Chapter 9
Nursing Perspective and Considerations

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Introduction

> Palliative Care is defined by the World Health Organization (WHO) as an approach that improves the quality of patients and their families facing the problem associated with life threatening illnesses, 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. [1]

Palliative Care aims to:

- Affirm life and regard dying as a normal process
- Provide relief from pain and other distressing symptoms
- Integrate the psychological and spiritual aspects of patient care
- Offer a support system to help patients live as actively as possible until death
- Offer a support system to help the family cope during the patient's illness and in their own bereavement

Palliative Care is provided by those providing the day-to-day care to patients and carers in their homes and hospitals as well as those who specialize in palliative care (consultants, medicine, and clinical nurse specialists, for example).

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This chapter will focus on the role of the nurse in palliative care and working with the multidisciplinary team. The main practice areas for the nurse involved in palliative care can be summarized into the following main focus areas:

1. Coordinating the program and treatment plan for patients and their families
2. Working with the multidisciplinary team
3. Symptom management
4. Education and research

The nurse spends the most time with the patient and therefore his or her role is to ensure the following:

1. Relief of physical symptoms
2. Helping the patient to achieve the highest quality of life
3. Assist the patient in maintaining his or her independence
4. Provide relief for mental anguish and social isolation
5. Support patient and family members
6. Assist the patient to reduce isolation, fear, and anxiety
7. Support the process of dying well

The nurse should be available to enable convenience, respond to anger, respond to colleagues, respond to family, and be present or available when death occurs. The importance of palliative care has led to a new field of Palliative Care Nursing. This type of nursing differs in essence from other areas of nursing care and reflects a "whole *person*" philosophy of care across the lifespan and across diverse health settings. It focuses on the patient and family as the unit of care.

In palliative nursing, the "*individual*" is recognized as a very important part of the healing relationship. This relationship of the nurse with the patient and family is crucial. Together with knowledge and skills, is the essence of palliative care nursing and sets it apart from other areas of nursing practice. However, palliative care as a therapeutic approach is appropriate for all nurses to practice. It is an integral part of many nurses' daily practice, as is clearly demonstrated in work with the elderly, the neurologically impaired, and infants in neonatal units. The palliative care nurse frequently cares for patients with major stressors, such as physical, psychological, spiritual, or existential [2]

In caring for the suffering, the role of the nurse is one of coaching. "Coaching is an interpersonal intervention that requires therapeutic use of self, involving one's own mind, past experiences, words, heart, and hand-to comfort those who suffer". In coaching, the nurse:

- Establishes a trusting partnership
- Assesses those who are at risk for suffering or who are vulnerable; reassures patients that although their suffering may not disappear, they will not be abandoned
- Identifies factors that may be eliminated or modified to alleviate suffering
- Intervenes to facilitate expression of feelings, find meaning in suffering, help patients and families redefine the quality of life

Table 9.1 Six ways the nurse/health professional can relieve suffering

1. Being a companion to sufferers by identifying the pain of their losses and exploring the circumstances and extent of their loss
2. By listening for statements of meaning from sufferers and allowing the person's natural instincts and energy to surface the issue of higher meaning
3. By valuing any self-disclosure on meaning that a sufferer offers, by analyzing the meaning of the statements and learning what the statements reveal about the sufferer's point of view of him or herself
4. By encouraging the sufferer's interpretation of their own experience
5. By validating the sufferer's interpretation of their own experience while clarifying the meaning and
6. The nurse can identify supportive resources and hope for the sufferer to extend his or her identity and meaning in the future

The nurse must be self-accepting, secure in his or her own self-concept, and feel confident in strengthening others.

Nurses and other health professionals can relieve suffering in six ways (see Table 9.1).

Palliative Nurse and Interdisciplinary Care Team

The team design and composition varies depending on the needs of the patient and available resources. What is most common is the presence of a nurse and a physician on the team. The nurse normally serves as the primary liaison between team members, patient, and family and also brings the team's plan to the bedside, whether at home, in the clinic of inpatient setting. The nurse can also work with the physician to adjust and determine changes in treatment. This is due to the fact that the nurse spends much time with the family and patient, and becomes intimate with the patients condition. Other members of the team often include the chaplain and social worker. No single discipline can meet the needs of most patients and their families; an interdisciplinary team (IDT) is highly preferred.

Apart from assessment and management of pain, in which the nurse's key role has been clearly recognized, the other most important process in palliative care is the family meeting to establish goals and objectives. This is a standard of practice in institutions and especially in the Intensive Care Unit where sometimes the outcome may be unknown for some time. It is in this meeting that families received clarification, have their questions answered and are helped to understand the patient's condition and prognosis, can share their knowledge of the patients values and preferences along with their concerns as well as receive emotional and practical support. This meeting is the backbone of the informed, patient-focused, decision-making about care goals and treatment. Nurses can contribute to these meetings in many important ways:

- The nurse usually has the most current and up-to-date information about the patient's condition.
- This nurse is usually the clinician with the best knowledge of the strongest relationship with the family.
- He/she has the most continuous presence, seeing and hearing interactions with patients and families by clinicians from all disciplines, including the many specialties that are involved in the patient's care.
- Following the family meeting, the nurse is the connectivity to all individuals who may not have been present at the family meeting to ensure continuity of care and treatment.
- Nurses are great at providing information that patients and families can understand.
- Palliative Care Nurse Specialists are specially trained to address communication and other needs of the patient and family in the context of complex and life-threatening situations.
- The nurse is usually the one who needs to carry out the orders decided on at the family meeting.

The essential role of the nurse cannot be understated in palliative care [3].

The Nurse and Hospice Care

Another area where nurses are essential and important is in hospice care of patient. Chapter 3 provides more details on the hospice care. The role of the nurse in hospice care which may occur at home or as inpatient involves three broad areas: (1) approaching care from a patient and family-based, interdimensional care focus; (2) expertise in end-stage disease symptom management; and (3) applying nursing process as a member of the hospice IDT through a critical thinking approach that supports the Hospice Experience Model. The hospice's nurse initial role in end-of-life care is to work with the patient and family to prevent or minimize the suffering that results from physical and functional decline of advancing age or from end-stage disease progression [2].

Nursing Pain Management of the Palliative Care Patients

Nursing Assessment of Pain

Pain is one of the most common but also one of the most feared symptoms that palliative care patients experience during the terminal phase of their lives. The cornerstone of adequate pain management of the palliative care patient is a thorough patient assessment and frequent reassessment. Nurses usually spend more time with a patient than any other health care professional and therefore have the ability and responsibility to perform a holistic pain evaluation. Pain is "whatever the experiencing person says it is, existing whenever and wherever the person say it does". According to the Agency of Healthcare Research and Quality (AHRQ), the most reliable indicator of the existence and intensity of pain is the patient's self-report. Pain is affected most importantly by physiological, psychological, and spiritual factors. The evaluation of pain must consider the evaluation of these factors. When the clinician needs to assess pain, there are some key areas or questions that are recommended (Table 9.2) [4].

The information obtained will help determine the cause of pain and the design of an appropriate pain management plan. It may help the clinician to determine if the pain is caused by disease (e.g., direct invasion by cancer), treatment (e.g., constipation with opioids), debility (e.g., pressure sores), or other unrelated pathology (e.g., arthritis). Pain management should always encompass a holistic approach to treat the cause of pain, including spiritual perspectives.

Care from Family Members and Education of Family and Patient

In some cultures, for instance in Chinese, Asian, as well as several other cultures, interactions with family are extremely important and family members value being able to help with each other. Family members play important roles in meeting both the patient's physical and psychosocial needs as well as accomplishing treatment goals. They perform a wide range of tasks and invest huge amounts of time in taking care of the patient. When the patient can no longer sit, walk, eat, or perform activities of daily living such as bathing, feeding, toileting, dressing, and turning they require total support and physical strength from the family members. In addition, family caregivers may be needed to assist with other necessary activities such as preparing meals, managing medications, observing disease progression, and building links with health professionals. Family caregivers could be parents, spouse, children, children-in-law, and relatives. Some of them may provide 24 h help when the patient has terminal cancer.

People who are dying need care in four areas:

1. Physical comfort
2. Mental and emotional needs
3. Spiritual issues and
4. Practical tasks

Pain is one of main causes of physical discomfort. Pain can affect mood. Being in pain can make someone seem angry or short-tempered. Irritability resulting from pain might make the patient hard to talk, hard to share thoughts and feelings. Experts believe that care for someone who is dying should focus on relieving pain without worrying about possible long-term problems, such as opioids dependence or abuse [5]. Family members should not be afraid of giving pain medicine as is prescribed by the doctor. Pain is easier to prevent than to relieve, and overwhelming pain is hard to manage. If the pain is not controlled well, the patient and his family members should communicate with the doctor. It can be relieved safely and rapidly.

Table 9.2 Pain assessment terminology

Term	Definition	How to use clinically
Duration	How long the pain has been experienced and continues to be present (lasting minutes or hours)	• This information is critical for evaluating the effectiveness of the treatment plan • Duration of pain can be gathered as part of a comprehensive history of the pain as well as each time pain is assessed
Frequency	The number of occurrences in a specified period of time; how often the pain is experienced in a given time period	• Knowing the frequency of pain is useful in developing treatment strategies and for individualized scheduling of care activities
Intensity (or severity)	The descriptive rating of the pain experience	• Usually helpful to identify intensity for the older adult's "worst pain" over a specified period of time as well as "the best the pain gets" in a particular time period • Assessing the present pain rating and an identified pain rating acceptable to the patient is also important • Use the most appropriate scale individualized to the patient's cognitive and sensory abilities (see Figs. Fig. 9.1 Example of a Numeric Pain Intensity Instrument/Scale Fig. 9.2 Example of a Pain Assessment Tool/Scale. Reprinted from Stuppy DJ. The faces pain scale: reliability and validity with mature adults. Appl Nurs Res. 1998;11(2):84–9. Copyright 1998, with permission from Elsevier 9.1 and 9.2)
Location	Anatomic site(s) of pain	• Older adults often have pain in more than one location • Identify and document all sites with corresponding intensity and character • Pain maps are very useful in documenting all pain locations, guiding therapy, and as a tool in providing daily care (e.g., CNAs can use the pain map to establish the least painful ways to turn and/or ambulate the person they are working with)
Onset	Description of the experience of the beginning of the pain	• The patient may describe a sudden or gradual development of the pain, associated with a known injury or illness • Asking about onset can also help identify pain triggered by specific movement or activity

Pattern (or rhythm)	The course of the pain over time including variations, often influenced by times of day (e.g., certain hours of the day, night or day, monthly patterns), periods of rest, or specific or general activity/movement	• Older adults can experience constant and/or episodic pain • Analgesic therapy should be tailored to these patterns • For example, short-acting analgesics are most appropriate for episodic pain, whereas long-acting agents are best for constant pain. Routinely dosed, short-acting agents may work well as an alternative to long-acting opioids in older adults • Older adults with both constant pain and episodic increases in pain (breakthrough pain) need both short-acting and long-acting medications
Quality (or character)	Description of the characteristics of the pain, preferably in the words used patient to describe the pain	• Helpful in determining the type of pain to guide the most appropriate analgesic • If the older adult has difficulty describing the pain, it may be helpful to offer examples of descriptions • These may include the following: aching, sore, cramping, pounding, sharp, throbbing, dull, nagging, penetrating, shooting, numb, tingling, spasm, burning, gnawing, pressure-like, radiating, stabbing, tingling, tender, knife-like, etc.

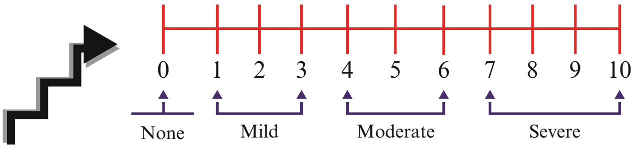
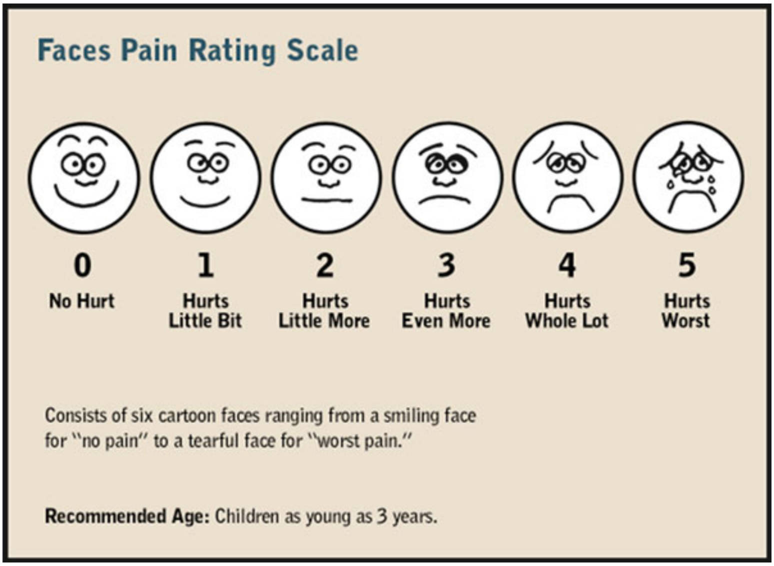


Fig. 9.1 Example of a Numeric Pain Intensity Instrument/Scale



Consists of six cartoon faces ranging from a smiling face for "no pain" to a tearful face for "worst pain."

Recommended Age: Children as young as 3 years.

Fig. 9.2 Example of a Pain Assessment Tool/Scale. Reprinted from Stuppy DJ. The faces pain scale: reliability and validity with mature adults. Appl Nurs Res. 1998;11(2):84–9. Copyright 1998, with permission from Elsevier

There are some myths about pain, which can hinder effective pain management. Nurses should attach great importance to these myths when they educate patients and their families (see Table 9.3).

Treatment Modalities for Pain

PCA and Other Treatment for Palliative Cancer Pain Patient

There are several treatment modalities that can be used to deliver effective pain management. One of these methods is the use of a patient controlled analgesia (PCA).

This is the technique whereby patients can self-administer small doses of parenteral analgesics by means of a simple push button mechanism. PCA is an effective and

Table 9.3 Common myths about dying and pain management

1. Myth: Dying is always painful	Not everyone who is dying experiences pain. Many people die without experiencing pain
2. Myth: There are some types of pain that cannot be relieved	Recent advances in medical area assure that all pain can be relieved by using combined approaches, such as medications and nerve block
3. Myth: If I get morphine, I will stop breathing	Morphine does slow down respirations in many people, however, proper doses of morphine usually do not cause someone to stop breathing
4. Myth: To get good pain relief, you have to take injections	We used to think that opioids were not effective unless administered by injection. We now know that morphine is effective when given orally or even by suppository. There are some long-acting preparations of morphine which can be given every 12 h, or some skin patches which can be applied every 72 h, to simply the route of pain control
5. Myth: People should wait until their pain is bad to take morphine so it will be effective when it is really needed	Using it when it is needed in the early phases of the disease does not mean that opioids and morphine will be ineffective in the advanced phases of the disease
6. Myth: Once you start taking morphine, the end of your life is always near	Morphine does not always cloud consciousness. It does not initiate the final phase of life or lead directly to death
7. Myth: Patients have to stay in a hospital to get effective pain relief	Patients can get safe and effective relief of severe pain at home. If treating the pain at home does not work, the patient may need further treatment in a hospital or outpatient setting or by a visiting nurse

safe treatment for cancer pain. PCA allows for more immediate relief of breakthrough pain and can provide patients with a greater sense of person control over their pain.

A number of parameters on the PCA pump can be set, including:

- **Drug concentration** in the drug reservoir.
- **Bolus dose** can be delivered by a permitted request.
- **Lockout time** is the interval between two bolus doses is set to allow time for the effect of the previous dose before the subsequent dose.
- **Rate of background infusion** is the amount of the continuous infusion. This feature is optional.
- **Hour limit** is set as the maximum amount the patient can receive in 1 or 4 h.

Patient and family education is critical for safe, effective use of PCA. Education must be provided to patients prior to initiation of PCA and must address their role in pain management. The family also needs to be educated on the use, dosage, and should be provided with answers and clarifications to questions they may ask. Education needs to both written and verbal and must include the following information:

- Definition of PCA and patient's responsibility in PCA therapy
- Pump operation

- PCA by proxy
- Description of when to alert the nurse include the following symptoms:
  - Inadequate pain relief
  - Side effects of nausea
  - Vomiting, constipation
  - Urinary retention
  - Itching

There are intravenous and subcutaneous routes of PCA. IV infusions require the need for an intravenous access. As death nears, the burden of maintaining IV access, especially in the home setting, can be enormous. The subcutaneous PCA route is an acceptable alternative to intravenous PCA.

Pain Team

In many countries, if a terminal ill inpatient needs a complex pain management, it is customary for the physician to refer the patient to a pain team. A pain team consists of pain doctors and pain management advanced practice nurses (APN). The pain doctor prescribes PCA orders based on the patient's current total daily opioid dose, and the pain management APN assesses the patient's cognitive function to determine if the patient is able to understand and participate in PCA therapy. In palliative care, pain management therapies including PCA therapy are often conducted in patient's homes. Nurses are a vital part of pain therapy at home since they are the liaison between patients and physicians in this setting.

After the initiation of PCA therapy, registered nurses assess the vital signs, pain, sedation, and respiratory rate and quality frequently. Assessment results are documented in the patient's chart. If the patient has any side effects related to pain treatment, registered nurses will contact the pain team [6].

The pain team will perform follow-up assessments every day and prescribe adjustments of PCA orders based on the patient's response to treatment. Meanwhile, a multimodal approach is combined with PCA therapy. The pain team will communicate strategies of pain treatment with the patient, family members, oncologists, and nurses.

Cultural and Spiritual Considerations

Losses and difficulties in life can challenge faith and philosophical systems. Those experiencing loss and grief may differ regarding religious and spiritual perspectives from which they seek answers, search for meaning, and to which they turn for ritual, comfort, and support [7]. It is important that the nurse understand the ways that spirituality or religion plays a role or not, facilitates or complicates the experience. The nurse also needs to be aware of his or her own beliefs and experiences and be careful not to allow those beliefs to negatively impact the patient and families in their care [8].

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Review Questions

1. Palliative Care is focused on only the care of the dying patient
   (a) False
   (b) True
2. Palliative care is defined by:
   (a) JCAHO
   (b) WHO
   (c) The state
   (d) Nurses
   (e) Physicians
3. Palliative nursing is a new field of nursing that
   (a) Differs in essence from other areas
   (b) Reflects a whole person philosophy
   (c) Focuses on the patient and family as a unit
   (d) a, b, & c
   (e) b only
4. The nurse can relieve suffering in the following ways
   (a) By listening for statements of meaning from sufferers and allowing the person's exploring circumstances to surface the issue of higher meaning
   (b) By encouraging the sufferer's interpretation of their own experience
   (c) By validating the sufferer's interpretation of their own experience while clarifying meaning
   (d) a & c only
   (e) All the above
5. What is the most common palliative team design
   (a) A nurse and a physician
   (b) A nurse only
   (c) A nurse and social worker
   (d) A physician and chaplain
   (e) A physical therapist and a nurse
6. Pain is defined as whatever the patient says it is
   (a) True
   (b) False
7. The healthcare provider should be worried about patients becoming addict because they need to take pain medicine over a period of time
   (a) True
   (b) False

Answers

1. (a)
2. (a)
3. (d)
4. (e)
5. (a)
6. (a)
7. (b)