

# Nurses' perspectives of loneliness amongst terminally ill patients



Mabenagha, Arlene

## ABSTRACT

LAUREA UNIVERSITY OF APPLIED SCIENCE  
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ARLENE YUH MABENAGHA

NURSES' PERSPECTIVES OF LONELINESS AMONGST TERMINALLY ILL PATIENTS

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The beginning of every serious illness is a halt, normal life seems to be replaced by another kind of life. Death which is inevitable, is not only distressing and overwhelming, but is often accompanied by the feeling of loneliness both for the dying and their care givers. The focus however, is not just the level of loneliness as a feeling, but rather how people cope with loneliness which may be an integral part of dying.

The purpose of this study was to describe from nurses' perspectives, the nursing care given to terminally ill patients so as to support and enable them to come into terms with their situation with strength, courage and dignity. This study was based on a literature review which described the characteristics of terminal illness in a context wherein loneliness was experienced, and the content of nursing care which acts as a support mechanism at the final phase of life. This study was carried out in the framework of the Loneliness project which was launched at Laurea University of Applied Sciences, with the aim of making findings on how people in the Espoo region, cope with loneliness from different perspectives.

Using the qualitative content analysis, the work was divided into 4 subsections which were believed to be very essential to the nursing care of terminally ill patients. They were; physical comfort, psychological wellbeing, social functioning and spiritual wellbeing.

The findings from this study proved that, nurses witness firsthand, the plight of patients throughout the dying process and are able to recognise their complex needs more than anyone else. Nurses thus use their skills, resources and ethical judgement to support their dying patients.

Key words: nursing care, loneliness, terminally ill

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## 1 INTRODUCTION

The beginning of every serious illness is a halt, normal life ends and another life takes its place. One suddenly becomes uncertain about things most taken for granted: faith and integrity of the body, one's role in other people's lives and their role in one's own life. The horizon of time is narrowed, plans of yesterday lose their meaning and importance (Small & Rhodes 2000). For those who are dying, life takes on a new shape as it narrows, sometimes to a single room, wherein work and running a household are no longer part of it, friends and family are seen in a new way. Values change, what was once important may seem insignificant, while other values once ignored have greater weight (Morris 1986, page 48).

In life, death is inevitable and for people who are at terminal stages of life and knowing they are going to die sooner or later, loneliness is most often than not, a feeling which is associated with the thought of dying. Good nursing care is required for dying patients so as to enable them to die with dignity. In relation to the quality of care given to dying patients, Costello (2004) states that the major issues associated with care in any given setting is the atmosphere created by those who live and work there. Good nursing care must include carrying out tasks efficiently and attending to the psychological and emotional needs of the client at terminal stages of life. The nurses thus play a vital role in the care of such patients.

This study was carried out in the framework of the Loneliness project which was launched at Laurea University of Applied Sciences, with the aim of making findings on how people in the Espoo region, cope with loneliness from different perspectives. The project thus seeks to pull together all different working units in order to develop prevention methods and combine forces in the fight to pro-actively prevent loneliness in Espoo region.

## 2. BACKGROUND

### 2.1 Loneliness

Loneliness can be described as a psychological experience related to social isolation and perceived lack of companionship which may directly or indirectly be a health risk. It is thus an emotional state in which a person experiences a powerful feeling of emptiness and isolation (Rokach & Brock 2007) Loneliness is positively associated with low emotional support, ratings of depression and hopelessness, as well as low self esteem. Loneliness is different from solitude or aloneness as loneliness often occurs in the presence of other individuals (Sullivan 1953).

However, in adult life, a situational stress such as chronic illness may combine with the early interpersonal experiences to precipitate what can be described as feelings more terrible than anxiety. In Sullivan's (1953) theory, sometimes unresolved issues from childhood are reactivated in the face of adult or managerial crisis precipitating an intense emotional reaction of loneliness. Intense loneliness may be manifested by diminished feelings of self-worth, lack of confidence in interpersonal relationships and disrupted decision-making abilities.

Nurses are in a strategic position to provide patients' need for holistic care and responsible for assessing the progress of patients with terminal illness and impact of the illness on family members. This care should include psychosocial as well as physical aspects of health. If loneliness and depression are prevalent among patients with terminal illness and their caregivers, adequate support is therefore required to forestall the potential health problems associated with the condition.

Terminal illness has a significant effect upon the healthy members of the family (Sexton & Munro 1988) especially, if the sick person has a spouse, who must adjust to significant changes in roles and lifestyle. People with terminal illnesses, feel helpless in dealing with their disease (Tsay 2004). This sense of helplessness or loss of control results in psychological responses such as loneliness and depression. Persons suffering from chronic illness often view themselves as different, feeling apart from healthy persons; these attitudes might result in social withdrawal (Weilitz & Sciver 1996). Friends who are

healthy might withdraw from the person possibly because of their discomfort over being healthy in the presence of someone who is dying. The disabling effects of the illness are magnified by the long periods during which the person is unable to fill former social and occupational roles, contributing even more to the feeling of isolation.

Death which is inevitable, is not only distressing and overwhelming, but is also accompanied by loneliness in any case, both for the dying and those who take care of them (Chentova et al; 2002). The focus here however, is not just the level of loneliness as a feeling, but rather how people cope with loneliness which may be such an integral part of dying.

## 2.2 Palliative Care

Palliative care is described as the active total care of patients whose disease are not responsive to curative treatment, thus reducing the severity of disease symptoms. According to Johnston (1999,) all life threatening illnesses be they cancer, neurological, cardiac or respiratory diseases, have implications for social, psychological and spiritual health for both individuals and their families. Control of pain, of other symptoms and of psychological, social and spiritual problems is the main goal of palliative care. Palliative care thus seeks to achieve the best possible quality of life for patients facing serious complex illnesses, and their families and to assist them in adjusting to the many losses they endured and may still face, so as to provide them with dignified treatment and lower distress for the rest of their days (Tang et al; 2004). Palliative care provides physical, emotional, spiritual and informational support to help improve the quality of a person's remaining life and recognizes the patient and family as the principal decision makers.

Palliative care, takes a holistic view and integrates the psychological, physical, social and spiritual aspects of a patient's care, thereby offering a support system that enables and encourages patients to live as actively as possible until death, as well as helps the family to cope during the patient's illness and with bereavement when death finally arrives.

The role of a palliative nurse is therefore to assess needs in relevant areas and to plan, implement and evaluate appropriate interventions in a bid to improve the quality of life and enable a dignified death.

The World Health Organization (W.H.O 2003) research regards palliative care as a domain of health care which, affirms life and regards dying as a natural process, neither hastens nor postpones death, provides relief from pain and other distressing symptoms as well as integrates the psychological and spiritual aspects of patient care as earlier mentioned. Palliative care also offers a support system to help the family cope during the patient's illness and in their own bereavement and it uses a team approach to address the needs of patients and their families, including bereavement counseling. The focus on this is therefore to enhance quality of life which may in turn, also positively influence the course of illness.

A dying person must however be aware of his or her prognosis and collaborate with health care professionals to make choices which are consistent with individual beliefs about the right way to die (Clark & Seymour 1999). The role of care givers especially nurses, are to provide safe feelings, reduce anxiety, bring comfort and to allow the patients to die with dignity.

Palliative care may be provided in a hospice or at home, with the goal of achieving the best possible quality of life for the dying patients and their families and to assist them in adjusting to the many losses they endured and may still face, to provide them with dignified treatment and lowered distress for the rest of their days. Palliative care thus provides physical, emotional, spiritual and informational help to improve quality of life, and recognizes the patient and family as the principal decision makers. (Rokach & Brock 2007). It thus offers a support system that encourages and enables the patients to live as actively as possible until death, and coping mechanisms for family members when their loved one finally die.

### 2.3 Hospice Care

This is the philosophy of care which recognizes death as the final stage of life and seeks to enable patients to continue an alert pain free life and to manage other symptoms so that their last days may be spent in dignity and quality, surrounded by their loved ones (Trevatt 2003). Hospice care is a health care system of interdisciplinary services provided to clients and their families during the final stage of life. The National Hospice Organization (2007), states that the purpose of hospice is to provide support and care for persons in the last phases of disease so they can live as fully and comfortably as possible.

Palliative and Hospice care are two concepts which can never be left out when dealing with dying patients. They are similar and closely associated with each other, yet different. Palliative care may be given at any time during a person's illness, from the time of diagnosis and is given together with curative treatment. The focus is on pain and symptom management and the patient must not necessarily be terminally ill (Trevatt 2003).

Hospice care on the other hand, always provides palliative care with the aim of pain and symptom management as well, but the focus is on terminally ill who no longer seek treatment to cure them, but have a specific life expectancy limit of less than six months.

### 2.4 Quality of Life

Quality of life (QOL), is believed to be the most important outcome of care at the end of life. It is regarded as the degree of well-being felt by an individual or group of people and consists of physical aspects such as health, diet, as well as protection against pain and disease, or psychological aspects such as stress, worry, pleasure and other positive or negative emotional states (Cohen & Mount 1992). Quality of life has been conceptualized

in two ways: Global quality of life and Health-related quality of life.

Global quality of life is defined as an individual's subjective well-being or a global evaluation of satisfaction with one's life (Nuamah, Cooley, Fawcett, & McCorkle, 1999).



Health related quality of life on the other hand, is a more focused concept related to the impact of a medical condition or the impact of specific medical interventions on a person's physical, psychological, and social well-being (Skeel, 1998, p. 876). Health related quality of life is thus, relevant for patients receiving active treatment for a disease. For individuals at the end of life, however, when the focus of treatment changes from curing disease to preserving QOL, global QOL becomes more relevant.

Increasing attention, is however being given to the way people die. Because the majority of older and seriously ill persons die in acute care hospitals or nursing homes, the quality of care provided during the last few months of life can strongly affect the quality of life of both patients and their loved ones, as well as the length of life of the patient. Nevertheless, patients are at risk for poor quality of care, particularly with increasing economic incentives on health care organizations to control costs at the end of life. This makes it increasingly important to document the quality of care and quality of life experiences of dying patients and their families (Stewart, Teno, Patrick, & Lynn, 1999)

Generally, the Quality of a person's life is determined both by the nature of his or her experiences and the values and meaning that the person attaches to those experiences. Therefore, in considering how to define quality of life, many may say that although dying is often thought as a time of suffering and severe problems, it also becomes a very important time for the patients and their love ones to share the last moments of a more intimate connection with each other as the thought of death and loss hovers around them. While at one time in their lives, perceived quality of life might have been determined largely by functional ability and psychological well-being; different domains may be more influential for dying persons. As stated by Morris (1986); "for those who are dying, life takes on a new shape: it narrows, sometimes to a single room; work and running a household are no longer part of it. Friends and family are seen in a new way. Values change, what was once important may seem insignificant, while things once ignored have greater weight" (Morris 1986, page 48).

Persons confronting death, and their loved ones, may thus define quality of life differently from those not facing imminent death. Quality of life at the end of life may focus to a greater extent on peace of mind, comfort, and spiritual understanding than when more interaction with the social and physical environment was possible. For many dying persons, attending to spirituality and transcendence is very important. Seeking resolution and making peace could substantially contribute to living well while dying. The spiritual dimension may be important at first recognition of the imminence of dying and again at the very end, when the physical or biological process of dying is in completion. Dying patients, during different phases of their experience, may concentrate more heavily on one aspect such as cognitive ability to recognize family and friends, than on others such as walking or even bodily functions. They may give more emphasis to personal dignity and the meaningfulness of life than to physical symptoms or functioning.

### 3. PURPOSE OF THE STUDY AND RESEARCH QUESTION

Loneliness is a universal phenomenon and the feeling is intensified with the diagnosis of a terminal illness. Nurses play an important role in the final stages of a patient's life, and the aim here is to describe the nurses' view of patients in terminal care and how they respond to the feeling of loneliness which often comes with the knowledge of pending death.

This study thus seeks to describe from nurses' perspective, how patients at terminal stage of an illness feel, and the possibility of the nurses enabling them to come in terms with their situation with strength, courage and dignity. The challenge here is describing loneliness as a feeling and the nurses' role in trying to instil, develop and maintain a generalized hope-filled state in both the patients and their families.

#### RESEARCH QUESTION:

How do nurses help/support patients with loneliness in terminal care?

## 4 METHODOLOGY

### 4.1 Qualitative research

This study was entirely based on a qualitative literature review. Qualitative research methods were developed in the social sciences to enable researchers to study social and cultural phenomena. Examples of qualitative methods are action research, case study research and ethnography. Qualitative data sources include observation and participant observation (fieldwork), interviews and questionnaires, documents and texts, and the researcher's impressions and reactions (Myers 2009). Qualitative research methods are therefore, designed to help researchers understand people and the social and cultural contexts within which they live.

Since the topic was a fragile one and is an inevitable aspect of life, the researcher choose qualitative literature review so as to see the earlier studies which have been done regarding this particular topic and assess how the writers have focused on improving the wellbeing of dying patients.

### 4.2 Data Collection

Data collection was divided into 3 phases; Literature searches, Data selection, Data Analysis as will be described subsequently.

#### 4.2.1 Literature searches

Extensive literature search was carried out so as to achieve current knowledge using a variety of electronic search engines, which were a basis to proceed with the study.

As the research progressed, demands became more specific and narrowed. It was important for the researcher to find appropriate material from the extensive variety and to know just what was in line with the research question.

Literature searches were made through virtual libraries such as OVID Medline, EBSCO, ELSEVIER, EBRARY, SAGE journals, W.H.O, as well as manual searches from books and journals collected from the school's library. Scope was limited to results from "key word" search. What was relevant to the research question was forefront in the search process while everything else with lesser meaning was left out.

Table 1 presents the results from the search engines, using the basic key words (see table 1).

Search Word	OVID	Elsevier	EBSCO(Cinahl)	SAGE journals
Loneliness	45	842	76	6332
Terminal care	46	3328	1721	9345
Loneliness+ Terminal illness	16	42	2	234
Nursing care + Terminal illness/EOLC	133 122	324	4	1940
Nursing care+ loneliness	104	-	9	127

*Table 1 Results of literature search using search engines*

#### 4.2.2 Data selection

As earlier mentioned, data was selected according to its relevance to the research question. However, certain criteria were followed for choosing this data:

- Articles must have been published in a scientific journal
- Articles should be full texts and research based.
- Articles should have been published within a 10year period of time
- Content of articles should reflect the purpose of my study
- Publications should be in English

However, some rare exceptions were made by including older articles in the data. This was due to the uniqueness of the contents of those journals.

Most often than not, the content of journals and articles which came up, covered a broad range of overlapping themes, thus making it cumbersome for the researcher who had to tie the relevance of the material at hand, to the research question.

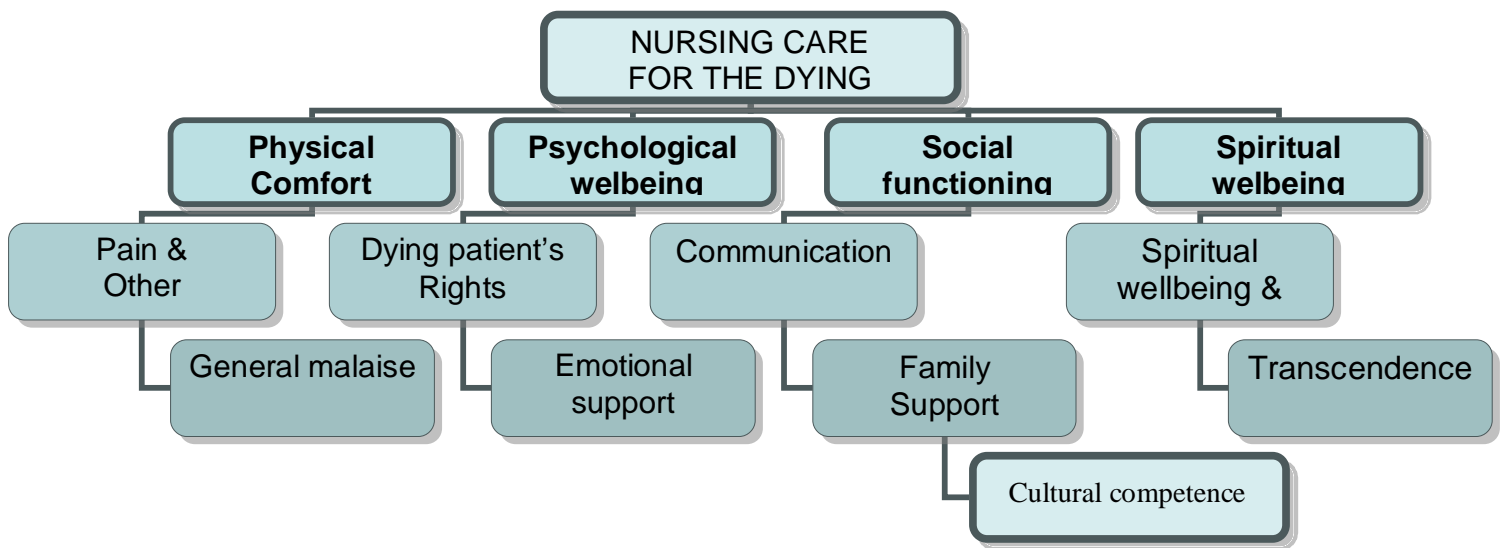
The articles which were reviewed in this work as shown on Appendix 1, describe the research done in detail by defining; the authors, year of publication, purpose of the study, method of data gathering, participants, central findings and significance to the thesis.

#### 4.2.2 Data Analysis

Analysing the data was carried out when data selection was completed, and the data was explored using the qualitative content analysis. Inductive technique was used where in, the content of the study provided titles to research entities. In other words, content analysis assisted in building a model, so as to illustrate the phenomenon of nursing support of terminally ill patients who suffered from loneliness as well.

The work was analyzed using 4 categories which also had their sub categories. They included; (see fig.1)

Physical comfort which comprised of pain management and general malaise, psychological wellbeing which on its part, comprised of emotional support and the rights of dying patients. Social functioning involved aspects like communication, family support and cultural competence. Furthermore, there was spirituality which looked into a person's perspective of life, God, and another life beyond.



*Fig 1 Nursing care of the dying*

## 5 FINDINGS

Clearly, physicians, nurses, and other caregivers possess a special moral privilege as they witness the efforts of patients who struggle to give their lives a sense of meaning and purpose in the face of disease or death (Rokach 1997). When cure is no longer possible, dying people primarily need good nursing care. Nurses witness firsthand the experiences of patients throughout the dying process and are able to recognize their complex needs more than anyone else. Patients often trust their nurses to guide them through the dying process and look to them to be their advocates when they cannot do so for themselves. This is because the nurse and patient share a special relationship at this end stage of life, wherein the nurses have a better insight as to what patient's value and desire for care at the end of life. The role of nurses is therefore to help terminally ill patients to come to terms with the imminence of death. Such work is highly demanding and often stressful.

Nurses have been, and will continue to be, leaders in end-of-life care. As the largest group of health professionals and those most connected with the comprehensive needs

of the terminally ill and their families, nurses have long advocated for humane and dignified care at the end of life. (Zerwekh 2006)

Providing end of life care is a key function for nursing that can bring about positive benefits for patients and families. Working to provide a peaceful and comfortable death is seen as rewarding as well as challenging. However, since attitudes about life and death also affect the nurses' ability to provide care to the dying patients, the inherent stresses can also lead to role strain, conflict and even burnout for nurse (Jean 2002). Nurses must therefore be aware of their own feelings, and to take care of themselves emotionally and physically. From my research, I came up with 4 categories which best helped to describe how nurses could support dying patients.

### 5.1 Physical Comfort

Comfort, is a basic human need and patients on their dying beds should not be deprived of this need. Kolcaba and Wykle (1997) proposed that 'comfortable patients heal faster, cope better, become rehabilitated more thoroughly, and die more peacefully than do the uncomfortable'. Nurses at end-of-life care must ensure that physical comfort such as pain management and general symptom relief are ensured.

#### *5.1.1 Pain assessment/ Management*

Many people approaching death fear pain. In fact, according to Gavrin & Chapman (1995), pain is the symptom dying patients fear the most and it is a common problem in many terminal illnesses, including cancer and the acquired immunodeficiency syndrome (AIDS). Patients who are near death, suffer in various ways be they psychologically, emotionally or even spiritually. Dying patients experience physical pain, the alleviation of which is a central task of health professionals.

Pain is defined by the International Association for the Study of Pain (IASP 1994) as 'an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage'. The pain is usually a direct result of the patient's disease, a side-effect of the treatments, or a result of other situational factors

(Vainio 2000). The emotional impact of pain is discussed by Barraclough (2000), who states that pain can be caused by acute mental and emotional distress or suffering. Total pain is a term used for complex pain, encompassing physical, psychological, social and spiritual aspects, and therefore requiring a combination of management approaches (Twycross and Wilcock 2001). Pain, suffering or aching are a powerful symptom of disease, which reduce the patient's quality of life (McMillan 1996).

The role of the nurse is therefore to be able to assess the pain of the patient as it is important to identify the intensity of the patient's pain, the characteristics of the pain, the patient's emotional response to the pain and the effect of the pain on the patient's ability to function. (Whitecar P & Jonas P 2000)

Pain assessment is invaluable. Initially it sets a baseline against which the effect of the intervention can be compared. Assessment is not a one-time event; it must be ongoing to be effective and is often based on the verbal report (Kaye 2003). An example of a pain assessment method is the use of pain scales such as the Visual Analogue Scale (VAS), a scoring tool commonly using the numbers 0-ten (0 indicating no pain and ten indicating extreme pain). If used, these scales should be valid and reliable and as with all other aspects of care, they require the use of good communication appropriate for the individual. Hunt (2002) says there is no single acceptable way to measure pain, which is a valid point in relation to care of the dying. Patients with cognitive impairment may be unable to describe their pain while semiconscious or unconscious patients are unable to verbalize their discomfort. In these situations the nurse should observe the patient for physiological and behavioral signs, and the family can often be helpful.

Management of pain is one of the most important goals when caring for the dying patient. Linklater (2002) states that 85 per cent of cancer pain can be managed using the World Health Organization (WHO) three-step analgesic ladder. Pain receptors, situated in the tissue of muscle, skin and nerves, transmit signals via pathways to the brain. Some structures such as the liver and bone only have receptors in the outer covering. Somatic and visceral pain are nociceptive in nature - from stimulation of nerve endings - and in the majority of instances opioid sensitive (Twycross and Wilcock 2001, WPP 2002).



### *5.1.2 General malaise*

General feelings of malaise, that is, not feeling well, are also considered as part of physical comfort in traditional approaches. Nausea and vomiting, breathlessness, restlessness and confusion, seizures and hemorrhages are all factors of general malaise. However, there are a number of ways that malaise could be defined based on available measures. These include assessing when patients do not feel well, as well as the extent to which they feel bad or somewhat ill. Therefore, knowledge of the symptoms and disorders that are associated with terminal phase of patients can help the nurses to improve the quality of dying. Through this, nurses can provide appropriate palliative care. From the research, the most common underlying symptoms which led to the general feeling of sickness were; general weakness, little or no fluid intake, respiratory problems, difficulty swallowing, re-current fever, extreme tiredness, and even dehydration. All these symptoms are as a result of the weakening immune systems of dying patients.

## 5.2 Psychological wellbeing

Patients at this point in time of their lives are often confronted with extreme anxiety which leaves them psychologically stressed. One of the most powerful albeit simple interventions at the end-of-life care is the nurse's use of presence. Presence is defined as being available to the patient with the wholeness of one's unique being (Costello 2004). The nurse is aware of more than the patient or family can verbalize and can intervene to produce positive outcomes and relieve emotional, financial and be able to make the patient understand his rights.

### *5.2.1 Dying Patient's rights*

Patients who are dying have unique needs and special rights which can not be overlooked. Allowing a patient to participate fully in care can be accomplished by developing a plan that respects a patient's basic rights. The Dying Person's Bill of Rights was seen as

an excellent template to frame the plan of care and to increase all caregivers' awareness of a patient's basic rights at the end of life. There are 8 basic rights of dying patients as described by Pitorack (2003);

The right to autonomy, which is the first basic principle of ethics. Individual autonomy is defined as having decisional capacity and the moral and legal right to determine what will be done with oneself. With each interaction with a dying patient, caregivers can ask: "Am I respecting the patient's autonomy?" As living human beings, we cannot experience the dying process; thus, we must be taught it. Dying patients can be our greatest teachers, provided we listen to their messages.

The Right to hear the truth as patients need to be told clearly their situation and its implications.

The Right to maintain hope as focus changes. It is often assumed that accepting the inevitability of death means losing hope. However, it is very possible for caregivers to help patients maintain hope and still interact truthfully and respectfully with those who ask: "Am I dying"? Nurses and caregivers can help patients with this shifting of the focus of hope, in whatever way is appropriate for the patient. Discovering hope is an ongoing- and very individual-process for terminally ill patients.

The Right to be in control, as being in control requires decision making from the global level of advanced care planning to the simplest daily decision such as eating. At the end of life, patients experience a succession of losses including health, job/profession, finances, and role in the family system. They need to be empowered to make decisions as long as they can and wish to do so.

Furthermore, patients should be allowed the right to express their emotions and feelings about approaching death. In order to do so, patients need an environment in which they feel safe. This environment can be created by the supportive presence of a loved one or caregiver.

Patients have the right to have their Spirituality respected. Patients, families, and professional caregivers frequently confuse religion and spirituality. Religion is a set of

practices and laws pertaining to a specific belief system, whereas spirituality is related to meaning and purpose in life, relationships such as with self, with one another, or to a higher belief system. It is generally acknowledged that people need to appreciate their reason for existing and for attaching meaning to their life. If approaching death is never acknowledged, the patient never has the opportunity to appreciate the meaning of his or her life. As always, the nurse's role is to listen with a nonjudgmental ear, whether patients question or affirm, doubt or praise. This is the patient's spiritual journey, and it is not our job to judge or try to change its direction.

The right to be free from pain. Although pain control is much better than it was even a few years ago, managing physical pain is only the beginning. Pain is multidimensional. For example, psychological or spiritual pain is much more complex to identify and treat.

Some patients want loved ones present at the moment of death while some prefer to die alone. They have the right of not dying alone. When planning for the time of death, caregivers can ask patients who they'll like to have at their bedside during their final moments. In this way, patients are participating in the way they die.

### *5.2.2 Emotional Support*

Most patients with terminal illnesses are often faced with the feeling of distress and lack of self worth. Nurses must be able to help these patients come into terms with their situation with strength; courage and dignity (see pg 4)

Certain characteristics were seen to be common with terminally ill patients suffering from distress as will be discussed in the subsequent paragraphs.

They express frustration, fear, hurt, or doubt, expressing feelings of loneliness and isolation, expressing lack of hope or feeling life is not worthwhile. Most often, these patients lose control and verbalize questions about faith or loss of faith. This showed immense expression of emotional suffering and lack of meaning to life as a whole. Anxiety and depression often follow, with a strong desire for death becoming apparent. Suicidal ideations become very common in such situations and should be looked out for.

Nurses working with terminally ill patients must try to encourage and instill hope in the minds of these dying patients. Research has found that hope is present even when a person is close to dying (Buckley & Herth, 2004). The dying person should not experience feelings of hopelessness and despair. Interventions for fostering hope in individuals who are terminally ill include helping the individuals foster affirming relationships, develop attainable goals, find meaning in their lives, live in the present, use their inner resources, reflect on uplifting memories, and appreciate their personal value (Herth, 1990; Post-White et al., 1996). Nursing interventions in giving out emotional support so as to instill hope vary.

Nurses should be able to develop caring and continuing interpersonal relationships with patients and their caregivers to facilitate a strong sense of belonging.

Nurses must be able to use inner spiritual resources to facilitate development of meanings and the creation or implementation of important rituals and traditions.

Furthermore, nurses must address the fears of the dying individuals with specific activities and coping strategies as part of a care plan. Use reminiscence and life review therapies to identify coping skills that have been successful in the past.

Patients can also be encouraged to mend damaged relationships, say good-bye to family and friends, give and receive forgiveness, and express their feelings openly.

Nurses should try as much as possible, to work with dying patients to help them achieve their goals, by asking them what they most want and creatively working toward helping them get it.

Another coping tool which could be used is sometimes to use past experiences and systems of meaning to understand values and reinforce coping skills for the patient and family/caregivers.

Nurses must work hand in hand with physicians to assure dying patients that they do not need to die alone or be uncomfortable and by so doing, create environments that ensure adequate rest and relaxation especially for older adults.

### 5.3 Social Functioning

Death is often associated with Loneliness, social isolation, depression, feeling of worthlessness, hopelessness and many more. Nurses can best observe their patients responses to social life upon knowledge of the fact that they are going to die. Sincere communication and strengthening of family ties have been seen to be very supportive measures in boosting the egos of dying patients.

#### *5.3.1 Communication*

Regardless of the underlying pathology of the dying patient, the care required needs to be organized and implemented by a multi-professional team. A team approach promotes open communication, thus reducing the risk of patients and care givers receiving mixed messages from healthcare professionals. This should also help realistic patient-centered goal setting with a supportive but structured approach (Adam 1997).

Communication is thus a very important skill needed by nurses in the care of dying patients as it is important to encourage patients to discuss their feelings and fears as well as ask questions about their situation. Nurses must be professional in discussing the patient's condition and not being emotional about it themselves. Listening to patients and picking up on their signals is improved through practice and active reflection, and requires skilful management (Wallace 2001)

Communication is more than just verbal interaction. Non-verbal communication is significant and the patient will develop a perception of nurses from the non-verbal cues they use (Lugton 2002). It has been documented that nursing staff can apply 'blocking' tactics when a patient begins to discuss sensitive topics such as talking about death and dying, can release a range of emotions and can feel awkward for the nurses especially when difficult questions are asked where answers could be complicated (Buckman 2000). Nurses can worry about not knowing what to say or saying the wrong thing when communicating with dying patients, which can create barriers to communication (Fallowfield and Jenkins 1999). Many patients would welcome the opportunity to discuss

their fears and a key skill of the nurse is to recognize such moments, being sensitive to the patient's verbal and non-verbal cues (Lugton 2002).

The use of touch (Buckman 2000) and listening - not necessarily speaking - explaining or instructing may prove significant. Because all patients are individuals, the use of touch may not always be appropriate but the nurse can assess the reaction and either continue or withdraw. Cooley (2000) acknowledges the requirement of all nurses to use basic interpersonal skills to appear 'warm and welcoming', allocating time and attention to communication. Being approachable, making eye contact and allowing the patient to feel valued as well as providing privacy and demonstrating interest will encourage conversation, and in the hospital setting this may be helped by actions such as closing the curtains around the bed.

Once patients have begun to verbalize their thoughts, feelings or concerns, it is important to let them explain at a pace that seems comfortable. Reiteration and reflection of patients' statements show they are being listened to, while the use of non-verbal skills, for example nodding, will encourage them to continue (Buckman 2000).

The patient is not the only person who requires support and derives benefit from effective communication. A range of emotions and fears will be experienced by the family members or care givers. These may or may not mirror the patient's emotions (Faulkner and Maguire 1996). It is important to encourage the patient and family to talk to each other because there may be decisions to be made or affairs to put in order, and unfinished business may lead to emotional distress for patients and care givers.

### *5.3.2 Family support*

Patients who are at the final stages of their lives are very fragile. It is true that the thought of death positively associates them with the feeling of loneliness depression, hopelessness and a low self esteem. The nurse, who is the care giver, also plays an important role in getting family involved in the care of a dying patient.

Although palliative nurses have become accustomed to working in such crisis situations, the families of dying patients may be overwhelmed by the patients' critical, and most

likely, deteriorating health situation. While the families experience the whirlwind of care, often without understanding what is happening, they must also address imminent death of their loved ones. This time can be extremely stressful for families. Indeed, the thought of losing a loved one is particularly stressful for patients' families, thus making them very vulnerable.

Appropriate interactions with the families are essential if nurses are to remain advocates for their patients and families and provide holistic nursing care. Determining better ways to empower patients' families and meet their needs requires learning what they perceive their needs to be such as ;( Engli and Kirsivali-Farmer 1993)

To know the prognosis

To have questions answered honestly

To be assured that the best possible care is being given to their family member

To be called at home about changes in the patient's condition

To feel that the hospital personnel care about the patient

To have a specific person to call at the hospital when unable to visit

To know how the patient is being treated medically

To have explanations that are understandable

To see the patient frequently

With measures such as these taken, families are rest assured that the care of their loved one is in good and trustworthy hands as they prepare for their journey into another world. All in all, the most specific needs of family members with patients under palliative care, is the need to know, the need for consistent information, the need for involvement, and the need to make sense of the experience as a whole. Such a model of holistic care will validate the role of patients' families during patients' hospitalization and improve acceptance for families when the event of death finally comes.

### *5.3.3 Cultural competence*

We live in a diverse multicultural and multi-faith society with customs, practices and religious beliefs passed on through generations. As professionals we need to overcome our inhibitions that may arise from gaps in generation, language or culture to meet the challenges that are associated with caring for the dying. The Commission for Racial Equality strives to reduce discrimination, and has produced a guide on how to care for people from various religious denominations (Moussa 1999).

Today, nurses are becoming sensitive to, and knowledgeable about cultural differences and similarities in people's care. They must recognize the values of all cultures, races and ethnic groups and respond to these differences. Increasing diversity and mobility of society accentuate an important need for professional nurses to render holistic, culturally competent nursing care. To be culturally competent, nurses must first be culturally aware and sensitive. Nurses are awaking to the critical need to become more knowledgeable and culturally competent to work with individuals from cultures (Tortumluoglu 2006).

Cultural competence has been defined as developing an awareness of one's own beliefs, sensations, and thoughts without letting it have an undue influence on those from other backgrounds. It can also be viewed as demonstrating knowledge and understanding of the client's culture (Tortumluoglu 2006).

As a result of profound worldwide demographic change, physicians will increasingly care for patients from cultural backgrounds other than their own. Differences in beliefs, values, and traditional health care practices are of particular relevance at the end of life. Health care providers and patients and families may not have shared understandings of the meaning of illness or death and may not agree on the best strategies to plan for the end of life or to alleviate pain and suffering. Good end-of-life care may be complicated by disagreements between physicians and patients, difficult interactions, or decisions the physician does not understand. Challenges may result from cultural differences between the patient's background and traditional medical practice. Nurses therefore need to be sensitive to cultural differences and to be culturally competent by developing the skills necessary to work with patients from diverse backgrounds.



#### 5.4 Spiritual Wellbeing

Imminent death causes physical, mental, social and spiritual distress (Corr 1992). Dying people may often seek the meaning of life. Spiritual issues often arise in the care of dying patients and the nurses should be able to recognize and understand how best to respond to their patient's spiritual needs. White (2000) argues that we all have a spiritual dimension - a personal view of meaning in life. Anxiety may arise if the dying lose sight of that meaning (Kuuppelomaki 2001).

For some people, spirituality is directly related to religion, but they are not the same because spirituality includes the patient's whole life experience (Stoter 2002, Twycross 1997). Ross (1997) states that nursing staff view spiritual support as listening to and being alongside the patient, adopting a non-judgmental approach, maintaining hope and providing religious and/or spiritual support, such as arranging visits from the priest or other appropriate religious leaders. However, Ross (1997) suggests that nurses do not always feel capable of providing this support, in part due to a possible lack of skills. Twycross (1997) says that health professionals will not have answers, nor should they impose their own beliefs, but they need to respond sensitively if the patient raises spiritual aspects for discussion. Spiritual peace can exist, and may be expressed through relationships with others, art, poetry and meditation, inner peace and for some a particular religion. Spirituality therefore could be described as the essence of that person.

In older adults however, spirituality is rooted in community, reflecting the importance of interpersonal relationships. Relationships with oneself, others, and God or a higher power provide a sense of belonging and support that can minimize feelings of loneliness and despair experienced during a terminal illness. Spiritual awareness increases with age and can thus provide older adults a sense of hope and support while coping with a terminal illness (Moberg, 2005).

## 6 DISCUSSION

### 6.1 Discussion of Findings

The purpose of this study was to describe how nurses view dying patients, especially those experiencing loneliness, so as to be able to support these patients throughout the final stages of life, and help them come into terms with their situation with strength, courage and dignity.

From this study, it could be said without doubt that nurses have been, and will continue to be, leaders in the end of life care. This is because they witness firsthand, the experiences of dying patients throughout the dying process and are able to recognise their complex needs and emotions more than anyone else. Of course, loneliness has over time, been a complex feeling or emotion which comes with the thought of death and dying. Thus, as seen from fig 1, nurses through training and experience, are uniquely equipped to locate and utilize support for improving end of life care for the dying through physical, psychological, social as well as spiritual support systems.

However, throughout the wide range of research made on this particular topic, I discovered that nurses can only begin to change the delivery of EOLC by confronting their own fears and emotions (Curtis Jr, Patrick DI 2001). In other words, nurses who view death from a neutral perspective without emotional entanglement with their patients were able to portray a more positive attitude towards caring for the dying and their families which without doubt, leads to more improved patient outcomes and satisfaction in providing End of life care (EOLC). Jean (2002) argued that, working to provide a peaceful and comfortable death is seen as rewarding as well as challenging. However, since attitudes about life and death also affect the nurses' ability to provide care to the dying patients, the inherent stresses can also lead to role strain, conflict and even burnout for nurses. Nurses must therefore be aware of their own feelings, and to take care of themselves emotionally and physically.

Nurses have to acknowledge death as a part of life in the same way as birth is also a part of life. When a nurse is able to maintain this inner consciousness and keep emotions in

check, then is better equipped too instil hope in the dying patient and by so doing, improve the quality of life for these patients.

Furthermore, as earlier mentioned nurses may have different beliefs and values about death and dying as they might come from different cultural backgrounds. In the health domain today, culture is also seen to play a major role which can not be left out. Death has different meanings to different people and such differences should be treated with sensitivity and respect (Steinhauser, Christakis, Clipp, 2000). Remember that the aim of every palliative nurse is to provide good/appropriate death to their patients. This was discussed as one of the rights of the dying patient, (see pg 18) which nurses are bound to respect, irrespective of cultural background.

All in all, care of dying patients requires the skills, knowledge, understanding, compassion and resources of nurses, so as to provide appropriate pain and symptom management, family support, assistance with decisions as stipulated by the rights of dying patients, and even bereavement support. All the studies agreed that the role of nurses was to communicate patient needs and in addition, provide comfort measures and pain management. Communication was therefore an outstanding tool required by all nurses during EOLC as patients and families depend on nurses for knowledge and guidance.

Furthermore, it was important to note that over the past decade, extensive research has been made on the domains of Terminal care or Loneliness. Interestingly enough, loneliness seemed to be a factor which is ever present in the patients in terminal care. This is so because in life, death is inevitable and even though some people such as cancer patients will happily welcome death and plead for euthanasia so as to alleviate pain and suffering, it was commonly agreed that the thought of death and dying is most often than not, associated with the feeling of loneliness. Patients start to manifest feelings of hopelessness, worthlessness, depression and social isolation. Death and loneliness are therefore inter-related, thus making this topic a fragile one to have researched on.

This study was carried out using the qualitative literature based review. This however, proved to be a very challenging task. Literature searches were made according to strict criteria (see chapter 5). However, with the extensive range of ideas acquired from the inputted key words via the search engines, I was faced with a great discrepancy on ideas which had to be taken or left out. It most often than not, left me psychologically worn out, but the outcome has been worthwhile. The major setbacks from some of these journals such as Sage, was the fact that the author found very useful journals which could greatly support the work, but could not afford to buy most of these journals as was required by the publishers.

I also believed that in order to get a better insight on nurses' perspectives, a better approach would have been to carry out interviews with nurses working at a Palliative or Hospice home. Then it would have been easier to get firsthand information about how these patients express loneliness and nurses' reactions, feelings and support mechanisms towards these patients. Unfortunately, I was confronted with 2 major obstacles in carrying out a questionnaire based study: first, there was the language problem as interviews were most definitely going to be done in Finnish and secondly, the project was introduced and concerned only the Espoo region which happens to be without a hospice home. The only other option was in Helsinki where there is the "TerhoKoti." Permission to go out of Espoo region was therefore denied. This topic is without doubt, important to this project and maybe in future, steps should be taken in relaxing terms of the research process as loneliness is a universal phenomenon which does not only involve the elderly.

In conclusion, this work has been an enriching, and a learning process. Loneliness is a feeling associated with death and dying. Nurses must be able to create a 'presence' for their dying patients as this is the major support mechanism. The key component of palliative care nurses in particular and nurses in general, should be an embodiment of attributes such as attentiveness, accountability, sensitivity, open mindedness and active listening skills. These all sum up to holistic nursing care, an aspect of care which I geared towards understanding and maximizing all throughout the process of professional growth.

## 6.2. Ethical Considerations

Ethics has been described as a systematic attempt to understand moral conceptions. It consists of ethical rules and principles, virtues and values. Ethical issues in qualitative research are often more subtle than issues in survey or experimental research. These issues are related to the characteristics of qualitative or field methodology which usually include long-term and close personal involvement, interviewing and participant observation. Field research is an approach based on human interaction, rather than one viewed as outside human interactions (Good & Gretchen, 2001).

Putting the research task is the initial question of ethnics in nursing. The research question described what is to be used as the component of the study. The research question thus, influences the personal ideals and perspective of the researcher. The ethics evaluation should reveal how the topic of the research is selected and the reason for the study (Padgett, 2000).

During the qualitative research, ethics accepts a definite meaning. This can be observed in the self-growth of the researcher and the selection of the right methods and questions. Through this whole data gathering process, the researcher has been committed to moral ethical values and taking responsibility for actions in the work carried out. Thus, the researcher was honest and faithful in reporting and evaluating herself. However, in the course of this study the researcher encountered vulnerable situations and it was important to seek for assistance, advice and guidance on solving difficult situations via the means of peer discussions, as well as assistance from the supervisor, all in a bid of obeying the values of ethics.

### 6.3.1 Trustworthiness

Trustworthiness is an essential component of qualitative research. The purpose of any research is to provide information which is considered trustworthy. The concept of information in this case, refers to construing, describing and explaining a phenomenon. Trustworthiness therefore means that the information is based on critical arguments.

The weaker the arguments the poorer is the researcher's ability to carry out objectives for the study, understand the nature of reality and explain it in the desired way (Karjalainen 2002 page 59).

Findings should reflect the reality of the study and the experience by providing the reader with the opportunity to review the researcher's interpretation of data (Koch 2006). The researcher in this case, provided opportunity for review of the interpretation of the data in order to identify the trustworthiness or credibility of the study. Also the interpretation of the researcher gives the scope for the whole study. Hence researcher education, skills and knowledge and experience were identified as important measures of trustworthiness (Padgett 2000).

Furthermore, the immediate attention of this study was to specify the research purpose and research question and the whole process was to align with these as well. The preliminary point in qualitative research is the open subjectivity of the researchers and proof that researchers are the vital tools in the whole process of the study. Therefore, the evaluation of trustworthiness hence related entirely to the research process. Quality of the research was also a priority. The researcher examined the quality of the research carefully to show how data was collected, analyzed and interpreted in the course of the study.

In addition, there was an exploration of the auditability of this work by the researcher. This was in order to determine whether the research process was documented clearly and whether the conclusion and interpretation are supported by the data and the warranted based on the documentation provided by the researcher.

Therefore, the researcher examined the auditability by questioning whether adequate information was provided on how they ended up with the conclusion of the study, by following the research process and the result of the study, so that another researcher can follow the flow of the research and replicate it.

It is important to keep in mind that all the original items selected for the study were full texts and research based articles. The articles were published in a scientific journal and

restricted in English language, so translation was not needed. However, the reference list at the end of the study, originated from accurate sources, cited and respected the copyright of the authors. All the references used need to be carefully checked for precision and completeness. The Abstracts of the articles were excluded from the study.

Moreover, the fittingness of the results employed in the study, enabled the researcher to assess if she presented detailed information, so that any reader can evaluate the meaning and necessity of the results. When the reader is convinced of these, the reader can transfer and apply the research result to another context if needed (Roberts 2006)

In this study, trustworthiness was achieved through valuable data sources used by the researcher such as, Ovid and MEDLINE that comprises of various methods or research, and also cross checking with documentary evidence and published literature. The researcher took time with the research articles, reading them through, and analyzing the findings. The outcomes therefore, show how nurses can support terminally ill patients who are overwhelmed by the emptiness of life at its final moments.

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## 8 APPENDICES

## APPENDIX 1: Analysis of Literature review of the data.

Authors and year of publication	Publication of articles	Purpose of the study	Methods of data gathering and participant	Central findings to the thesis
Adam Jim (1997)	British Medical Journal	To control symptoms and support families in the last 48 hours of patients life	Literature review of related studies	Support systems are very important in end of life care
Buckley, J., & Herth, K. (2004)	Journal of Nursing Standards. 19(10):33-41, November 17, 2004.	To investigate the meaning of hope, and identifying strategies terminally ill patients use in maintaining and fostering hope at final stages of life	Cross sectional data selection from 16 participants	Hope remained present regardless to nearness of death. They came up with 7 hope rendering and 3 hope hindering categories
Buckman R (2000)	British Medical online journals	Assessing the importance of good communication skills in EOLC	Survey on patients attitudes and feelings towards communication with nurses and physicians	It is not easy to meet expectations, but skills and efforts put in, can create an unforgettable and appreciated impression.
Clark David, Jane Seymour - 1999	Open University Press	To measure the feelings of isolation and uncertainty towards approaching death	Longitudinal study over a 12 year period of time	Findings showed nurses use their skills and abilities to encourage patients and improve QOL
Cohen SR, Mount BM (1992)	Journal of Palliative care	Defining & measuring subjective wellbeing in the dying.	They used the McGill Quality of life questionnaire	Results showed that physical an existential wellbeing were essential in

				improving EOLC
Cooley C ( June 2009)	Professional Nursing journal (London, England)	Evaluating the ability of nurses to communicate appropriately with dying patients	A general survey on 12 nurses from 4 Hospice homes	Self-awareness and willingness to improve socialization skills is the basis of improving communication skills.
Curtis JR, Patrick DL(2001)	Journal of pain and Symptom management	Steps to facilitate discussion of death and dying with family members and patients	Organisation of conferences attended by family members and ICU team workers	Results showed Improved communication and EOLC in ICU
Field MJ, Cassel CK (1997)	Journal of Palliative care	Meeting the needs of multicultural communities in palliative care	4 case studies	Developed a framework within which to work with the terminally ill and their families to elicit their model of belief about the illness, its meaning for them, their expectations, and their needs.
Johnston B, Smith LN(June 2006)	Journal of advanced nursing	Research on nurses and patients perceptions of good palliative nursing care	A study was carried out using in-depth interviews and thematic content analysis. A sample of 22 Registered Nurses and 22 dying patients were interviewed within a year	Findings showed that globally, nurses using interpersonal and caring skills, were able to build therapeutic relationships with their patients.
Kaye P (2003)	EBL (Eskind Biomedical Library) publications	To promote a problem solving, holistic approach to the evidence-based	Patients diagnosed with terminal illness and who have been in	Prevention and alleviation of suffering were the key to ensuring effective

		assessment and management of symptoms experienced,, which are associated with potentially life threatening illnesses	palliative care within a 5 year period.	palliative care.
Koch, T. (January 2006)	Journal of Advanced nursing	To show the way in which the decision trail of a qualitative research process can be maintained	The study took place in 2 elderly wards in a 1000-bed National Health Service hospital in the UK, in 1991.14 patients were interviewed, each on several occasions,	Presenting multiple data sources is an important aspect of the existential phenomenological research process and its recording contributes to the trustworthiness of the research process
Kuuppelomäki.M (2003)	European Journal of Oncology Nursing	To describe and explain the provision of emotional support to dying patients from nurses' perspectives.	Sample consisted of 328 nurses from 32 health centres. Data was collected using a structured questionnaire in which emotional support was measured by multiple-choice items and one open-ended question.	Listening, touching, expressing empathy, attending to the patients' wishes, comforting, encouraging and being present were the most common forms of emotional support.
Pitorak, E.F ( 2003)	Home Health Care( the journal for home care and hospice professionals)	To describe the 8 basic, unique needs and basic rights of dying patients	Article based on 8 rights	The birth of Dying Patients' Bill of Rights
Roberts, P., Priest, H.,	Nursing	examines	Wide scale	Using either

Traynor, M. 1999	Standard	reliability and validity as ways to demonstrate the rigour and trustworthiness of quantitative and qualitative research	literature research on reliability and validity of quantitative research	established or more novel approaches to assessing the reliability and validity of research is one way of producing useful and trustworthy research findings
Rokach.A, Brock.H. (1997,2007	American Journal of Hospice and Palliative medicine	Aims at comparing the manner in which the dying, their care givers and general population cope with loneliness	37 cancer patients, 78 caregivers, and 128 participants from the general population took part. The participants anonymously answered a 34-item questionnaire which endorsed those items that described their strategies of successfully coping with loneliness	Results suggested the dying patient, his or her caregiver, and the general population cope with loneliness differently.
Ross L (1997)	Journal of Advanced Nursing	sample of elderly dying patients, designed to ascertain their perceptions of their spiritual needs and care	10 patients from an elderly unit located in a hospital in Edinburgh, Scotland were interviewed in the summer of 1995.	8patients admitted to having experienced spiritual needs at some time in their lives, six while in hospital.Needs experienced related to religion, meaning, love and belonging, morality, and death and dying.
Tang SI, McCorkle R,	Nursing	To identify	Secondary	64 (50.4%) out of

Bradley EH (2004)	research Journal	determinants of the use of hospice home care services for terminally ill cancer patients during their final days of life.	analysis of data from 127 terminally ill cancer patients who participated in an exploratory study aimed at identifying determinants of congruence between the preferred and actual place of death.	the 127 participants had used hospice home care services before death. Providing nursing care that enables family care-taking at home may facilitate hospice home care use for patients.
Tortumluoglu 2006	ICU Nurses Web Journal	aim was to define 4 of the most commonly used models implemented in transcultural nursing,	Questionnaires, interviews and observation forms Were used in collecting cultural data by using the main concepts of all of the four models defined in the research.	It stimulated the interest of the nurses with these models and thus to encouraged them to use these models in order to make cultural definitions and evaluation in their own fields.
Whitecar. p,Jonas.P, Clasen.M (2001)	American Family Physician	purposes of this study was to survey hospice patient care coordinators to gain an understanding pain management services, attitudes toward the necessity of anesthesia pain management services	Questionnaires	52 %reported that patients could benefit from invasive treatments offered by anesthesia practitioners. 40% responded that more patients could be considered as candidates for invasive pain management techniques if performed in the patient's home or hospice.



Zerwekh.V.J. (2006)	Health services research Journal	To determine the degree to which patients and families enrolled with hospice received services across key categories of palliative care, the extent of hospice-level variability in services delivered, and changes over time in services delivered.	Observational, cross-sectional study conducted from 1992 to 2000. The primary outcome is the receipt of services across five key categories of palliative care: nursing care, physician care, medication management, psychosocial care, and caregiver support	In 2000, 22 % of patients enrolled with hospice received services across 5 key categories of palliative care., whereas 14 % of hospices provided services across five key categories of palliative care
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## APPENDIX 2: Meaning of acronyms

QOL- Quality of life

WHO-World health organisation

EOLC- End of Life Care