



Perspectives on Hospice Palliative Care



Nursing

**Hospice Palliative Care Nursing Standards:
How do these apply to our practice?**

End-of-Life Care: Whose business is it?

Common Myths of Hospice Palliative Care



Hospice Palliative Care Nursing Standards: How do these apply to our practice?

Jacquie Peden, Darlene Grantham and Marie-Josée Paquin

Nursing standards, which are based on the values of the nursing profession, are developed by provincial and territorial regulatory bodies across Canada to guide and direct nursing practice. Specialty groups in conjunction with the Canadian Nurses Association (CNA), promote nursing standards to serve as a basis for nursing certification within each specialty area. Hospice palliative care (HPC) is one specialty area that has recently created nursing standards. The purpose of HPC is to relieve suffering and improve the quality of life for persons who are living with or dying from advanced illness, or are bereaved (4).

Why are Hospice Palliative Care Nursing Standards (HPCNS) important? How can these standards be applied to our nursing practice? According to the CNA (2), “Standards are necessary to demonstrate to the public, government and other stakeholders that a profession is dedicated to maintaining public trust and upholding the criteria of its professional practice.” Standards are a measure of performance that reflect the values of the nursing profession and enable nurses to promote safe, competent and ethical practice. HPCNS serve as a guide for nursing practice and clearly identify the role of the hospice palliative care nurse (1).

The purpose of HPCNS is to define the standard of care that can be expected, establish requisite knowledge for nursing persons and families with advanced illness, support on-going development of hospice palliative care nursing, promote hospice palliative care nursing as a specialty and serve as the foundation for the development of certification in hospice palliative care.

The HPCNS are reflective of the CPCA 2001 Proposed Norms of Practice for hospice palliative care. The framework used for these standards is based on six dimensions: valuing, connecting, empowering, doing for,



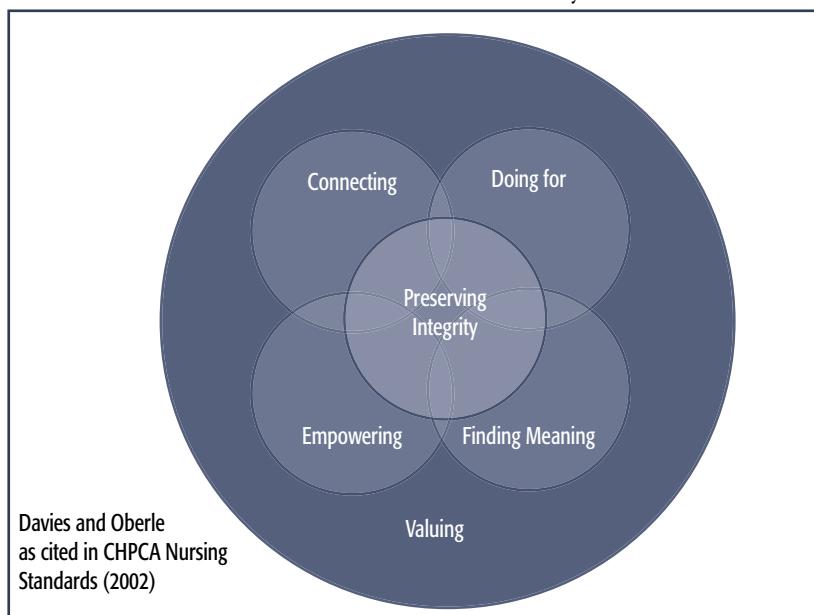
Hospice palliative care is aimed at relief of suffering and improving the quality of life for persons who are living with or dying from advanced illness or are bereaved.

finding meaning, and preserving integrity, of the Supportive Care Model (4). Each dimension represents a standard:

- I. The hospice palliative care nurse believes in the intrinsic worth of others, the value of life and that death is a natural process.
- II. The hospice palliative care nurse establishes a therapeutic connection (relationship) with the person and family through making, sustaining and closing the relationship.
- III. The hospice palliative care nurse provides care in a manner that is empowering for the person and family.
- IV. The hospice palliative care nurse provides care based on best practice and/or evidence-based practice in the following areas: pain and symptom management, coordination of care, and advocacy.
- V. The hospice palliative care nurse assists the person and family to find meaning in their lives and their experience of illness.
- VI. The hospice palliative care nurse preserves the integrity of self, person and family.

Although these standards are specific to hospice palliative care nursing, there are components of the standards that are fundamental to nursing practice and can guide nurses who provide end-of-life care. For example, the nurse advocates for persons and families, listens actively as an integral part of communication, establishes a plan of care in collaboration with the person and family, advocates for appropriate pain and symptom management, assists the person and family to maintain a sense of control, and provides comprehensive, compassionate and co-ordinated care (1).

However, these standards also demonstrate how hospice palliative care nursing is a specialty that requires specialized knowledge and skills. Grantham (5), in a Manitoba study, found that, in general, hospice palliative care nurses felt prepared to use these standards. However, she reported practice challenges in all six standards. With regard to Standard I (Valuing), 70% of nurses felt prepared to advocate for all persons at end of life but not prepared to assist the person in finding meaning in life and achieving the best quality of life as defined by the person. In Standard II (Connecting) all nurses felt prepared to connect with persons and families by establishing therapeutic relationships, but 50% of them felt unprepared in conducting a cultural and spiritual assessment. In Standard III (Empowering) 65% of nurses felt unprepared to address sensitive and emotionally charged issues. Standard IV (Doing For) concerns focused on end-of-life policy (55%) while 50% of nurses were concerned about dealing with special populations. Standard V (Finding Meaning) raised





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education concerns about the balance between hope and suffering (65%) and results relating to Standard VI (Preserving Integrity of the Supportive Care Model) showed that 50% of the nurses were concerned about participating in research activities appropriate to practice. Palliative care nurses also reported that lack of time was a practice challenge: they would like to have more time to establish therapeutic relationships and to spend at the bedside.

Nursing standards not only guide nursing practice but can be applied in the following ways:

- by developing new models of nursing care delivery, through staff orientation and continuing education programs, when

evaluating performance with career planning and professional development

- by determining appropriate referrals for nursing consultation within a specialty area
- by ensuring quality of nursing care through increasing public awareness about the nursing roles of a specialty area
- by creating an environment for excellence in nursing practice (3).

Nursing standards are designed as benchmarks to measure a nurse's performance but are also used as the foundation for the development of nursing competencies and guidelines for practice. Therefore, nursing standards are useful tools for nurses in determining what knowledge and skills are required to provide quality care.

Resources

Canadian Hospice Palliative Care Association Nursing Standards

[http://www.chpca.net/interest_groups/nurses/Hospice Palliative Care Nursing Standards of Practice.pdf](http://www.chpca.net/interest_groups/nurses/Hospice_Palliative_Care_Nursing_Standards_of_Practice.pdf)

A Model to Guide Hospice Palliative Care http://www.chpca.net/publications/norms_of_practice.htm

Canadian Hospice Palliative Care Association <http://www.chpca.net/home.htm>

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End-of-Life Care: Whose business is it?

Jacquie Peden, Carolyn Tayler and Carleen Brenneis

End-of-life care is provided in many health care settings including intensive care, emergency departments, renal dialysis and neonatal units, as well as at home and in residential care for patients of all ages, including children. While we often think of cancer patients as at end of life, a prolonged period of time preceding death is a part of many chronic disease trajectories. End-of-life care is every nurse's business. Therefore, wherever a nurse is working he or she will need to be skilled in providing compassionate and effective end-of-life care.

Strategies for ensuring quality end-of-life care should be integrated into every nurse's practice. These include:

- communicating openly, honestly and in a timely fashion
- maintaining comfort
- ensuring social support and care for caregivers
- applying the principles of palliative care
- ensuring that care is ethically, spiritually and culturally appropriate (3).

Effective communication is one of the foundational concepts that form the bases of hospice palliative care (1). Communicating effectively involves providing patients and their families with information so that they are able to make decisions about care, initiating discussions about end-of-life care when the patient can actively participate, and facilitating discussions with patients and their families in a supportive and compassionate manner.

Hospice palliative care is aimed at relief of suffering and improving the quality of life for persons who are living with or dying from advanced illness, or are bereaved (1). Hospice palliative care is more focused than end-of-life care and can be provided along the disease trajectory where people need help with suffering and symptom management. It tends to be organized as a set of services. End-of-life care refers to the reliable, skillful





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and supportive care of people with advanced, potentially fatal illness and those close to them (2).

Information sharing and decision making are essential and basic steps in the process of providing and planning care. Several principles of palliative care are:

- the patient and family are treated as a unit of care and the family should be included in decision-making processes whenever possible
- patients and family members need to be informed so that they are able to make decisions, determine goals for care and establish present and future priorities for care (1).

It is important to provide seniors and their caregivers with information so that they are able to make appropriate care decisions, but this information needs to be given incrementally so it is not overwhelming (3).

Nurses in all areas of health care play a key role in initiating discussions with patients about end-of-life decisions regarding care. In chronic disease, where patients slowly

decline or their health status fluctuates, it is often difficult to determine when the end-of-life is approaching. Discussions with patients failing to improve in an intensive care setting need to take place at the earliest possible opportunity (7). In a document about promoting excellence in end of life care for individuals with amyotrophic lateral sclerosis (ALS), six triggers for initiating discussion about end-of-life issues were listed:

- the patient or family opening the door to discussions about end-of-life care
- evidence of severe psychological, social or spiritual distress or pain which requires high doses of analgesic
- the occurrence of dyspnea, requiring a feeding tube,
- dyspnea
- forced vital capacity of less than 50%
- loss of function in two body regions (5).

With patients experiencing these kinds of signs and symptoms it is important to initiate a discussions about end-of-life care before a crisis occurs that prevents patients from being active participants in planning their care.

Discussions with patients and their families about end-of-life care are challenging and difficult to initiate. How does the nurse talk about death and dying? Nurses need to explore their own attitudes, values and beliefs about issues surrounding death to improve communication and maximize end of life care (8). When assisting patients and families to make decisions about end-of-life care the nurse should:

- be clear and avoid euphemisms
- be specific about goals and expectations of treatment

- be willing to initiate and engage in discussion
 - use the words the “death” and “dying”
 - talk about hope, clarify goals and burdens of treatment and prognosis
 - collaborate with other providers to give consistent information (6).
- Effective communication is every nurse’s business when providing end-of-life care. During a therapeutic encounter the nurse assesses whether the patient and family have an understanding and sense of complexity of the patient’s illness, explores concerns, and answers questions. Effective communication, when combined with informed and skilled decision making, leads to better care delivery decisions, less conflict, a more effective plan of care, greater patient, family and caregiver satisfaction with therapeutic relationships, fewer caregiver errors, less stress and fewer burnout and retention problems (1).

Resources

- Canadian Hospice Palliative Care Association <http://www.chpca.net/home.htm>
- A Model to Guide Hospice Palliative Care
http://www.chpca.net/publications/norms_of_practice.htm
- Completing the continuum of ALS care: A consensus document.
http://www.promotingexcellence.org/als/als_report/
- A Guide to End-of-Life Care for Seniors www.rgp.toronto.on.ca/iddg/index.htm

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Common Myths of Hospice Palliative Care

Jacquie Peden, Elizabeth Hill, Daphne Powell

“People with cancer die in excruciating pain.” Parents, grandparents and great-grandparents have heard stories about people with cancer who died in pain and continue to believe that this is true. This belief is becoming a myth as countries advance in the understanding of cancer pain and its management. What do you believe about hospice palliative care? Do you believe that this type of care means comfort at the end of life, that it is only for those with a cancer diagnosis, or that telling someone they are dying will take away their hope?

We will discuss these and other common myths about hospice palliative care and will suggest how to dispel them.

The first step is to explain what hospice palliative care is. According to Ferris, the term “hospice palliative care” was coined so that the hospice and palliative care movements could become one with the same principles and norms of practice. Hospice palliative care is aimed at the relief of suffering and improving the quality of life for persons who are living with or dying from advanced illness, or are bereaved. “Hospice palliative care strives to help patients and families: address physical, psychological, social, spiritual, and practical issues, and their associated expectations, needs, hopes, and fears; prepare for and manage self-determined life closure and the dying process; [and] cope with loss and grief during the illness and bereavement” (4).

Myth: Hospice palliative care means providing comfort when someone is dying.

Hospice palliative care is much more than providing comfort. “Hospice palliative care aims to: treat all active issues, prevent new issues from occurring [and] promote opportunities for meaningful and valuable experiences, personal



Hope is influenced by physical condition, pain, relationships, faith and the focus of hope changes as the patient's condition deteriorates.

and spiritual growth, and self-actualization” (4). The active treatment of issues may mean administering blood transfusions to a patient experiencing dyspnea due to low hemoglobin or administering antibiotics to a patient with pneumonia suffering from fever and chills at the end of life. These treatments are not meant to cure the problems but are given to relieve the symptoms. Symptom management is primary and it is important to treat sources of suffering whether the suffering is physical, emotional, social, or spiritual (2).

Myth: Hospice palliative care starts when someone is close to dying and ends at death.

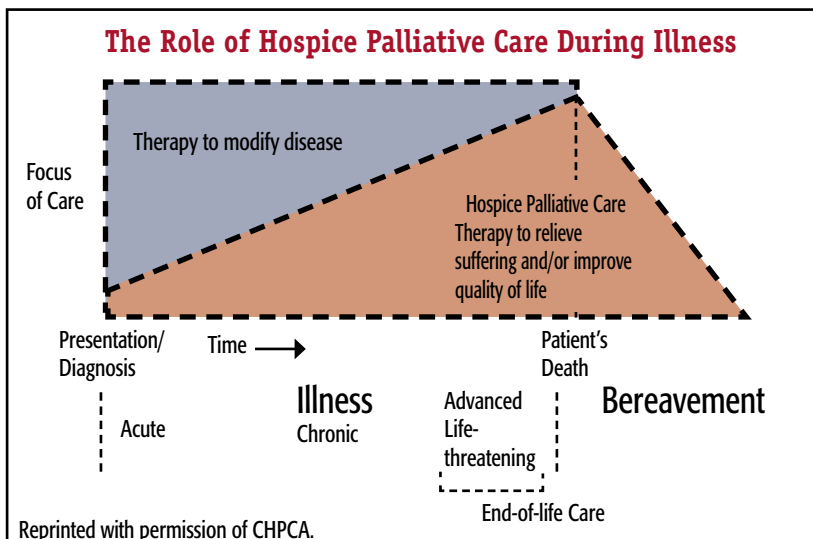
The focus of hospice palliative care starts at the time of diagnosis or acute phase of the terminal illness, continues through the trajectory of the illness and extends beyond the patient's death to the family during bereavement. Care during this time depends on the patient's and family's goals of care and priorities for treatment (4). The intensity of care fluctuates and increases closer to the end of life.

Myth: Hospice palliative care is for people dying with cancer.

Traditionally this has been so, but patients with a life-threatening chronic illness do benefit from hospice palliative care services that promote quality end-of-life care: “Hospice palliative care is appropriate for any patient and/or family living with, or at risk of developing, a life-threatening illness due to any diagnosis, with any prognosis, regardless of age, and at any time they have unmet expectations and/or needs and are prepared to accept care” (4).

Myth: Telling patients they are dying takes away their hope.

This may seem true initially but, when faced with a life-threatening illness, patients often go through a grieving process that includes anger, denial, blaming, and depression. Hope is influenced by physical condition, pain, relationships, faith and the focus of hope changes as the patient's condition deteriorates (3). According to Duggleby (3), the focus of hope is described differently by the terminally ill patient. She reviewed findings from a number of research studies and found that terminally ill patients describe hope as “living day to day, feeling better, relief of pain, not suffering more, peaceful death, life after death and hope for families.” It is important to tell patients that they are dying so that they have opportunities to process the implications of dying, can reconcile with loved ones, leave legacies or explore the meaning of their lives.



Myth: Increasing the dose of opioids causes respiratory depression and quickens death.

“Respiratory depression may occur if the initial dose is far too high, doses are increased too rapidly, dose increases are too great in people with respiratory disorders, other centrally acting drugs such as benzodiazepines or alcohol are concurrently given, [or] an opioid switch to methadone has occurred [and the dose of methadone is too high]” (1). Over time, patients become tolerant to opioid side effects such as respiratory depression, sedation and nausea (5). Perceived risks of respiratory depression and lethargy act as barriers to the

treatment of pain and decreasing or eliminating an opioid because a patient near death experiences decreased levels of consciousness is not appropriate (6). Patients who have not had significant increases in their opioid are likely tolerant to its sedative effects so decreasing an opioid because of lethargy puts the patient at risk of dying in pain (6).

Health care professionals often feel they have failed when someone dies. Dying is a natural part of life. Life is terminal. Therefore it is important that nurses become aware of hospice palliative care principles, services and practices so that misconceptions do not influence the care of the dying patient and their families.

Resources

Canadian Hospice Palliative Care Association Nursing Standards

[http://www.chpca.net/interest_groups/nurses/Hospice Palliative Care Nursing Standards of Practice.pdf](http://www.chpca.net/interest_groups/nurses/Hospice_Palliative_Care_Nursing_Standards_of_Practice.pdf)

A Model to Guide Hospice Palliative Care

http://www.chpca.net/publications/norms_of_practice.htm

Canadian Hospice Palliative Care Association http://www.chpca.net/sigs/nurse_sig.htm

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About this Monograph

The Pallium Project is a strategic initiative focused on facilitating improved access, enhanced quality and additional capacity for hospice palliative care (HPC) within Canada's primary health care renewal framework. The Project is based on the idea that *many hands make light work*. The Project functions as a Community of Practice (CoP). Communities of Practice are self-organized, deliberate collaborations of people who share common practices, interests and aims and want to advance their specific domain of knowledge.

As a CoP, the Pallium Project links a range of teaching-learning, service and policy development, knowledge management, change management and related collaborative initiatives to tangible short- and medium-term results which are essential building blocks for longer-term sustainability in caring for those with life-threatening and life-limiting illness. Collaborators are committed to building on the vision of *Quality End-of-Life Care* for every person in Canada - one which assures comfort, dignity, peace of mind, reduces the burden of undue pain and suffering, and supports the health status of all caregivers and the bereaved.

Recognizing that registered nurses often serve informal roles as sources of health information and health system navigation for family and friends, particularly in times of crisis that involve life-threatening and life-limiting illness, the Pallium Project commissioned a nursing communications initiative in 2004. This initiative sought to engage Canadian registered nurses who are

authority sources in Hospice Palliative Care (HPC) in a collaborative writing project to inform a broad audience of the registered nursing profession about the current state of palliative and end-of-life care in Canada.

The three articles which appear in this monograph have been published in several provincial registered nursing professional association magazines in Canada and are available to nursing professional association/regulatory colleges on a licensed, royalty-free publication basis for the purpose of informing members about Hospice Palliative Care. If your association/regulatory college is interested in reprint rights please contact the Pallium Project at Pallium Project Development Office, Box 60639, University of Alberta RPO, Edmonton, Alberta, Canada, T6G-2S8, Attn: Nursing Communications Initiative.

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