CANADIAN HOSPICE PALLIATIVE CARE NURSING STANDARDS OF PRACTICE

This work is dedicated to those who have motivated us to improve hospice palliative care nursing practice.

CHPCA Nursing Standards Committee, 2009

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FOREWORD

Since the publication of the first Canadian Hospice Palliative Care (HPC) Nursing Standards edition in 2002, the Canadian HPC Nurses Group has had a continuing commitment to the ongoing development and revision of the HPC Nursing Standards to support the delivery of high quality (HPC) nursing. The 2002 edition encompassed specific competencies as well as general standards because there were no detailed competencies developed in Canadian HPC nursing at that time. Competency development advanced in 2003 when the Canadian HPC Nurses Group advocated for and succeeded in establishing HPC nursing as a Canadian Nurses Association (CNA) specialty. The first CNA development and administration of the HPC nursing certification exam occurred in 2004. The 2009 Canadian HPC Nursing Standards will be the foundation for future revisions to competencies, certification exams and programs of professional development.

This edition of the Canadian HPC Nursing Standards involved extensive consultation with HPC nurses across Canada. Nurses indicated that the *Supportive Care Model* (Oberle and Davies, 1992) chosen as a framework for the 2002 HPC Nursing Standards would continue to be a resource for HPC nursing. However, the majority indicated that HPC Nursing Standards should be aligned more closely with the Ferris et al. (2002) *Canadian Hospice Palliative Care Association (CHPCA) Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice* (Appendix A). While members of the 2009 Canadian HPC nursing standards, they also strived to broadly represent HPC nursing practice. Future revisions will involve dialogue with nurses to reflect evolving understandings and standards of nursing practices.

These 2009 Canadian HPC nursing standards are best read in conjunction with the 2008 CNA HPC nursing competencies. Both the standards and competencies provide a framework for building professional HPC nursing practice and will guide discussion and policy development.

HOSPICE PALLIATIVE CARE NURSING IN CANADA

The role of the nurse has been and continues to be an integral component of the HPC movement. Influenced by the development of hospice care at St. Christopher's Hospice in England in the 1960s, the first interprofessional Canadian palliative care services, which included nursing, were opened in November 1974 at St. Boniface Hospital, Winnipeg, Manitoba, closely followed by the Royal Victoria Hospital, Montreal, Quebec, in January 1975.

The ongoing recognition and desire to establish a formal specialization for HPC nursing in Canada was brought to the forefront by a CHPCA Nurses Group that held its first meeting in Winnipeg, Manitoba, in 1993. The main purpose of this meeting was to network and advance HPC nursing in Canada. Two major goals of the group were to establish Canadian HPC Nursing Standards and to have HPC nursing recognized as a specialty practice with the Canadian Nurses Association (CNA). These goals were achieved in 2002. The overwhelming original and ongoing response to write the CNA exam and renew certification attests to the dedication of HPC nurses to advance their practice. In 2008, the Canadian HPC Nurses Group also became an Associate Member of CNA.

The Canadian HPC Nurses Group continues to be an active member of CHPCA, which has a large nursing membership and supports a computer list serve for networking and discussions related to best practice. The HPC Nurses Group has an elected national executive board that hosts an annual general meeting for paid members and other interested nurses at the CHPCA conference.

HPC nurses have been and remain committed to providing quality hospice palliative care. They advocate and provide care for the "whole person" and family. The HPC nurse possesses an extensive specialized body of knowledge to attend to the physical, emotional, psychosocial, cultural, and spiritual considerations for each person, including an emphasis on the provision of skilled and timely pain and symptom assessment/management as a fundamental component of HPC (adapted from HPC Nursing Standards of Practice, 2002).

Nurses are integral members of HPC teams. They serve as the main professional contact and primary liaison with the person and family and other team members. HPC nurses complete comprehensive assessments, interventions and evaluations, establish mutually agreed upon goals of care, monitor the person's health and disease progression, and attend to complex multidimensional palliative care needs. HPC nurses often coordinate services across the continuum of care and collaborate with various interprofessional team members including volunteers (adapted from CHPCA Pan Canadian Gold Standards, 2006). HPC nurses will continue to play a critical role in advocating for better access to services and the promotion of clinical excellence to improve the quality of living-dying for those with life-limiting illness.

Nursing care of people who are living with and dying from a life-limiting illness, along with equal supportive care of their families, is undertaken by nurses in all settings with varying levels of expertise. HPC nurses strongly support that comprehensive hospice palliative care should be available in all settings, including but not limited to private homes, prisons, group homes, rehabilitation centres, on the street and specialized facilities such as mental health facilities, cancer centres, schools, workplaces and day hospice programs (adapted from HPC Nursing Standards of Practice, CHPCA 2002).

DEFINITION OF HOSPICE PALLIATIVE CARE

The CHPCA defines hospice palliative care as "the combination of active and compassionate therapies intended to comfort and support persons and families who are living with, or dying from, a progressive life-limiting illness, or are bereaved" (CHPCA, 1995). Hospice palliative care is "whole-person health care that aims to relieve suffering and improve the quality of living and dying" (CHPCA 2009).

The CHPCA norms (2002) further state the following.

HPC strives to help persons 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.

HPC aims to:

- treat all active issues;
- prevent new issues from occurring; and
- promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization.

HPC is appropriate for any person and family living with, or at a risk of developing, a lifelimiting 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.

HPC may complement and enhance disease-modifying therapy or it may become the total focus of care.

HPC is most effectively delivered by an interprofessional team of health-care providers who are both knowledgeable and skilled in all aspects of the caring process related to their discipline of practice. The professional providers are typically educated by schools or organizations that are governed by educational standards. Once licensed, providers are accountable to standards of professional conduct that are set by licensing bodies and/or professional associations. Trained volunteers are equal respected members of the HPC team.

The CHPCA definition is consistent with the definition established by the World Health Organization (WHO) 2005, which describes palliative care as:

...an approach that improves quality of life of clients and their families facing the problem associated with life-threatening illness, through the prevention of suffering by early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates psychological and spiritual aspects of client care;
- offers a support system to help clients live as actively as possible until death;
- offers a support system to help the family cope during the client's illness and in bereavement;
- uses a team approach to address the needs of clients and their families, including bereavement counselling if indicated;
- will enhance quality of life, and may also positively influence the course of illness; and
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

VISION

All persons and their families living with and dying from life-limiting illness will have access to nurses who provide knowledgeable and compassionate care to lessen the burden of suffering and improve the quality of living and dying.

MISSION

HPC nurses bring specialized knowledge, skills and attitudes to the delivery of comprehensive, coordinated and compassionate care to all persons with life-limiting illness and their families in the setting of their choice. Through a commitment to public and professional education, mentorship, leadership, research and advocacy, HPC nurses strive to achieve the highest possible quality of life through the illness continuum, dying and bereavement.

PURPOSE

The purpose of Canadian HPC nursing standards is to:

- define the standard of care that can be expected by all persons receiving HPC nursing care;
- guide the continuous development of related competencies;
- support ongoing development of HPC nursing;
- promote HPC nursing practice as a specialty;
- serve as a foundation for the development of certification in HPC nursing; and
- provide a framework for desired and achievable level of performance against which actual performance can be compared.

ASSUMPTIONS AND VALUES

Listed below are assumptions and values about person, environment, health and nursing, which underpin HPC nursing practice. The *CNA Code of Ethics for Registered Nurses* (2008) is central to HPC nursing.

<u>Person</u>

"You matter because you are you and you matter to the last moment of your life. We will do all we can to help you, not only to die peacefully but to live until you die" (Saunders, 1976).

- The unit of care is the person living-dying with life-limiting illness and the person's family.
- The family is defined by the person.
- Each person is unique and has intrinsic value.
- The person and family have the right to be informed and to participate in decisions and care to the degree that they wish.
- The person has the right to receive individualized care as personal meanings and hopes change.
- The person refers to all ages across the lifespan.

Environment

- Care is provided, as much as possible, in the setting chosen by the person and family.
- Care should be accessible at the primary, secondary and tertiary levels, in the community, acute care, and long-term/complex care settings in urban, rural and remote areas.
- Care resources may vary widely and are best provided through the collaborative practice of members of an interprofessional team to meet the holistic needs of the person and the family living with advanced illness.
- Care spans the continuum from diagnosis until death of the person and includes the bereavement period for the family.

<u>Health</u>

- Health is a dynamic and continuous process in which a person aspires to well-being and quality of life.
- Each person defines his/her quality of life.
- Living-dying is a natural process.
- Health includes experiences of living-dying, loss, grief and suffering. These experiences may provide opportunities for personal growth.
- Health promotion, in the setting of life-limiting illness, relates to quality of life.

Nursing

- Nurses advocate for and support persons in their experience of living-dying.
- Nurses provide comprehensive, coordinated, compassionate and holistic care.
- HPC nursing practice attends to pain and symptom management and provides psychosocial, grief and bereavement support.
- HPC nursing includes all areas of practice: clinical, education, administration, research and advocacy.

CANADIAN HOSPICE PALLIATIVE CARE NURSING STANDARDS

The HPC nurse maintains and conducts practice in a manner that is consistent with the *CNA Code of Ethics*, provincial standards, territorial standards and CHPCA guiding principles and foundational concepts. The following standards are in addition to this and are specific to HPC nursing. Ethical and collaborative practice is embedded throughout the provision of HPC.

1. Quality of Living-Dying

The HPC nurse focuses on the quality of the experience of the person who is living with and dying from a life-limiting illness, as well as the experience of the family.

The HPC nurse practises with respect for the personal meanings, specific needs and hopes of the person who is living in the last phase of his/her life and his/her family.

2. Comfort

The HPC nurse utilizes a knowledge-based, systematic, holistic and evolving approach to address symptoms and issues specific to the living-dying experience.

3. Transitions

The HPC nurse provides care throughout multiple illness trajectories of life-limiting illnesses, which may occur over a short period of time (sudden death) or may be a longer process (exacerbations of chronic illness or recurrences of cancer). The HPC nurse supports the individual and his/her family through these transitions, the dying process and throughout the grief and bereavement processes.

The HPC nurse assists persons and families to access and navigate the health-care system.

4. Quality and Safety

The HPC nurse practises in accordance with legislation, policies, guidelines and tools pertaining to assessment, information sharing, decision-making, advance care planning, pronouncement of death, after death care, and grief and bereavement support.

5. Leadership

The HPC nurse advocates for and promotes high quality and safe palliative care.

The HPC nurse advances HPC nursing through the generation and application of knowledge and research.

The HPC nurse is an essential team member of the interprofessional team and establishes collegial partnerships and contributes to the professional development of students, peers, colleagues and others through consultation, education, leadership and mentorship.

The HPC nurse communicates and advances the distinct contribution of nursing to the interprofessional team.

6. Personal and Professional Growth

The HPC nurse recognizes the privileges and challenges of working with persons who are living-dying and their families.

The HPC nurse understands his/her own personal experience in response to suffering and death.

The HPC nurse recognizes his/her personal needs and practices self-care while experiencing multiple losses during the care of persons who are dying and their families.

GLOSSARY

These definitions are to assist registered nurses in understanding the context of the standards.

Accountability: Nurses are accountable for their actions and answerable for their practice. Nurses, as members of a self-regulating profession, practise according to the values and responsibilities in the *Code of Ethics for Registered Nurses* and in keeping with the professional standards, laws and regulations supporting ethical practice (*CNA Code of Ethics for Registered Nurses*, 2008).

Advance care planning: The process by which people consider their values regarding future health-care choices, obtain medical information relevant to their health concerns, communicate requests to their loved ones or agents, and document their plans so that the decisions are available to health-care providers wherever they may reside (Fraser Health Authority, 2007).

Advocacy: Becoming knowledgeable and working with others to raise awareness of an issue or injustice and to affect change (CHPCA, 2007).

Bereavement: Bereavement is not only the loss of a significant person but also the period of transition for the bereaved individual following that person's death (Stroebe & Schut, 1999). Bereavement is also used as a broad term that encompasses the entire experience of family members and friends in the anticipation, death and subsequent adjustment to living following the death of a loved one (Christ, Bonanno, Malkinson & Rubin, 2003).

Competencies: Significant job-related knowledge, skills, abilities, attitudes and judgment required for competent performance by members of the profession. Competencies tend to be more detailed, actionable and suitable for examination purposes (ASI, 2009).

Comprehensive, coordinated and compassionate care: Service that integrates key dimensions in palliative care related to pain and symptom management, supportive care, grief and bereavement care. The care is guided by an identified interprofessional team member who assumes the lead in linking the services and the caregivers (both formal and informal) across all care settings. The person and family have an ongoing relationship with specific providers who have standardized approaches to care. Services are integrated and consistent, ensuring that information about the disease process or the individual's preferences and values follow the person across settings of care (Lorenz et al., 2004).

Continuum of care/Illness trajectory: The period of time throughout the illness and bereavement experience (CHPCA, 2002).

Family: Those closest to the person in knowledge, care and affection. This may include the biological family, the family of acquisition (related by marriage/contract); or the family of choice and friends. The person defines who will be involved in his/her care and present at the bedside (CHPCA, 2002).

Grief: Sorrow experienced in anticipation of, during and after a loss (CHPCA, 2002). The diverse natural reactions, such as psychological, physical and social reactions, to the loss of a significant person are characterized by both suffering and growth (Stroebe, Hansson, Stroebe, & Schut, 2001). Grief is a process that requires time. It is normal to experience grief for many months and years after death (Pereira, 2008).

Holistic care: Holistic refers to a whole made up of interdependent parts. As such, authors discuss mind/body connection, mind/body/spirit, or physical/mental/emotional/spiritual and practical aspects of persons. The principles of palliative care are framed around holistic care and the interdependent physical, social, emotional, cultural and spiritual aspects of persons (Palliative Care Australia, 2008).

Holistic nursing: "All nursing practice that has healing the whole person as its goal." Holistic nursing is a practice that draws on nursing knowledge, theories, expertise and intuition to guide nurses in becoming therapeutic partners with people in their care. This practice recognizes the totality of the human being-the interconnectedness of body, mind, emotion, spirit, social/cultural factors, relationship, context and environment (American Holistic Nurses' Association, 1998).

Illness: Absence of wellness due to disease, another condition or aging.

An acute illness is one that is recent in onset and likely to be time-limited. If severe, it could be life-threatening.

A chronic illness is likely to persist for months to years. With progression, it may become lifethreatening.

An advanced illness is likely to be progressive and life-threatening.

A life-limiting illness is likely to lead to death in the near future (CHPCA, 2002).

Interprofessional team: A team of caregivers who work together to develop and implement a plan of care. Membership varies depending on the services required to address the identified expectations and needs (CHPCA, 2002).

Living-Dying: The term *living-dying* is used to honour the belief that persons are simultaneously living and dying. It is also described as a dynamic, constantly changing journey of living while dying/dying while living (McWilliam, 2008).

Mentoring: A voluntary, mutually beneficial and long-term relationship in which an experienced and knowledgeable leader (mentor) supports the maturation of a lesser experienced nurse with leadership potential (mentee) (CNA, 2004).

Pain: An unpleasant sensory and emotional experience that is primarily associated with tissue damage (CHPCA, 2002). Pain, as defined by Dame Cicely Saunders, relates to the person's physical, psychological, social, spiritual and practical condition (Ong & Forbes, 2005).

Place of care: Settings for hospice palliative care may include the person's home, an acute, chronic or long-term care facility, a nursing home/skilled nursing facility, a hospice or palliative care unit or freestanding facility, a jail or prison, the street or any location where care is provided (CHPCA, 2002).

Quality of life: Well-being as defined by the person living with advanced illness. It relates to experiences that are meaningful to the individual (CHPCA, 2002). It is the gold standard for palliative care.

Spirituality: An existential construct inclusive of all the ways in which a person makes meaning and organizes sense of self around a personal set of beliefs, values and relationships. This is sometimes understood in terms of transcendence or inspiration. Involvement in a community of faith and practice may be a part of an individual's spirituality (CHPCA, 2002).

Standards: Defined as broad in scope, reflecting all aspects of the profession, standards can be used as a guideline for practice and can be understood by general members of the public who may not have a complete knowledge of HPC nursing in Canada (ASI, 2009).

Transitions: Changes that occur on a continuum from wellness to death, commonly identified in hospice palliative care practice using various palliative performance scales (Victoria Hospice Society, 2001). Transitions can also refer to changes in place of care and across care settings, such as when the person moves from home to hospital or hospice (Burge, Lawson, Critchley, & Maxwell, 2005).

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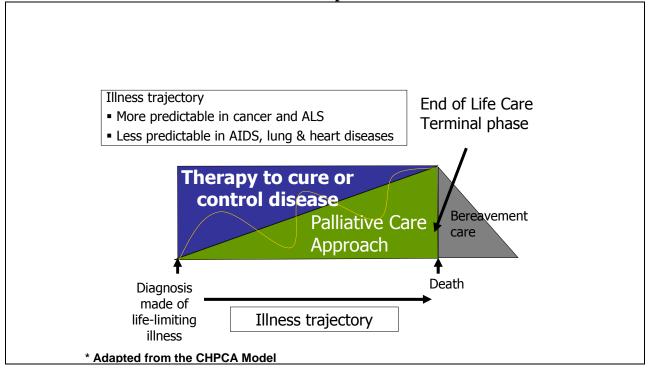
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APPENDIX A

A Model to Guide Hospice Palliative Care



Source: Pereira (2008, Chapter 2, page 4)

In cancer, and to some degree in ALS, the illness trajectory is more predictable and a progressively increasing attention to palliative care is required over time. There are some exceptions though. An example may be a client with breast cancer metastatic to bone only. Second or third-line treatments may bring the disease under control and improve symptoms, decreasing the need for palliative care.

Some illnesses are less predictable than cancer, illnesses such as end-stage heart or lung diseases (COPD). The wave-like line in the diagram illustrates that clients may rebound after treatment of an acute superimposed illness or flare-up of their heart failure. This is one of the challenges of providing palliative care to these clients, but should not deter HPC nurses from providing optimal care. An example of a disease trajectory that weaves in and out of palliative care is COPD where the client may have multiple episodes of near death during exacerbations of the disease.

The HPC nurse supports persons and families during these transitions, the dying process, grief and bereavement.