Palliative care

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* **Defining Nursing:**

In the context of palliative care, perhaps the most succinct and relevant one is that written by Virginia Henderson (1997): ‘Nursing is primarily assisting the individual in the performance of those activities contributing to health and its recovery, or to a peaceful death.’

The statement suggests partnership, helping and dignity – all concepts that are central to the palliative approach to nursing.

* **Palliative care:**

World Health Organization (WHO) first defined palliative care in the early 1990s. at this time the focus of palliative care was undoubtedly cancer; however, WHO was updated the definition to encompass all life-limiting conditions.

"Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of pain and 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 distressing symptoms;
* Affirms life and regards dying as a normal process;
* Intends to neither 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 counselling, 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 investigations needed to better understand and manage distressing clinical complications. (WHO 2009)
* **Palliative care in the UK:**

The National Council for Palliative Care (NCPC), which is an umbrella organization for setting standards in specialist palliative care in the UK, published its current definition in 2002.

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* Offers a support system to help the family cope during the patient’s illness and in their own environment.

The main part of the definition is simply a shortened and adapted version of the one discussed above (WHO, 2009). What is significantly different, however, is the emphasis on the phrase ‘supportive care’, a term that is widely used today to describe both general and specialist services that may be required to support people at the end of life. It is based on an assumption that people have needs for supportive care from the time their possible diagnosis is first mentioned.

The influential strategy document on the development of palliative care services produced by NICE (2004) uses this definition widely.

It states: ***‘Palliative care*** *is the active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.*

***‘Supportive care i****s that which helps the patient and their family to cope with cancer and treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximize the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment.’*

* **Standards and guidelines:**

One important aspect of modern palliative care is its attempt to encourage the sharing of good practice through the setting of standards and guidelines and the application of best practice statements.

The **standards** seek to assess eight aspect of care ( Clinical Standard Board for Scotland, 2002) :

1. Access to services
2. Key elements of specialist palliative care
3. Managing people and resources
4. Professional education
5. Inter-professional communication
6. Communication with patients
7. Therapeutic interventions
8. Patient activity

The **guidelines** approach adopted by NICE follows a 13 topic formal which includes (National Institute for Health and Clinical Excellence, 2004:

* Co-ordination of care
* User involvement
* Face to face communication
* Information
* Psychological support services
* Social support cervices
* Spiritual support services
* General palliative care services
* Specialist palliative care services
* Rehabilitation services
* Complementary therapy services
* Services for families and carers including bereavement
* Research in supportive palliative care.
* **Care at the end of life**

In CCUs, the mortality rate is high, with some estimates as high as 69%. Although the goal of critical care has traditionally been to preserve and restore life, nurses working in ICU will necessarily provide care to patients at the end of life.

* Experiences with patients’ deaths in the CCU can be viewed on a continuum. There are times when death occurs suddenly and unexpectedly in the ICU, after aggressive resuscitative efforts have failed. Other times, death is expected, even anticipated.
* In such cases there may be a conscious movement that occurs over time in which treatment goals change from providing aggressive curative therapies to a comfort-focused plan of care. This comfort plan of care may involve withdrawing or withholding specific therapies. Along this continuum of care, there is a multitude of complex issues and possible scenarios that patients and their families, physicians, and nurses must work through to optimize care of dying patients.
* **Barriers to Care**

The landmark Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) revealed several shortcomings of care provided to seriously ill hospitalized patients. Specifically, family members of half of the patients who were conscious at the end of life reported that the patients’ last few days were spent in moderate to severe pain. In addition, most of the orders for “Do Not Resuscitate,” indicating a transition in the plan of care, were written in the last 2 days of life. Half of the over 4,000 patients in phase I of the study spent their last days of hospitalization in undesirable states that is, comatose or in an ICU on a mechanical ventilator. In Phase II of the study, specific interventions were undertaken to improve the quality of care at the end of life. These interventions were targeted at enhancing opportunities for more patient–physician interaction, but were not successful in improving the desired outcomes. The authors propose greater individual and societal commitment to enhancing care of the dying, hospitalized patient.

* **Communication about patient wishes, prognosis, goals, and treatment interventions remains a significant barrier to providing end-of-life care.** In patients who cannot communicate their wishes, we must rely on surrogates to help us identify patient values, beliefs, and past experiences or verbalizations that may provide clues to their wishes regarding invasive therapies or life support.
* Other barriers create **difficulties in providing adequate pain relief**. Most nurses working in the ICU understand the principle of double effect. This principle acknowledges that providing comfort or pain medications to dying patients may have a side effect of hastening the time to death, but this is preferable to having a patient in pain or distress. In establishing a pain management plan, it is important to implement the plan consistently between nurses and between shifts. Pain consultants may be asked to evaluate the patient for further recommendations and management strategies. Pain may also be a symptom of emotional or spiritual distress. Interventions would therefore be directed at the etiology of the pain or distress and may be culturally based.
* **Nursing Interventions**
  1. **COMPASSION**
* Most nurses recognize the importance of compassion and the development of a trusting relationship as key elements to providing quality care at the end of life. Benner describes death as a human passage where nurses can help patients and families by fostering leave-taking rituals and including the family in decision making and care.
* Nurses use all of their skills of caring touch, cultural sensitivity, and patient advocacy to demonstrate their compassion and support in the care of the dying.
  1. **COMFORT**
* Caring for the patient at the end of life in the ICU may be as demanding in terms of nursing time and energy as caring for the critically ill patient who is being aggressively managed.
* In general, attention is directed at comfort measures: positioning, skin and mouth care, pain and anxiety management, and addressing communication and Spiritual needs. Practical information is provided on giving bad news to patients and families, administering to patients’ emotional needs, and forgoing life-sustaining therapy.
  1. **COMMUNICATION**
* Critical care nurses need to be involved in patient–family–physician discussions about treatment decisions and goals of care. At times, physicians will discuss treatment options, including a decision to withdraw or withhold therapy, away from the patient or unit.
* The nurse may be in a position to understand and interpret patient wishes based on his or her intense contact with the patient. The nurse may also be able to reiterate messages about prognosis and answer patient and family questions based on his or her involvement in the discussions. Consistent, congruent messages are important for maintaining patient and family trust and optimizing satisfaction with care.
* Listening well is the cornerstone of effective communication. Although we want patients and families to have realistic expectations of care, we do not want to strip them of their hope. Involving spiritual consultants in the care of dying patients may be useful for patients and families struggling to come to terms with the patient’s impending death. Some patients do not want to talk about dying; to do so strips them of whatever hope they hold. Others deal with death in a symbolic way. They speak of “autumns” and “winters” and other subjects that symbolize endings. This is an effective way of terminating one’s life; no interpretation is necessary, and to do so would be inappropriate.
* Communication is also expressed by the nurse’s attitude. Empathy and concern do not need to be expressed in a discouraging manner. Even dying people want to be cared for by a pleasant nurse. A good joke or a smile can be appreciated by a dying patient. Sensitivity to the patient’s mood and a sense of timing are useful in assessing a patient’s receptivity to lightheartedness.
  1. **CONFLICT RESOLUTION/ DEBRIEFING**
* Despite our best intentions and efforts, conflicting emotions and perceptions may exist among patients, families, and caregivers regarding end-of-life care. Many institutions have established ethics committees or have ethical/palliative care experts available for consultation. These experts may be consulted proactively to help resolve a conflict or brought in to review a case for quality purposes. Debriefing after a death in the ICU rarely occurs, but may be a useful strategy for staff to support one another and identify areas for improving care

**Palliative care for critically ill patients:**

Those patients who are identified as being near the end of life require aggressive care for their symptom management, provided by a team of health professionals. The most relevant clinical goal should be to palliate these unpleasant situations by assessing for them and implementing appropriate interventions. Palliative care guidelines have been released by a consortium of organizations concerned with palliative care and end-of-life care, and these may provide guidance when the usual first-line treatments do not promote comfort for critically ill patients who are near death] Palliative care has been thought of as desirable only when the patient nears death or when several interventions have been tried for management of symptoms without success. However, recent publications such as these guidelines and the IOM report *Improving Palliative Care for Cancer* stated that palliative care ideally begins at the time of diagnosis of a life-threatening illness and continues through cure, or until death and into the family's bereavement period.

**Principles of Symptom Management**

1. Remember to consider the ‘whole patient’. Symptoms are never purely physical or purely psychological, and all symptoms and treatments will have an impact on the patient, their family and friends.

2. Evaluate symptoms thoroughly. Consider potential causes and remember to consider causes other than cancer. Consider the impact of the symptom on the patient’s quality of life.

3. Effective communication is essential. Explain in simple terms and avoid medical jargon. Discuss treatment options with patients and their families, and involve them in the management plan.

4. Correct the correctable, as long as the treatment is practical and not overly burdensome. Remember non-drug treatments e.g. palliative radiotherapy for metastatic bone pain.

5. When using drug treatments for persistent symptoms, give regularly and also ‘as needed’. Keep drug treatment as simple as possible.

6. Review regularly and adjust treatment.

7. Remember to consider non-pharmacological strategies to help relieve symptoms e.g. simple repositioning, or the use of a TENS machine may help pain; complementary therapies may help psychological distress. Although the evidence base for such treatments is not robust, some patients find them helpful.

8. Plan in advance. Good communication is essential in establishing patients’ wishes for their future care and treatment. Patients may want to document their wishes.

9. Keep other staff informed.

10. Ask for help. Refer to local guidelines or speak to the local Specialist Palliative Care team (SPCT).

***Pain Management***

***Pain assessment***

* Since many critical care patients are not conscious, assessment of pain and other symptoms becomes more difficult.
  + What helps? What makes it worse? Review and review again.
  + Investigate appropriately. Think of X-ray for pathological fracture or bone metastases; ultrasound or CT scan for deep soft tissue tumors.
  + Remember common non-malignant causes e.g. arthritis, tension headache, infections including oral thrush.
* It was recommended that using signs of body movements, neuromuscular signs, facial expressions, or response to physical examination for pain assessment in patients with altered consciousness.
* In advanced, progressive disease there are usually multiple causes of pain and a management plan will be needed for each of these.
* Non-opioid drugs are the first-line approach, followed by adding an opioid for additional analgesia when relief is not obtained. Since opioids provide sedation and anxiolysis as well as analgesia, they are particularly beneficial in the ventilated patient.
* Morphine is the drug of choice, and there is no upper limit in dosing. In nonventilated patients, sedation may cause respiratory depression, and non-opioids or specific anesthetic agents may be more appropriate.

**SYMPTOM MANAGEMENT**

The following symptoms as necessary parts of the assessment: dyspnea, nausea and vomiting, edema and pulmonary edema, anxiety and delirium, metabolic derangements, skin integrity, and anemia and hemorrhage.

***Dyspnea***

* Dyspnea is best managed with close evaluation of the patient and the use of opioids, sedatives, and nonpharmacologic interventions (oxygen, positioning, and increased ambient air flow).
* Morphine reduces anxiety and muscle tension and increases pulmonary vasodilation.
* Benzodiazepines may be used in patients who are not able to take opioids, or for whom the respiratory effects are minimal. Benzodiazepines and opioids should be titrated to effect.

***Nausea and Vomiting***

* Nausea and vomiting are common and should be treated with antiemetic's.
* The cause of nausea and vomiting may be intestinal obstruction.
* Treatment for decompression may be uncomfortable in dying patients, so its use should be weighed using a benefit/burden ratio.

***Fever and infection***

* Fever and infection will necessitate assessment of the benefits of continuing antibiotics so as not to prolong the dying process.
* Management of the fever with antipyretics may be appropriate for patient comfort, but other methods such as ice or hypothermia blankets should be balanced against the amount of distress the patient would experience.

***Edema***

* Edema may cause discomfort, and diuretics may be effective if kidney function is intact. Certainly dialysis would not be warranted at end of life.
* The use of fluids may contribute to the edema when kidney function is impaired and the body is slowing its functions.
* In a Database of Abstracts of Reviews of Effectiveness (DARE) report, little relationship was found between thirst and fluid therapy or fluid status.

***Anxiety***

* Anxiety should be assessed verbally, if possible, or by changes in vital signs or restlessness.
* Benzodiazepines, especially midazolam with its rapid onset and short half-life, are frequently used.

***Delirium***

* Delirium is commonly observed in the critically ill and in those approaching death.
* Haloperidol is recommended as useful, and restraints should be avoided.
* There are recommendations of most authors to use neuroleptic medications as a treatment for restlessness, a number of studies demonstrated the effectiveness of other medications such as benzodiazepines (notablymidazolam and lorazepam), or phenothiazines, either alone or in combination.

***Metabolic Derangement***

* Treatments for metabolic derangements, skin problems, anemia, and hemorrhage should be tempered with concerns for patient comfort. Only those interventions promoting comfort should be performed. Patients do not necessarily feel better “when the lab values are right,” if they had to have invasive treatments to get there.

***Providing Comfort***

* The nursing interventions at end of life should focus on the provision of comfort care as an active, desirable, and important service.
* Unnecessary checks of vital signs, laboratory work, and any treatment that does not promote comfort should be avoided.
* Positioning the patient who is actively dying has as its purpose only comfort, not the schedule to promote skin integrity.
* Coordinating this care with the many members of the critical care team is important to ensure consistency across disciplines and across shifts. When symptom management is not successful in ensuring comfort, the services of the Pain Team or the Palliative Care Service may be required.

**References:**

1. Urden L, Stacy K, Lough M. (2010) Critical care nursing: diagnosis and management; 6th ed. St. Louis; Mosby, an imprint of Elsevier Inc.
2. Morton P, Fontaine D. (2009) Critical care nursing; a holistic approach. 9th ed. Philadelphia: Lippincott Williams & Wilkins.
3. **National Council for Palliative Care** (formerly the National Council for Hospice and Specialist Palliative Care Services) (2002) [Definitions of Supportive and Palliative Care](http://tinyurl.com/palliative-archive). Briefing Bulletin 11. London: NCfPC.
4. **NICE** (2004) [*Improving Supportive and Palliative Care for Adults with Cancer*](http://www.nice.org.uk/Guidance/CSGSP)***.***
5. **Nightingale, F.** (1860) *Notes on Nursing:What It Is, and What It Is Not*. New York, NY: D. Appleton and Company.
6. **NHS Confederation** (2005) [*Leading Edge, issue 12: Improving End-of-Life Care.*](http://tinyurl.com/nhsconfed-endoflife)
7. **Storey, L. et al** (2003) Place of death: Hobson’s choice or patients’ choice? *Cancer Nursing Practice*; 2: 33–38.
8. **Thomas, K.** (2003) *Caring for the Dying at Home: Companions on the Journey.* Oxford: Radcliffe Medical Press.
9. **Thompson, G. et al** (2006) Nurses’ perceptions of quality end of life care on an acute medical ward. *Journalof Advanced Nursing;* 53: 169–177.
10. **World Health Organization** (2009) [WHO Definition of Palliative Care](http://tinyurl.com/WHO-definition). Geneva: WHO.