involves bereavement and grief support both for the family and other caregivers during the life of the patient and continuing after the death of the patient. Palliative care aims at maximizing quality of life for the dying patient. Palliation is more than a physical experience, the effect of cultural, spiritual, emotional and mental wellbeing on the dying process asks for a style of care that doesn't look at death from a medical point of view rather it should be viewed as a process. Most palliative care patients desire an end of life experience that is peaceful and dignified, where they can exercise their own autonomy and remain in control to the greatest extent possible (Breier-Mackie, 2001).

Terminally ill patients can exhibit numerous emotions and reactions for example sadness, helplessness, hopelessness anxiety, fear and even distress. Palliative care treatment is tailored and based on the individual patient's physical, mental wellbeing, and spiritual needs, because each patient is different from the other (Lawton and Carroll 2005). Nurses must develop skills that will help terminally ill patients face these emotions, and support the patient's emotional and mental wellbeing. Palliative care renders treatment for symptoms regardless of whether the underlying sickness is being cured. When diagnosis of a terminal illness is made patients initially react in shock and disbelief, often characterized by indifference, disbelief, and not acknowledging the reality of the diagnosis. Nurses are uniquely situated to address mental wellbeing issues and to establish trust and good therapeutic relationship with dying people and families. (Engler et al., 2004).

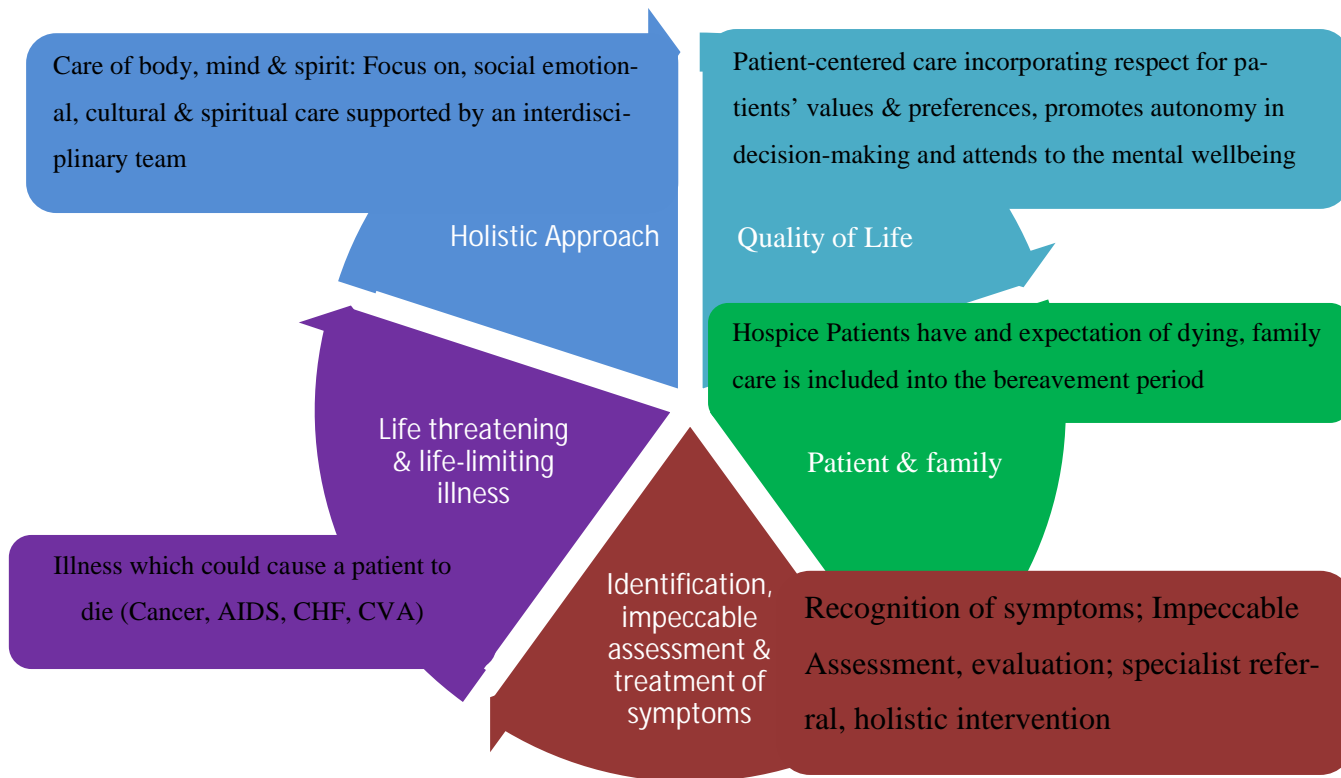


Diagram 1: Palliative care (Adapted from the English Journal of Palliative Care)

## 4.2 Mental wellbeing

Cronin de Chavez et al., (2005) has noted that mental wellbeing is difficult to define; there is currently no consensus as to what constitutes mental wellbeing, although generally speaking there is a convergence in theoretical understandings focalizing on three major aspects of physical social and mental wellbeing (psychological wellbeing).

Disease trajectories are changing, people who have been diagnosed with terminal illnesses today will most likely live longer with that illness. But living longer does not mean living better. In the course of this time terminally ill patients will likely encounter pain, discomfort, and other symptoms related the illness or the treatment. They will likely also have mental wellbeing challenges that are part of living with a life threatening illness (Cochrane et al, 2008).

Patients facing end of life care need a lot of support both from the family and the caring team, patients with improved mental wellbeing, develop emotionally, continue to initiate, develop and get involved in mutually satisfying personal relationships. They continue to develop individual resources such as self-esteem optimism, and a sense of mastery and coherence, they remain aware of others and empathize with them, and they use and enjoy solitude. From a subjective point of view an individual's level of wellbeing or happiness can be identified easily (Ryan and Deci 2001).

Supporting the mental wellbeing of patients undergoing palliative care is an important aspect of their care. Mental wellbeing impacts many aspects of health and social functioning including survival (Danner and Snowdon et al., 2001). Mental wellbeing encompasses the capacity to realize one's abilities, and live life with purpose and meaning, feeling connected and supported, experiencing contentment and peace of mind (Keyes and Dhingra et al., 2010).

The Public Health Agency of Canada (PHAC), defines mental wellbeing as the capacity of each and all of us to feel, think, and act in ways that enhance our ability to enjoy life and deal with the challenges we face. It is a positive sense of emotional and spiritual well-being that respects the importance of culture, equity, social justice, interconnections and personal dignity (PHAC 2006).

According to the World Health Organization (WHO), mental health is “a state of well-being in which the individuals realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully and is able to make a contribution to his or her community (WHO 2001).

Researchers argue that mental wellbeing in palliative care is better understood in terms of overall happiness or satisfaction with life. However, other models Marks (2005), add two dimensions to this view. Satisfaction; this includes pleasure and enjoyment, Personal development; entails being engaged in life, curiosity, autonomy, fulfilling potential and feeling that life has meaning.

Mental health can also be defined as the emotional resilience that enables us to survive pain, disappointment and sadness. It can include many different experiences or situations that affect the health and wellbeing of an individual. Mental health is an important component of the overall wellbeing. Mental wellbeing details how we think and feel both for self and others, confidence

and ability to control things in our life. Mental wellbeing goes beyond having mental health problems, and is not the presence or absence of a diagnosed mental ailment (Lyubomirsky et al., 2005).

According to Huppert (2009) mental wellbeing in palliative care is a sum total of feeling good and functioning effectively, this doesn't not mean that the individual feels good all the time, painful emotions like grief, failure and unmet needs is a normal part of life. The ability to manage these negative emotions is important to supporting mental wellbeing. An individual's resilience to cope with life's difficulties and the potential of enjoying life can be promoted by looking after his or her mental wellbeing. This can be done for example, through availing relaxation and social activities.

The concept of feeling good in palliative care encompasses positive emotions of happiness and contentment, together with interest, engagement, confidence, and affection, whereas the concept of functioning effectively entails developing an individual's potential, maintaining some control over his or her life, experiencing positive relationships and maintain a sense of purpose.

### **4.3 End-of-Life Care**

There is no clear cut definition of end of life care; generally it refers to the last few moments when the patient is irreversibly dying. Whilst there are cases where identifying the end of life stage accurately is possible, most illnesses progress and exacerbate which makes the transition to the end of life hard to identify (Lunney, Foley, Smith and Gelband 2003).

Lorenz and Lynn et al., (2008) identify that there is a lot of ambiguity in defining end of life care, it's defined as a phase in the spectrum of palliative care which is rendered when a patient's course of illness is determined to be progressively heading towards death and interventions that prolong life are no longer desired, effective or appropriate. This care is not limited to the brief period when the dying patient is moribund. Effective nursing care can prevent or alleviate suffering at the end of life by assessing symptoms and availing social and mental wellbeing support to patients and families.

End of life decision making is complex, it involves making difficult decisions for example when is life support initiated or discontinued, when is a feeding tube placed or when does feeding stop, or when is a tracheostomy placed. Sometimes the patient doesn't have the capacity to make such decisions hence the family assume the role of decision maker. One of the biggest challenges in end of life care is deciding when to initiate talks about end of life with the family or patient (Orbele and Hughes 2001).

## **5 THEORETICAL FRAMEWORK**

Theoretical framework is a compilation of organized concepts or ideas that guide the research. It provides a particular perspective, or lens through which to examine the topic under study. The theoretical framework used for this literature review is "The Peaceful End of Life Theory". This theory was developed by Cornelia Ruland and Shirley M. Moore in 1998. Establishment of this theory was based on standards of care that were developed by nurses from Norway; these nurses were clinical experts in the surgical gastroenterology unit at the university hospital.

It's a relatively young, middle range theory developed with a nursing goal of managing patients with terminal illnesses, enhancing quality of life and ensuring achievement of a peaceful end of life. Peaceful end of life relates to nursing interventions and outcomes specific to terminally ill patients. The standards of care were known empirical evidences that examined the link between process and outcome.

Ruland and Moore (1998) outline that nurses are integral to the support and promotion of peaceful end of life. It's the duty of nurses as caregivers to strive to improve the quality of life for patients facing the end of their lives. Facing life with a terminal illness impacts all aspects of life, this affects the physical, mental spiritual and social wellbeing components of the patient's life. This impact is not only felt by the patient under palliative care, but also by his or her support system too. Ruland and Moore (1998) emphasized focus on the holistic nursing care needs of the individual patient, this acted as a guide for practice.

The final standard of care had sixteen (16) outcome criteria which were critically examined and consequently reduced to five (5) common themes or concepts, also called outcome indicators. These five concepts are:

- (a) Absence of pain,
- (b) Feeling of being at peace,
- (c) Experiencing comfort,
- (d) Respect and dignity,
- (e) Being close to significant others and feeling connected to people who care.

To be free of pain is defined within the peaceful end of life theory as not experiencing pain. The theory also describes pain as an unpleasant, sensory, and emotional experience associated with actual and potential tissue damage. Feeling of being at peace involves feelings of calmness, harmony and contentment. It advocates for provision of freedom from anxiety, fear and worry. Relief from discomfort means, having the ease and peaceful contentment, experiencing those things that make life easy and pleasurable (Ruland and Moore 1998).

Social support at the end of life is important in promoting the mental wellbeing of the patient undergoing palliative care. This support when offered at the right time helps the patient to feel cared for, loved, appreciated, esteemed and valued and that he or she belongs to a network of people who are close. Peaceful end of life theory has highlighted the concept of closeness to significant others which means that the patient is closely connected to other human beings who care. Highlighted also is the concept of dignity and respect, this entails being appreciated, respected and valued as a human being. The feeling of respect and being treated with dignity improves the dying patient's mental wellbeing. The main focus of developing this theory was not on the dying moment itself, or the process of dying but rather it proposes peaceful and meaningful living for the entire duration from diagnoses to death, irrespective of the length of life remaining (Ruland and Moore 1998).



The patient and the family according to the theory, have confidence that they will get the best available care, they are able to maintain hope, and meaningfulness, and they are able to take part in the decision making process regarding the care of the dying patient. The theorists continue to say that both the patient and the family will be assisted in sorting out and addressing practical and economic issues pertaining to their loved one's coming to an end of life. (Ruland and Moore 1998).

The theory advocates for the family or significant others to be given an opportunity to take part in the care as they desire, and in accordance to their beliefs, cultural rites, wishes and they be able to bid farewell to the patient. The family should be informed about various funeral procedures and possibilities and a follow up visit should be organized into the bereavement phase.

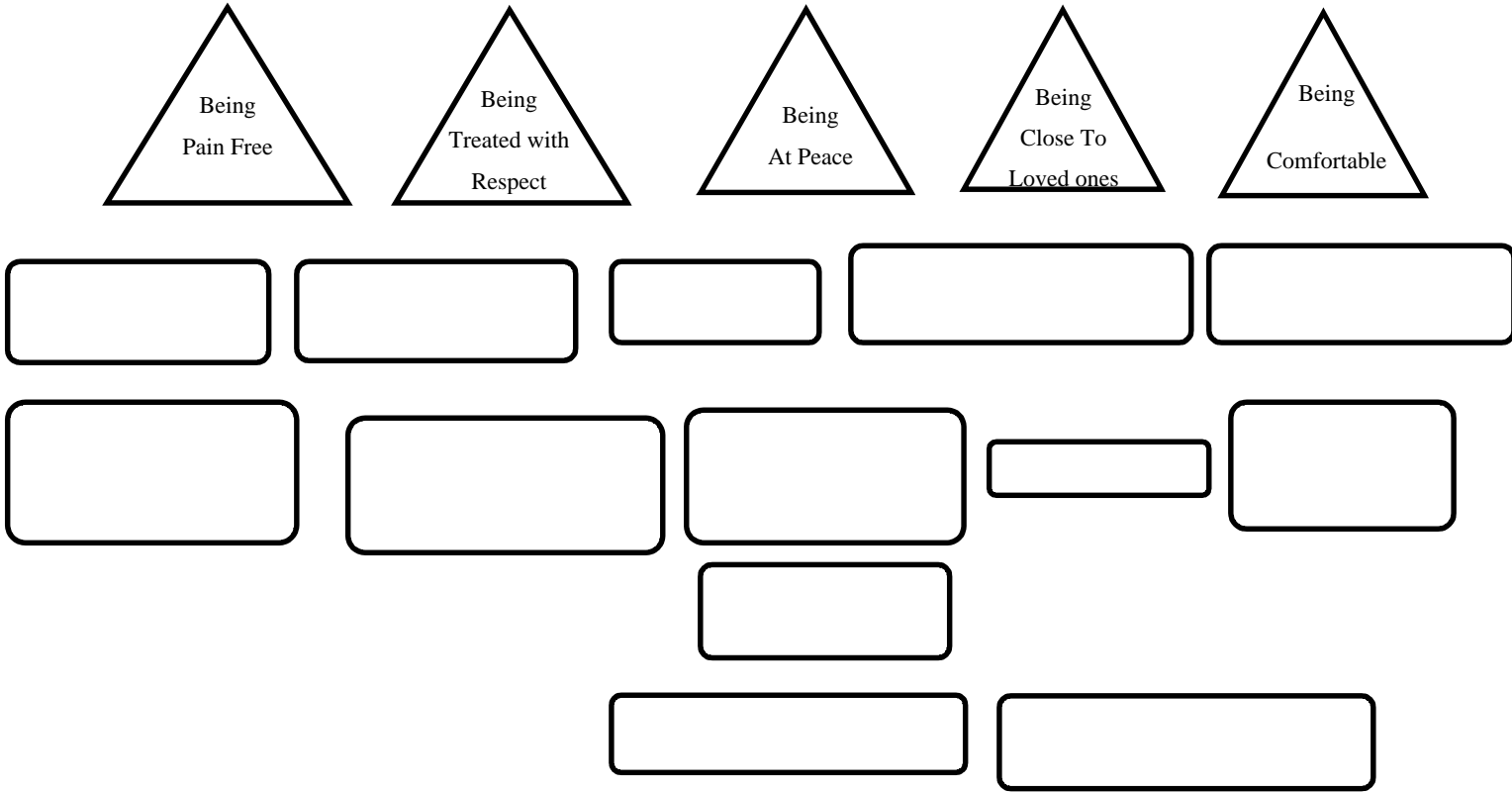
## **5.1 Assumptions of the end of life theory**

Ruland and Moore started by making two main assumptions to the theory of peaceful end of life, the first basic assumption was that the feelings and experiences felt by a person approaching the end of life are personal and specific to each individual. The second assumption is that in order for a patient approaching the end of life to have a peaceful experience, nursing care is critical. Nursing care presents the opportunity to observe and interpret signals expressed by patients regarding comfort level and state of peace, and allows interventions to be implemented.

Two implicit assumptions were added, which are (a) Family also referred to as significant others, is an integral part of end of life care. (b) The main focus of end-of-life care is to maximize treatment. The best available care will be provided by judiciously using comfort measures and technology, so as to enhance quality of life and attain a peaceful death. (Ruland and Moore 1998).

Table 1. Below shows the outcome indicators

PEACEFUL END OF LIFE THEORY, RULAND AND MOORE



*Table 1: Conceptual relationships for a peaceful end of life.*

*(Derived from “theory construction based on standards of care: A proposed theory of the peaceful end of life” by C.M Ruland and S.M Moore, 1998.)*

The author considered a few theories, including Kubler-Ross five stages of grief model, and Watson's theory of human caring, but after reviewing them the author settled for the peaceful end of life theory. Reasons for choosing this theory it's simple and easy to understand, it addresses patient specific interventions that shed a light to the research questions, for example beneath each of the five concepts or outcome indicators are specific nursing interventions that address the various problems or needs that are encountered near the end-of-life. This theory was found to be straightforward, patient specific and less likely to contain vague perspective of a dying patient.

The peaceful end of life theory, in part answers the second research question, it describes nursing interventions and outcomes specific to dying patients. The six relational statements which were identified as theoretical assertions for theory by Ruland and Moore, when applied in a timely manner, they contribute to the overall mental wellbeing of the dying patient. The assertions are actual interventions that nurses can utilize to arrive at a peaceful death, while ensuring that the patient's mental wellbeing is addressed. The theoretical assertions and propositions are:

- (a) Assess, monitor and give pain relief using pharmacological and non-pharmacological interventions ensuring that the patient experiences not being in pain.
- (b) For a patient to experience comfort, complications should be prevented, contentment and relaxation to facilitate rest should be provided while eliminating physical discomfort.
- (c) Giving the family the possibilities to participate in decision making process, and ensuring that the patient is accorded respect, empathy, dignity and that the wishes and preferences of the patient are given attention.
- (d) Assess and administer anti-anxiety medications when the patient needs them, building mutual trust between the nurse, the patient and the family, giving psychological and emotional support while providing guidance in practical issues and allowing the preference of another caring person all result in patients experience of being at peace.
- (e) Accommodate family's worries, grief, questions while availing opportunities for family closeness leads to the patient's experience of closeness to family and the caregiver.

(f) Patient's experience of being pain free, comfort, dignity, and respect, having peace, closeness to significant others or family who contribute to peaceful end of life.

A palliative care patient who is experiencing peace, is comfortable and enjoys good quality of life has improved mental wellbeing, and is able to enjoy life to the fullest regardless of how long it will last. Significant level of improvement in the patients mental wellbeing is attained when the outlined nursing interventions are applied in a timely manner bearing in mind the patient's wishes, culture, spirituality and belief system. Knowing that economic/financial issues at the end of life are being addressed promotes the mental wellbeing in a terminally ill patient (Ruland and Moore 1998).

## **6 AIMS AND RESEARCH QUESTIONS**

The aim of this review is to elicit knowledge and understanding of current nursing interventions that promote mental wellbeing of patients in palliative care. The purpose of this literature review is to explore and identify existing evidence on the link between mental wellbeing and patients in palliative care.

### ***Research Questions***

The review considered the following research questions in relation to mental wellbeing.

- a) What is the connection between mental wellbeing and palliative care?
- b) What interventions are central for promoting mental wellbeing of patients in palliative care?

## **7 METHODOLOGY**

Research methodology refers to the overall approach to the research process, it entails choosing and using particular strategies and tools to gather, analyze data and provide answers to the research question. The type of methodology used depends on the nature of the research question (Dillon 2005).

The method used by the author was literature review using inductive content analysis as the method of analyzing the data. Webster and Watson (2002), define an effective literature review as an illustration of literature relevant to a particular topic or field. Literature review describes an overview of what has been said, the main writers are, what are the existing hypotheses and theories, what questions are being asked. In general a literature review should be organized around and directly related to the thesis or research question that is being developed. A literature review should synthesize findings into a summary of what is known and what is not known, point out areas of controversy in the literature and finally formulate questions for further research.

## 7.1 Data collection

Prior to data collection, an approval for the thesis commission was sought from the commissioning party; subsequently all relevant paperwork was signed. Through Arcada University of Applied Science, Nelli-Portal database was accessed and a number of databases were searched for pre-existing articles. These articles will provide background information about the topic, and answer the research questions.

Keywords to be used in searching and exploring the databases were set. In the beginning there were three keywords “palliative care”, “mental wellbeing” and “end of life”. These were classified as the search categories, words that have similar meaning were applied under each search category, as seen in figure below.

<b>SEARCH CATEGORY</b>	1. Palliative care	1. Mental Wellbeing	2. End of life care
<b>SEARCH TERMS</b>	Hospice	Psychological wellbeing.	Death and dying, Terminal care

Table 2: The search categories.

In EBSCO and MEDLINE the interface is designed in a way that the use of AND during searching is possible, and if necessary additional rows of ANDs can be created to further expand the search. Boolean logic was used for these searches. Boolean operators (and, or) were used to link the search terms. 'Or' was used to link the search terms within each search category, whilst 'And' was used to link the search categories together. Words were truncated with an asterisk (\*) to allow for multiple endings for these words.

However in some databases such as PUBMED and SCIENCEDIRECT, the interface is different from EBSCO and MEDLINE, the search field is designed in a sentence form. Keywords from the search category were used to form well-structured sentences to be used in searching for relevant articles. Example of sentences used to search articles in SCIENCEDIRECT and PUBMED were, 'what is mental wellbeing at the end of life', 'end of life nursing interventions' and hospice nursing interventions that promote mental wellbeing.

The author examined the articles to ensure that majority of the articles that provided answers to the research questions were contact based and only a few of them were theory based, the rationale for this is based on the fact that theory based articles and researches utilize arguments as a basis of deriving conclusions, hence a high probability of making errors in the results/ conclusion. Contact based studies on the other hand utilize real life data that has been drawn from questionnaires and interviews thereby minimizing the chance of errors.

<b>Data-bases</b>	<b>Search Category Combination</b>	<b>Number of Hits</b>	<b>Evolved Articles</b>	<b>Relevant Articles</b>	<b>Selected articles</b>
MEDLINE	'Palliative care OR hospice'	2,207	11	4	6
	'Mental wellbeing AND palliative care'	1,194	24	6	
	'End of life care and mental wellbeing'	967	19	3	
EBSCO	'Palliative care OR hospice'	853	27	13	5
	'Mental wellbeing AND palliative care'	117	9	2	
	'End of life care and mental wellbeing'	241	12	1	
SCIENCE DIRECT	'Palliative care OR hospice'	19,521	56	24	11
	'Mental wellbeing AND palliative care'	4,161	34	11	
	'End of life care and mental wellbeing'	12,017	28	7	
PUBMED	'Palliative care OR hospice'	42,962	76	17	18
	'Mental wellbeing AND palliative care'	347	37	2	
	'End of life care and mental wellbeing'	964	51	5	

*Table 3: Articles retrieval*

### ***Including criteria***

Prior to the search, research questions were formulated in order to identify articles that will provide relevant information. An inclusion criteria was formulated, with an aim of ensuring only articles that met the criteria were selected. Only academic databases such as CINAHL, SCIENCE DIRECT, PUBMED, and MEDLINE were used to search for articles for the study. All articles must be published in English and are free to access that is no price tag attached for the article since the study was not a sponsored or funded study.

The articles must have been published from 1995-2013, this is to ensure only recent articles were included for this study. Initially the year of publication was set as 2008, but it was observed that majority of the relevant articles developed concepts and ideas from earlier articles, i.e. articles published prior to 2008. The publication year was adjusted to accommodate this situation in order to allow access to more relevant articles. The year 1995 was set as the year of publication; however the number of old articles was kept in check to limit having numerous old articles for the review. Room for flexibility when selecting the articles was considered because of the number of articles kept changing. In total forty two articles were considered for the review.

### ***Excluding criteria***

It was necessary for the author to include some criteria in excluding articles; this will ensure reliability of the study and establish articles that are relevant to this review

All articles whose material was irrelevant and non-scientific were not considered. Articles below the year 1995 were eliminated. Biased articles were excluded, in order to attain credibility for the study. The selection criterion is summarized in the table below. The criterion used is presented in the table below.



<b>Including criteria</b>	<b>Excluding criteria</b>
<ol style="list-style-type: none"> <li>1. Must be retrieved from an academic database For example CINAHL, PUBMED, SCIENCEDIRECT, SAGE, ACADEMIC SEARCH ELITE (EBSCO) AND OVID</li> <li>2. Must be written in English language only</li> <li>3. Year of publication must be from 1995 and above.</li> <li>4. The content must not be biased</li> <li>5. Articles must be relevant to the topic</li> </ol>	<ol style="list-style-type: none"> <li>1. Not from academic database, articles from conference papers, trade journals, blogs, magazines.</li> <li>2. Articles not written in English language</li> <li>3. Articles published below year 1995</li> <li>4. Articles whose content is biased</li> <li>5. Irrelevant articles</li> </ol>

*Table 4: Including and excluding criteria table*

**7.2 Data Analysis**

In qualitative research, data analysis process is fundamental in determining credibility of the results. Essentially it entails transformation of raw data into a narrative or categories and themes. There is a variation in how data analysis is undertaken depending on the approach taken by the researcher and the research question (Vishnevsky and Beanlands 2004).

The method used by the author in analyzing data for this study is qualitative content analysis. According to Kondracki and Wellman (2002) content analysis is a research method for the subjective interpretation of data content through the systematic classification process of coding and identifying themes or patterns. Qualitative content analysis seeks to provide knowledge and understanding of the phenomenon which is being studied, in this case the mental wellbeing of palliative care patients.

Qualitative content analysis helps the researcher to understand social reality in a subjective but scientific way through evaluating content, recurrent themes, and implications in a particular volume of data. It details unique themes that show the range of meanings of phenomenon rather than the statistical implication of an occurrence of particular texts or concepts (Hsieh and Shannon 2005).

Content analysis as a research method is objective and systematic. Replicable and valid inferences are made from data with the goal of providing insights, knowledge, and a working action guide. The benefit of using content analysis is that it is it's flexible in terms of research design and also content sensitive. Some critics in the quantitative field argue that the method is too simplistic and not sufficiently qualitative. However, other researchers call it easy or as difficult as the researcher wants it to be (Elo and Kyngäs 2008).

The author selected qualitative content analysis because of the following advantages:

1. It is un-obstructive
2. It is used to interpret texts for a wide range of purposes and most specifically in health care.
3. Its context-sensitive
4. Inexpensive (minimum monetary investment, if any)
5. Can be used to analyze large bodies of texts.

However as with any other research method qualitative content analysis has its limitations for example when conducting a manual content analysis can be an enormous labor intensive project, mostly because the coding scheme becomes more complex or the data to be studied increases (Kondracki and Wellman 2002). The author ensured that sufficient time was allocated to reading the articles and developing the categories.

Graneheim and Lundman (2004) point out that content analysis focuses to a great extent on the context, emphasizing differences between and similarities within codes and categories. It deals with both manifest and latent content in a text. What the text says (manifest content), is normally

presented in categories, whereas themes are viewed as expressions of the latent content (what the text is talking about). The researcher at the beginning of the study must make a decision on what to analyze, latent or manifest content. This study will consider the manifest content.

The study by Elo and Kyngäs (2008) is noteworthy in that it explains that content analysis method can be used to analyze both quantitative and qualitative data, either inductively or deductively. In cases where scarce previous knowledge exists about a phenomenon, or the existing knowledge is fragmented, the inductive approach is applied. When there is a surplus of already existing knowledge, the deductive approach is used.

Initially the author considered both deductive and inductive approaches, but when the search for the articles commenced it was realized that few or no previous studies existed about the mental wellbeing in palliative care. Due to the scarcity of data about previous studies in mental wellbeing of patients in palliative care, an inductive approach was considered appropriate for this study. In this approach concepts will be derived from the data as opposed to a deductive approach where the structure of analysis is based on previous knowledge. An inductive approach starts from the specific to the general; here particular instances are taken into consideration and later put together into a larger whole. The value of content analysis lies in its capacity to explore questions which cannot be answered by quantitative methods Kohlbacher F. (2005).

### ***Inductive vs. Deductive***

Qualitative content analysis involves a process of condensing raw data into categories to themes based on valid inferences and interpretation. It can be used both with quantitative and qualitative data. This process applies inductive reasoning, whereby themes and categories emerge from the data through the researcher's careful examination and constant comparison (Elo and Kyngas 2008).

Hsieh and Shannon (2005) have put forward three approaches to qualitative content analysis, based on the degree of involvement of inductive reasoning.

(a). Conventional qualitative content analysis, here coding categories are derived directly and inductively from the raw data. This is the approach used for grounded theory development.

(b). Directed content analysis in which initial coding commences with a theory or relevant research findings, then when analyzing the data, the researcher allows themes to emerge from the data. The purpose of this approach is to validate or extend a conceptual framework or theory

(c). Summative content analysis begins with the counting of words or manifest content, then extends the analysis to encompass latent meanings and themes. It may appear quantitative in the early phase, but its aim is to explore the usage of words indicators in an inductive manner.

Qualitative content analysis allows the author to assign a unit of text to more than one category simultaneously unlike quantitative content analysis where categories are mutually exclusive, which means that a phrase, sentence or word must belong to only one category.

Based on the above definitions and descriptions of content analysis the author decided that content analysis is the best method to analyze data for this study. In analyzing the data, attention was reflected back to the research questions, “What is the connection between mental wellbeing and palliative care and what are the nursing interventions central to promoting the mental wellbeing of patients in palliative care. The author then tried to make sense of the data and understand it as a whole in order to ensure focus on specific, relevant aspects of the content.

The author began by organizing the articles using the open coding process; first the articles were numbered in the following manner [1], [2], [3]..... [15], in referencing the text this numbers were used as representatives of the articles. Elo and Kyngäs (2008) state that, when analyzing data, open coding is applied whereby the researcher first reads the material thoroughly, identifying key words that relate to the research question. In open coding the researcher reviews the material, making notes and headings in the text as they read. This process often requires repeated reading of the articles. The articles were read several times, brief notes of interesting or relevant information were written on the margins. The notes made on the margins were re-read again and the different types of information listed.

Examining the list that was made, each item was categorized in a way that offers a description of what it's about. Identification of whether or not the categories were linked in any way was undertaken and the categories were listed as major categories (or themes) and/ or minor categories (or themes). At this point both the major and the minor categories were examined in detail to see

if they fit, are relevant and if the information is categorized as it should be. A review of the categories was made to ascertain whether some categories can be merged or if some categories need to be sub-categorized. Finally the author returned to the original articles to ensure that all the information that needed to be categorized had been done.

The categories were in response to the research questions, and the classification that will most efficiently yield the data needed to provide solutions to the research questions. Using the inductive content analysis approach, a theme for the study was formulated, grouped into 3 categories and 9 sub categories.

<b>Author</b>	<b>Title</b>	<b>Year</b>	<b>Methods used</b>	<b>Results/ Conclusion</b>
<b>Article 1</b> RJ Uitterhoev, M Vernooy, M Litjens, K Potting, J Bensing, P De Mulder & T van Achterberg	Psychosocial inter- ventions for patients with advanced can- cer- a systematic re- view of the literature	2004	Systematic review	Evidence shows that psy- chosocial interventions pertaining to behavior therapy were beneficial for patients with ad- vanced cancer.
<b>Article 2</b> R.T Disler, D.C Currow, J.L Phil- lips, T.Smith, M.J Johnson & P.M Davidson	Interventions to sup- port a palliative care approach in patients with chronic obstruc- tive pulmonary dis- ease: An integrative review.	2012	Integrative review	This review has shown that a range of palliative interventions are used to address the needs of in- dividuals with end stage COPD.
<b>Article 3</b> David B.Bekelman, E.Hutt, F.A Masoudi, J.S Kutner, J.S. Rumsfeld	Defining the role of palliative care in old- er adults with heart failure	2007	Case study	Evidence shows that pal- liative and supportive care needs is beneficial for patients with heart failure and their families.
<b>Article 4</b> P.Boston, A. Bruce, & R. Schreiber	Existential suffering in the palliative care setting: An integrated literature review.	2011	An Integrated Literature review	Findings from this re- view reveal that existen- tial suffering and deep personal anguish at that end of life are some of the most debilitating conditions that occur in dying patients.

<b>Article 5</b> G. Moore, A. Collins, C. Brand, M. Gold, C. Lethborg, M. Murphy, V. Sundararajan, J. Phillip	Palliative and supportive care needs of patients with high grade glioma and their carers: A systematic review of qualitative literature	2012	Systematic literature review	This study identified key themes related to the need for consistent well-delivered information around the disease trajectory, the need for psychological and social support in caring for patients in palliative care.
<b>Article 6</b> B.C Evans & E. Ume	Psychosocial, cultural, and spiritual health disparities in end of life and palliative care: Where we are and where we need to go.	2012	Systematic literature review	This study shows that minorities make little use of palliative care, family-centered cultures, and preferences for more aggressive end of life care than hospice allows.
<b>Article 7</b> L. Rayner, A. Price, M. Hotopf, I.J. Higginson.	The development of evidence-based European guidelines on the management of depression in palliative cancer care	2010	The Delphi method	The guideline that was developed has 3 main sections: prevention; detection; diagnosis and treatment. It outlines strategies such as optimal palliative care and support, effective communication and giving information.
<b>Article 8</b> D.B McGuire, M. Grant, J. Park	Palliative care and end of life: The caregiver	2012	Systematic literature review	The results of this article show that informal caregivers are the bedrock of palliative care and they are also increasingly recognized as recipients of care.
<b>Article 9</b> U. Ostlund, H. Brown, B. Johnston	Dignity conserving care at the end of life: A narrative review	2012	Narrative review	This study identified several actions that relate to themes contained within the dignity model.
<b>Article 10</b> R. L Beckstrand, L. C Callister and K. T Kirchhoff	Providing a “Good Death” : Critical care nurses suggestions for improving end of life care			861 critical care nurses took the survey, 485 offered about 530 suggestions for improving end of life care.
<b>Article 11</b> B. Johnston, M. McGill, S. Milligan, D. McElroy, C. Foster &	Self-care and end of life in advanced cancer: Literature review.	2009	Literature review	This study identified themes such as interventions for end of life care; self-care behaviors used by patients, factors that

N.Kearney				prevent patients self-care
<b>Article 12</b> N. Reavley, J.F Pallant, &A.Sali	Evaluation of the effects of a psychosocial intervention on mood, coping and quality of life in cancer	2009		This study describes the social, medical and psychological characteristics of participants in a psychosocial intervention designed for cancer patients. Results suggest that the program has significant beneficial effects on adjustment.
<b>Article 13</b> S. Kaasa & J. H. Loge	Quality of life in palliative care: principles and practice.	2003		This study suggests that outcome measures in palliative care need constructs that show particular goals of palliative care for example controlling symptoms.
<b>Article 14</b> C. Gardiner, M. Harrison, T.Ryan& A. Jones	Provision of palliative and end of life care in stroke units: A qualitative study.	2013	Qualitative study	From the data three themes emerged, In care of patients diagnosed with a stroke, palliative care emerged as an important component of care.
<b>Article 15</b> W. Gao, M.I. Bennett, D. Stark, S. Murray, and I.J. Higginson	Psychological distress in cancer from survivorship to end of life care: Prevalence, associated factors and clinical implications	2010	Interviews and questionnaires	This study results indicate cancer patients approaching end of life have an elevated level of mental distress

Table 5: Summary of the articles used in content analysis

### **7.3 Abstraction and Interpretation**

Using data from the articles collected this chapter will attempt to answer the research questions. After the author read and analyzed the articles, patient being viewed and treated as a holistic being emerged as the central theme, every intervention for improving the patient's mental wellbeing was centered on this area. In general the focus was looked at from a nursing point of view.

Using the data that was gathered from the articles the author was able to develop the theme and also provide answers to the research questions, the categories and subcategories were based on paper aim and research questions. Table 6. Shows how the theme emerged or was formulated.



Theme

Category

Sub-category

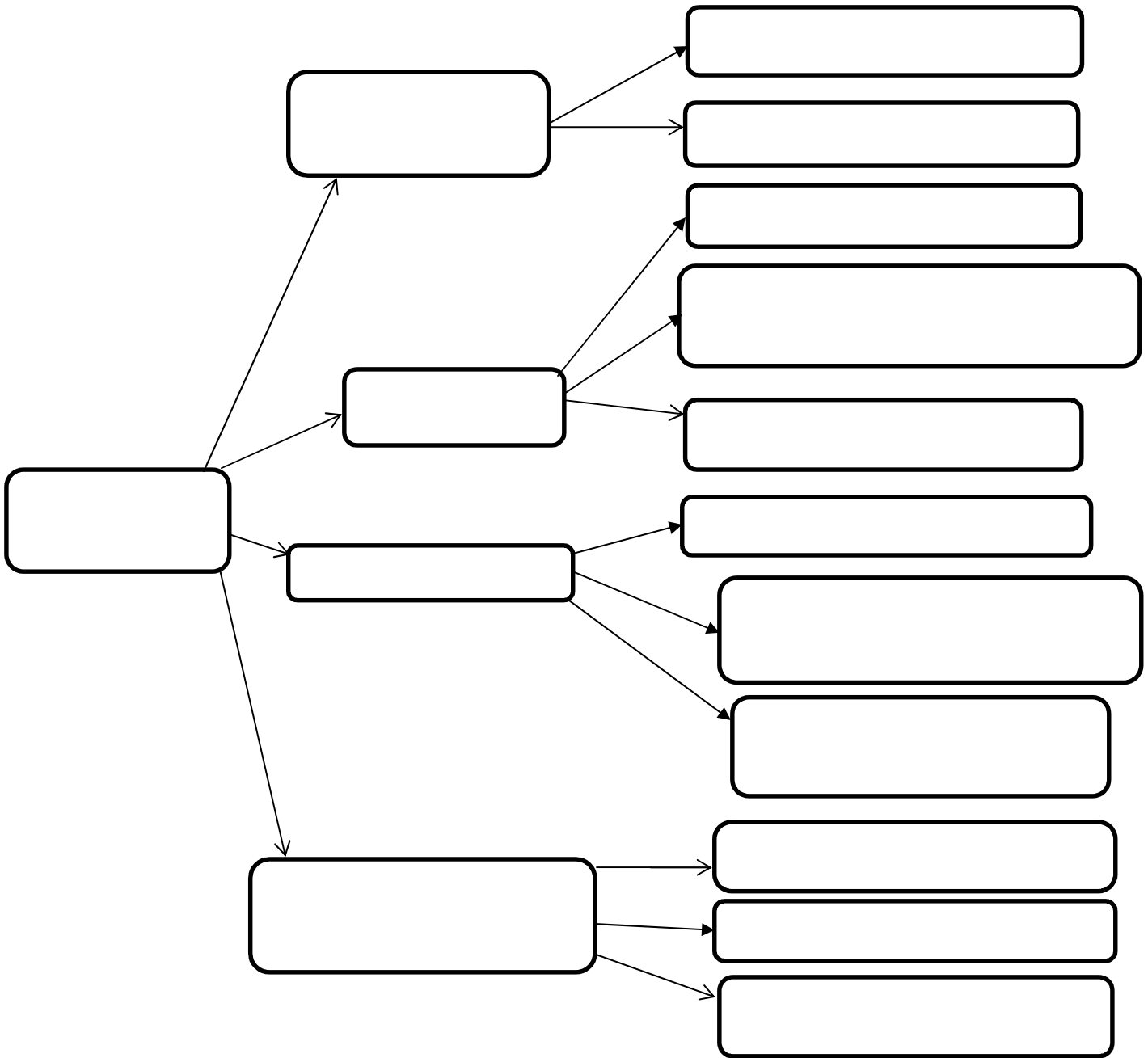


Table 6: Theme, categories and sub-categories formation

## **8 RESULTS**

Here the author further describes the categories that were formulated for this study and how the results of the study answer the research questions.

### **8.1.1 Palliative Patient as a Holistic Being**

Treating a palliative care patient in a holistic manner emerged as the main theme in the study, it involves assessing, planning and delivering care in an approach that takes into consideration the physical, social, economic, psychological and spiritual needs. The palliative patient is cared for and viewed as a whole entity, focus is no longer on the individual ailment but on the patient as a whole. [2, 6, 8, 11].

Each palliative patient is made up of body mind and soul, viewed as a unified total and not just a sum of his/her body parts. In this approach, how a life limiting illness manifests is treated in a more integrated manner. The core of nursing care is intrinsically holistic because from earlier on it had been clarified that care of a patient cannot be single dimensional. This approach puts the palliative patient in a specific time and ethno cultural context. [2, 3, 5, 7, 15].

To answer the first research question, one needs to first understand the holistic approach to palliative care. Holism in palliative care means that the dying patient is viewed as a whole being. It is a philosophy that came about from Florence Nightingale, who believed that care should be focused on wellness, unity, and the interrelationship between human beings, events and the environment. Its goal is promoting health and wellness, assisting in healing and preventing and alleviating suffering. [2, 5, 6, 8, 13]

A connection exists between mental wellbeing and palliative care, a positive mental wellbeing is a key therapeutic variable, which affects the coping skills and adjustment of patients with terminal illnesses, patients at the end of life or palliative care. [2, 7, 11]. Mental wellbeing of a patient in palliative care has a direct effect on the overall wellbeing, quality of life and immune function. Conversely, decreasing levels of positive mental wellbeing also known as negative mental well-

being leads to hopelessness and often results in poor quality of life, depression and a desire to quicken the dying process.

A patient in palliative care needs to be treated with a holistic view in mind. [2,3,4,7,9,10,11] The goal of caring needs to take a holistic basis, taking into consideration the mind, the body, the spirit and the emotional environment of the patient, this will ultimately have an effect on the dying patient's mental wellbeing. Holistic care is based on the philosophy of caring, relationship and interconnectedness [7, 8, 11, 13, and 15]. The caregiver or the person taking care of a palliative patient and in this care it's the nurse needs to recognize and integrate the principles and elements of holistic care in the care of the patient.

Care is focused on improving the quality of life for both the palliative patient and the family. The primary goal here is to provide comfort, relieve physical, emotional, and spiritual suffering and promote dignity of patients facing a life limiting illness. The goal is neither to prolong life nor hasten the dying process. [2, 3, 4, 5, 6, 7, 9, 10 and 11] The whole person is treated and not the disease, the health care team consults and helps in practical needs such as insurance coverage where applicable, advance directives, transportation, emotional and spiritual needs.

### **8.1.2 Socio-cultural factors**

Cultural factors certainly affect patients' mental well-being and their reactions to life limiting illnesses as well as decisions about their end-of-life care. Different ethnic groupings differ in the use of advance directives for example, or the desire for autonomy in making decisions, because doing so may collide with the family-centered values or religious beliefs and values. The nurse or caregiver can also have personal biases that can impact the therapeutic treatment or care of the palliative patient. [7, 8, 12, 15] Asking the patient and the family about their social-cultural beliefs as they relate to death and dying is vital. The nursing staff must commit to respect competent patient requests even if they conflict with the nurses/caregivers personal views.

The patient's and family's understanding of the patient's condition should be evaluated and issues relating to death and dying explored appropriately and sensitively. The patient and the family need to be updated regularly on the patient's condition.

### **8.1.3 Spirituality**

To support the mental wellbeing of a terminally ill patient the caregiver or the nurse but be sensitive to the patient's and family's religious background and views. Some families may request for formal religious rituals to be done in the course of the dying process and this may subsequently influence the care of the body after death has occurred. When the patient passes on the family and the body of the deceased should be treated with respect and compassion. [2, 4, 5, 8, 12, 14 and 15]

Studies are increasingly recognizing spirituality as a crucial element of health and wellbeing of palliative patients. Spirituality brings meaning to the dying patients and family's lives and can be an important tool to help in coping and that may help the patient manage his or her mental wellbeing. Spirituality is identified as a useful resource in finding meaning, comfort, and inner peace. Spirituality brings the concept of hope, coming into terms and accepting the diagnosis is a process, the palliative care team aids the patient in finding objects and ways to find hope. [2, 3, 4, 5, 8 and 9]

To assess a family's sense of hope the caregiver can suggest that the patient hopes not to be in pain, hopes to be treated with respect and dignity, hope to find peace, in some patients hope may lie in being forgiven by God, the promise of life after death, reunion with loved ones. Other patients may be hoping for death, and this is identified as normal, sometimes the hope patients and families hope that there will be an end to the suffering, or an end to what is experienced or perceived as unnecessary existence. [1, 4, 5 and 7]

Spirituality helps the patient's mental wellbeing by helping the patient to find meaning, and address the question "why" which is common in end of life. Many terminally ill patients in palliative care ask the question "why" this is due to the various forms of suffering that the patient may encounter for example loss of independence, watching a loved one decline, feeling of helplessness and powerlessness, all this may affect the mental wellbeing of the dying patient and lead the

patient to ask questions such as what is happening to me, or is there a reason or purpose for this life altering occurrence. Suffering can be made bearable and the patient can be given an opportunity for personal growth and healing. The palliative team needs to respond to expressions of self-blame or anger at God, patients and families need room to express their sense of meaning and purpose. [2, 3, 5, 7, 9 and 11]

#### **8.1.4 Communication**

End-of-life communication is a vital aspect for the palliative care team, when communicating the issue of privacy is of uttermost importance. Ensuring an uninterrupted time to talk with the family and the patient is recommended. When communicating the nurse or caregiver should show empathy, care and compassion, what to expect should be communicated to the patient in a way that he/she will understand. Pacing the information to the patient's speed and preferences circumstances and understanding, while avoiding being too exact with time frames unless in the last few hours before death occurs. The nurse should avoid using technical terms, euphemisms, or jargon and should speak in a clear easy to understand way, explaining the limitations and undependability of prognostic and end of life information. [2, 4, 5, 8 and 9]

To promote the mental wellbeing of the patient the nurse needs to explore and acknowledge the emotions exhibited by the patient, while also addressing the fears and concerns in an empathetic way. The nurse needs to be honest and avoid being blunt by giving more than necessary information to the patient. Reassurance that the patient will be offered support, timely medication and pain relieving measures is encouraged. Facilitating and exploring realistic goals and patient wishes and coping mechanisms on an hour-to-hour basis where applicable. The patient and the family should be encouraged to ask questions and clarifications, and the nurse should from time to time check to see that understanding of what has been discussed is well understood.

Feeling and showing emotions of fear, anger and sadness are normal and cannot be avoided in end-of-life communication. These feelings maybe expressed or experienced alone or together with other feelings. The nurse and the inter-disciplinary care team or palliative care team should be prepared to deal and handle this feelings compassionately. The team also needs to decide on

what information the patient need to hear, when to give the information and be sensitive to who the information about the patient condition is addressed to. [2, 4, 5, 6, 7, 13, 14 and 15]

The family should be informed respectfully and sensitively that the clinical outcome of the patient is death and that the patient will die. The nurse must avoid use of ambiguous terms such as “the patient may not get better” which can lead to misinterpretation and confusion. Several articles stated that a common complaint amongst palliative patients is that nobody discussed with them what is happening and what to expect. Proper communication especially during this time is essential because if the patient is informed clearly that he is dying he/she has the opportunity to ask questions, spend time with family and say their goodbyes, contacting the relevant family members and communicating timely is crucial. [2, 4, 6, 11]

The nurse/caregiver needs to recognize that different patients handle information differently depending on many factors such as level of education, culture, religion, socioeconomic factors age and the developmental level. Sometimes the patients may prefer not to be given critical information the nurse with the aid of the patients’ needs to identify to whom the information should be given. Beliefs, maintenance of legal and ethical care, acknowledgement of grief and loss, assessment of pain and symptoms are all dependent on good communication. [5, 6, 15]

Barriers to effective communication at the end of life may affect the psychological wellbeing of the patient. Such barriers include, fear of own mortality and being insensitive to the situation, interrupting communication, patronizing and denying patient time to express fears and concerns. In end of life nonverbal communication is important and should be encouraged, eye contact should be maintained unless it conflicts with the cultural beliefs of the patient. Team approach when communicating information at the end-of-life care is crucial, while maintaining closeness and normalcy with the family until death is encouraged. [1, 2, 4, 5, 7, 13, 15]

### **8.1.5 Symptom control and management**

The major fear that most dying patients identified is the fear of uncontrolled symptoms. The main symptoms include pain, breathlessness, nausea and vomiting and fatigue. Each person will have different experience and symptoms depending on their prevailing condition, and the treat-

ment that they are receiving. Pain is a major concern of patients in palliative care, this will subsequently have an effect on their mental wellbeing, but however it is worth noting that not all patients at the end of life or palliative care experiences pain. The nurse should assess the patient regularly and administer pain medication timely. Effective pain management is a core element in palliative care. Sometimes treatment is ineffective in relieving suffering and at this point the patient is sedated as a symptom management option. Careful assessment of the palliative patient should be done before any medication is prescribed. The doses of medication that has been prescribed should be proportionate to the symptoms exhibited by the terminally ill patient. Potential side effects to the medication should be minimized. [1, 2, 4, 8, 12, 14 and 15]

Anxiety has been identified as a major worry by patients at the end-of-life, as patients face fears and concerns over the impending death, they may experience anxiety, it is important to note that anxiety is not a normal, inevitable result of the dying process, it should be addressed timely. When the patient accepts anxiety to be a normal phase in the dying process, it results to the patient suffering mentally and emotionally without receiving medication, therapy or social care that would alleviate the suffering. [3, 4, 8, 12] Treatment of anxiety involves both psychosocial support and medication; the nurse will promote the mental wellbeing of the patient by providing an environment that is conducive for discussing concerns and fears. If medication is needed, benzodiazepines are generally the first line of medication to be given to relieve anxiety. Sometimes when medication fails adjunctive therapies like acupuncture and guided imagery with relaxation therapy has been found helpful. Literature has identified delirium as the most difficult symptom to diagnose, treat or manage whereas it remains the most common neuropsychiatric disorder that affects patients approaching death. [3, 4, 8, 14 and 15]

Delirium is described as a state of declining cognitive abilities, usually with a fast onset and unlike dementia it is potentially reversible. Dying patients experiencing delirium exhibit changes in the sleeping pattern, and may have reversed sleep-wake cycles with changing levels of consciousness. The nurse must assess the patient frequently and timely and watch for adverse effects of medications, infection, dehydration and how the disease process has affected the central nervous system which can all lead to the dying patient exhibiting delirium. [8, 12 and 15]

## **8.2 Relating findings to the theoretical framework**

The results of this study were examined against Ruland and Moore's theory of Peaceful End of Life, under each outcome indicators highlighted by the theory are nursing interventions that are applied to a terminally ill patient while examining the patient holistically. In the study an in depth analysis of fifteen articles was conducted, Evans et al., (2012) point out that at the center of care is the patient with a life limiting illness and family, care delivery is built upon this idea that the patient is a unique human being that should be viewed and treated like so. Every terminally ill patient is made up of body mind and soul, that should be viewed as a unified total and not just a sum of his/her body parts. Evans et al., (2012) also state that the focus at this time of care is provide comfort, to offer relieve from physical, emotional, and spiritual suffering and promote dignity of patients facing a life limiting illness.

According to Dislar et al., (2012) nurses play a very important role in palliative care and providing care at the end of life and during the bereavement period. They are uniquely placed to interact with the patient, the care team and the family. The nurse is the patient and family advocate whose main responsibility is to help the patient live as comfortable and free from anxiety as possible, maintaining a high level of independence and respect.

Gao et al., (2010) point out that palliative care encourages awareness and development of each patient's spirituality, in some cases spirituality is expressed within the context of faith and finding meaning in religion. Spirituality is shown in many other forms for example love for a pet, family art or nature. It entails how patients at the end of life make sense of the world, connect themselves with the environment and to other beings. This factors bring about the experience of peace that necessitates a peaceful closure. The Peaceful End of Life Theory points out the experience of peace as one of the core elements of care, addressing patients concerns that involve relationships sensitively with empathy and dignity.

Gao et al., (2010) also describe the importance of effective communication during care delivery in palliative care, when the patient is involved in the decision making and there is awareness and preparedness of the approaching death. Delay by either the multi-disciplinary team or the family to disclose information regarding the patient's changing condition can make the patient anxious.



The nurse is in a unique position as a caregiver to facilitate the patients' and family acceptance of the impending death this will in turn help increase the likelihood of a good death.

Rayner et al., (2010) point out that as the patient enters into the terminal phase, good management of the symptoms is a major concern for most patients and families. Careful prescribing of available medication, thorough assessment of the patient's needs, wishes and concerns accompanied by competent nursing care are the key elements in promoting a positive mental wellbeing. The concept of good symptom management is also brought forth by the theory.

## **9 ETHICAL CONSIDERATION**

Ethical issues are present in any kind of research. Ethics is about doing "good" and avoiding harm. Harm can be avoided or mitigated by applying appropriate ethical principles Angelica et al., (2000). To avoid violating any possible rules in writing thesis, the topic was discussed with the supervisor for consent and appropriate guidance of the topic of study. The topic was extensively discussed with the commissioning party (Terhokoti) before commencing the study. All the material used were obtained from official academic databases of which the author had an official right to access by being a registered student at Arcada university of applied sciences.

All the quotations in this study came from the articles and are not directly quoted to avoid plagiarism. All the quotations are referenced accordingly with honesty and truth to the extent of the author's ethical know-how. In all the articles used, participants personal information for example names, date of birth, addresses were not revealed to protect their identity and privacy.

Themes, concepts and ideas in all the journals used were not fabricated by the author in any way. No real life photograph was used to prevent copyright violation. Evidence based ideas were not affected by the authors emotions or opinion.

Arcada University of Applied Sciences has outlined some good scientific practices that the student is mandated to conform with while doing research. Integrity, meticulousness and accuracy in conducting, recording and reporting results for the study were observed. Ethically sustainable ways of collecting material, research and analysis methods that conform to scientific criteria were observed. Results and work that is accomplished by others is given due recognition, this ensures that their work is respected and their achievements accredited.

## **10 CRITICAL ANALYSIS**

This study was done by reviewing evidence based scientific literature; the questions that were formulated could have been answered better if the author had access to specific articles that are available only for sale. End of life experiences are very personalized and no specific study can be an exact representation of what really happens as people approach death.

The area of study is very broad; it entails first giving a background detail of what palliative care is and what are the areas in specific patient's needs to be addressed. It was observed from many research articles that it's hard to determine when to begin hospice care, typically hospice care starts when care shifts from being curative to alleviating symptoms, it's difficult to draw a line when to begin and by the time a patient is referred to palliative care they are already experiencing emotional issues that affect the mental wellbeing that could have been addressed earlier if the referral was made sooner.

In the search the author did not find a single pre-existing article that based its research on only analyzing the mental wellbeing of patients as they approach death because the experiences are too many and personalized. It was also observed that in some articles with the same objective draw different results when mental wellbeing is not properly defined. The time a person enters hospice is different in many countries and it was realized that the time that hospice starts influences the results of studies but the target of mental wellbeing may remain the same.

This study was limited to scientific journals from recognized academic data bases, the author would have preferred limiting the year of publication to 2005 and above, in order to deal with recent articles only but a lot of the relevant articles and journals have their basis on literature that was conducted in the 1990's. The articles that were considered are from the year 1998 and onwards and this may make the results of this study to have the same elements as other results of researches conducted in the same field.

During this study evolving ideas were given equal attention, this was done in order to eliminate bias, Ruland and Moore's theory of peaceful end of life was used to explaining the experiences of patients at the end of life that affect the mental wellbeing of patients, theories that talk about care of a dying patient and issues surrounding death and dying were also examined before finally settling to peaceful end of life theory.

The author encountered the following problems during the study, initially the challenge was that during the data collection process, some recent articles that could have provided a better understanding of the area of study needed passwords to access and/or were available only upon subscription. The author felt that if access to such articles was possible, understanding of the area of study would have been better, however with full utilization of the available articles the author at the end of the study was satisfied with the results.

Validity and reliability issues must be addressed in all studies. The dependability, credibility and accuracy of the information are dependent on it. Selecting the most suitable content unit is the basis of achieving credibility. To attain this, the author included only articles that are relevant while disregarding the irrelevant ones. Dependability is defined as the extent to which the data changes over time, while transferability is the level to which the results can be transferred to other settings. The author has clearly outlined the process undertaken to collect the articles. Graneheim and Lundman (2004) states that, in order to achieve transferability, it's crucial to clearly describe the selection of units, the data collection and data analysis on processes.

In this study validity refers to the level in which the research method used has been able to achieve the aim of the study. The aim of this study is to elicit knowledge and understanding of current nursing interventions that promote mental wellbeing of patients in palliative care. Providing answers to the research questions using information and knowledge from scientific based articles the author believes that this review was valid and attained its aim.

According to Graneheim and Lundman (2004) reliability refers to the degree in which an assessment tool produces stable and consistent results. In this study, reliability is yielding the same or compatible results with earlier research. Drawing articles from the databases suggested by

Arcada University of Applied Sciences means the articles are reliable and therefore the results of the study are also reliable.

## **11 DISCUSSION**

Mental wellbeing at the end of life is an aspect of palliative care that should be given attention and treated from a team approach, every member of the multidisciplinary care team is responsible to ensure that the patients has a positive experience of quality of life at the end of life. Nurses play a crucial and integral role in the enhancement and delivery of end-of-life care that is competent, safe, and compassionate. Death can be uncertain and hard to predict, but the issues faced by the patient are not unpredictable. Patients approaching death may experience psychological problems that affect their mental wellbeing as well as physical symptoms for example pain and loss of function for example to limbs that have a negative effect to their mental wellbeing (Gillick, 2005).

The next of kin, including the children, friends and the informal caregivers of patients approaching the dying phase, play a crucial role in delivery of the care. The patient if possible should be involved in planning, and decision making process on issues that affect his/her mental wellbeing. The family needs to be given emotional support during this period of care.

The findings are analyzed in light of “The Peaceful End of Life Theory by Ruland and Moore, they indicate that health care and social care providers at all levels should have the necessary training skills and attitudes that pertain to care of a dying person, providing competent care that is evidence based will help promote the mental wellbeing of the palliative patient, and the patient will feel safe and well cared for by staff that is well trained.

The results of this study show that when a dying patient is treated as a holistic being, with all the aspects of care being considered, improves and promotes their mental wellbeing. A negative experience at the terminal phase will with passage of time negatively affect the patient’s wellbeing, coping strategy and will lead to more distress. There is a pervasive interconnectedness between mental wellbeing of a terminally ill patient, palliative care and how this care is delivered. Recent studies have pointed out barriers to a good end of life experience some of which include lack of

care continuity from one phase of the dying process to the other, patient or family member's avoidance of death, lack of resources (economic reasons). A nursing intervention relevant to this situation would be establishing rapport with the patient, building trust and respect.

## **12 CONCLUSION AND RECOMMENDATIONS**

Mental wellbeing of a patient at the end of life is supported by a number of the articles that were reviewed, the main focus is that mental wellbeing cannot be addressed separately. Patient's at the end of life need to be focused upon using a holistic approach. It is the total sum of treating a palliative patient as a whole that results in a positive mental wellbeing, all aspects of care must be balanced and addressed in a timely manner.

Patients at the end of life may experience fear and anxiety, sometimes separately or both at once, their concerns and what frightens them needs to be established so far and anxiety can be addressed. Majority of patients at the end of life are afraid of being in pain, nurses should reassure the patients' and families that with proper adherence and appropriate medication the patient can have a pain free experience till the dying process begins.

Depression in palliative care is the most frequently observed symptom in patients with a life limiting disease, this can have a bad effect over time on the mental wellbeing of the patient leading to increased likelihood of having an experience of a bad death. The nurse should offer an intervention of planning care so that the patient is not lonely, is treated with compassion and dignity.

Peaceful closure is a critical part of the dying process, accepting or acknowledging the inevitable finality helps the patient face death with transcendence, whereby the patient acknowledges death but is able to rise and experience reunion of a higher level. Adequate time, room and privacy must be availed to the patient to address this issues.

Patient and family education regarding death and the dying process is encouraged and should be facilitated, involving the family in the care of the dying patient is important because it helps add to positive mental wellbeing, for some of the family members it would be their first experience with death, therefore advance teaching and allowing room for questions is encouraged.

In recommendation, the author would like to recommend future research on how mental wellbeing in palliative care is affected by culture. In the future for example a researcher can explore how palliative care is given in particular cultural settings and its effect on the mental wellbeing of the patients. Such a research or study would allow the researcher to explore more on how different ethnic classifications of people deliver palliative care and how the mental aspects of the patients are addressed. Another area of research could be the effect of nurse's mental wellbeing and how it influences care delivery in palliative care.

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