

II. Hospice Palliative Care: Definition, Values, Principles and Foundational Concepts

Definition of Hospice Palliative Care

Hospice palliative care aims to relieve suffering and improve the quality of living and dying.

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
- cope with loss and grief during the illness and bereavement.

Hospice palliative care aims to:

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

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.

The Origins of “Hospice Palliative Care”

Dame Cicely Saunders first conceived of the modern hospice movement in the United Kingdom in the mid 1960s to care for the dying.¹ Balfour Mount coined the term “palliative care” in 1975 so that one term would be acceptable in both English and French as he brought the movement to Canada (from Latin palliare = *to cloak or cover*²).

Both hospice and palliative care movements have flourished in Canada, and internationally. Palliative care programs developed primarily within larger healthcare institutions, while hospice care developed within the community as free-standing, primarily volunteer programs. Over time, these programs gradually evolved from individual, grass roots efforts to a cohesive movement that aims to relieve suffering and improve quality of life for those who are living with, or dying from, an illness.

To recognize the convergence of hospice and palliative care into one movement, and their common norms of practice, the term “hospice palliative care” was coined. While hospice palliative care is the nationally accepted term to describe care aimed at relieving suffering and improving quality of life, individual organizations may continue to use “hospice,” “palliative care,” or another similarly acceptable term to describe their organization and the services they are providing.

¹ Saunders C. *A personal therapeutic journey*. *BMJ* 1996; 313(7072): 1599-601

² Little W, Fowler HW, Coulson J. *The Shorter Oxford English Dictionary* (Onions CT (ed.)). Toronto, Ontario: Oxford University Press, 1970: 1418

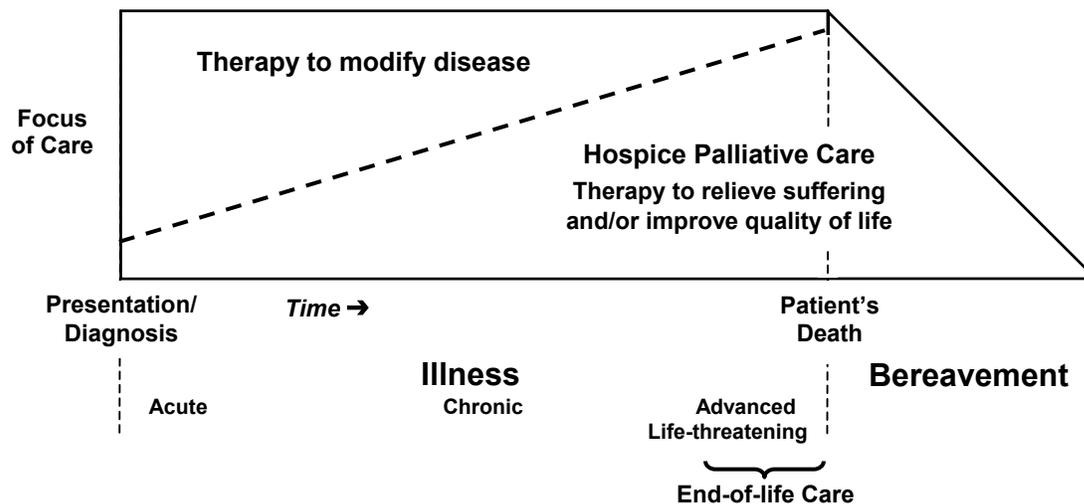
Hospice palliative care may complement and enhance disease-modifying therapy or it may become the total focus of care.

Hospice palliative care is most effectively delivered by an interdisciplinary team of healthcare providers who are both knowledgeable and skilled in all aspects of the caring process related to their discipline of practice. These providers are typically trained 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.

The Role of Hospice Palliative Care During Illness

While hospice palliative care has grown out of and includes care for patients at the end of life, today it should be available to patients and families throughout the illness and bereavement experiences. The following figure illustrates the typical shift in focus of care over time.²²

Figure #8: The Role of Hospice Palliative Care During Illness



The top line represents the total 'quantity' of concurrent therapies. The dashed line distinguishes therapies intended to modify disease from therapies intended to relieve suffering and/or improve quality of life (labeled hospice palliative care). The lines are straight for simplicity. In reality, the total 'quantity' of therapy and the mix of concurrent therapies will fluctuate based on the patient's and family's issues, their goals for care and treatment priorities. At times, there may not be any therapy in use at all.

Some aspects of hospice palliative care may also be applicable to patients and families at risk of developing an illness (see the side box on page 53).

Values

All hospice palliative care activities recognize and support the following values:

- V1. The intrinsic value of each person as an autonomous and unique individual.
- V2. The value of life, the natural process of death, and the fact that both provide opportunities for personal growth and self-actualization.
- V3. The need to address patients' and families' suffering, expectations, needs, hopes and fears.
- V4. Care is only provided when the patient and/or family is prepared to accept it.
- V5. Care is guided by quality of life as defined by the individual.
- V6. Caregivers enter into a therapeutic relationship with patients and families based on dignity and integrity.
- V7. A unified response to suffering strengthens communities.

Guiding Principles

The following principles guide all aspects of hospice palliative care:

GP1. Patient/Family Focused. As patients are typically part of a family, when care is provided the patient and family are treated as a unit. All aspects of care are provided in a manner that is sensitive to the patient's and family's personal, cultural, and religious values, beliefs and practices, their developmental state and preparedness to deal with the dying process.

GP2. High Quality. All hospice palliative care activities are guided by:

- the ethical principles of autonomy, beneficence, nonmaleficence, justice, truth-telling and confidentiality^{23,24}
- standards of practice that are based on nationally-accepted principles and norms of practice, and standards of professional conduct for each discipline
- policies and procedures that are based on the best available evidence or opinion-based preferred practice guidelines
- data collection/documentation guidelines that are based on validated measurement tools.

GP3. Safe and Effective. All hospice palliative care activities are conducted in a manner that:

- is collaborative
- ensures confidentiality and privacy
- is without coercion, discrimination, harassment or prejudice
- ensures safety and security for all participants
- ensures continuity and accountability
- aims to minimize unnecessary duplication and repetition

- complies with laws, regulations and policies in effect within the jurisdiction, host and hospice palliative care organizations.

GP4. Accessible. All patients and families have equal access to hospice palliative care services:

- wherever they live
- at home, or within a reasonable distance from their home
- in a timely manner.ⁱ

GP5. Adequately Resourced. The financial, human, information, physical and community resources are sufficient to sustain the organization's activities, and its strategic and business plans. Sufficient resources are allocated to each of the organization's activities.

GP6. Collaborative. Each community's needs for hospice palliative care are assessed and addressed through the collaborative efforts of available organizations and services in partnership.

GP7. Knowledge Based. Ongoing education of all patients, families, caregivers, staff and stakeholders is integral to the provision and advancement of quality hospice palliative care.

GP8. Advocacy Based. Regular interaction with legislators, regulators, policy makers, healthcare funders, other hospice palliative care providers, professional societies and associations, and the public is essential to increase awareness about, and develop hospice palliative care activities and the resources that support them. All advocacy is based on the Canadian Hospice Palliative Care Association's model to guide hospice palliative care.

GP9. Research Based. The development, dissemination, and integration of new knowledge are critical to the advancement of quality hospice palliative care. Where possible, all activities are based on the best available evidence. All research protocols comply with legislation and regulations governing research and the involvement of human subjects in effect within the jurisdiction.

ⁱ Timelines will be defined by each organization based on its activities.

Foundational Concepts

Hospice palliative care is based on three foundational concepts: effective communication, effective group function, and the ability to promote and manage change.

FC1. Effective Communication

Effective communication is fundamental to both the process of providing care and the function of a hospice palliative care organization. When combined with informed and skilled decision-making, it leads to better care delivery decisions, less conflict, a more effective plan of care, greater patient/family/caregiver satisfaction with the therapeutic relationship, fewer caregiver errors, less stress and fewer burnout/retention problems.

To be effective, hospice palliative caregivers must:

- FC1.1 Share a common language** and understanding of the definitions of the terms they use during the process of providing care; and ensure that commonly used terms are clearly defined, readily available in written format, and integrated into all educational activities. It cannot be assumed that the meaning of critical terms is understood. To assist with effective communication in hospice palliative care, the CHPCA has developed a lexicon of commonly used terms (see appendices, page 91).
- FC1.2 Use a standard protocol to communicate, and to listen and respond to the reactions** that information creates (e.g., the six-step protocol for effective communication developed by Robert Buckman²⁵). An effective protocol to guide communication ensures that information is shared appropriately, and promotes understanding.
- FC1.3 Collect data that documents** the patient's and family's status, and provides a record of each therapeutic encounter. Ensure that data is collected in a manner that is clinically useful, enhances the quality of care, makes it easy to review clinical outcomes and resource utilization, and identify errors and potential risks (see page 38).
- FC1.4 Educate patients, families and caregivers** using strategies that are built on the principles of adult education, i.e., education should be practical, participatory, considerate of the learners' multiple demands, and include strategies to develop the learners' attitudes, knowledge, skills and behaviours.²⁶ Patients, families and careteam members will have varying levels of understanding, knowledge and skill with each part of the process of providing hospice palliative care. They will also have different learning styles, and their capacity to learn will diminish when they are under stress. Teaching strategies and supporting materials should include a careful assessment of the learning styles and capabilities of the learners and be planned carefully. Many tools are available to guide formal caregiver education.^{27,28,29,30,31}

FC2. Effective Group Function

All activities related to hospice palliative care revolve around multiple groups that have specific purposes and tasks. Each group is subject to all of the dynamics of group formation and function. As groups develop and mature, they move through a series of stages. One theory of group formation and function suggests that they start by forming and then move through storming and norming until the group begins performing their tasks effectively together (see the side box on page 4). Each participant plays a role. At the end, every group adjourns. Whenever group composition changes, the group must re-establish itself by again moving through the stages until it is performing effectively.^{32,33,34}

To be effective, all groups need skilled leadership that facilitates their activities and promotes effective group dynamics.

Groups in hospice palliative care include (see figure #9 on the next page):

The patient and family. Patients typically live in long-standing family groups with well-established group leadership and dynamics (which may or many not be effective). During an illness and bereavement, membership, roles, group dynamics and leadership may change dramatically, particularly as the patient dies, and a new family group forms (see figure #5 on page 13).

The careteam. Hospice palliative care is most effectively provided by interdisciplinary careteams. These teams form around individual patient/family units to provide care through a therapeutic relationship. They adjourn when care is no longer needed. Typically, careteams include both formal and informal caregivers, and the patient and family. They require leadership from a formal caregiver who is skilled at group formation/function/dynamics, as well as care delivery. As with any group, it is difficult to establish or maintain a therapeutic relationship if the members are constantly changing.³⁵

Regional teams of formal caregivers. Most hospice palliative care organizations develop regional teams of formal caregivers to help provide hospice palliative care within a specified geographic region or setting. They work together, share caseloads and discuss cases routinely at regional team meetings. Each formal caregiver may contribute to a number of different patient/family careteams for varying lengths of time.

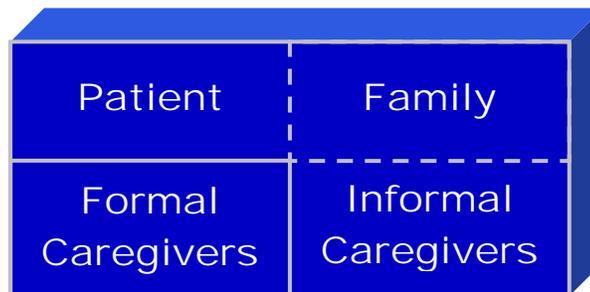
The organization's management team(s), committees and workgroups. Strong and effective group function is also essential to the development of hospice palliative care organizations and their management team(s), committees and workgroups. These groups must function effectively to manage the organization's functions, resources and principal activities.

Figure #9: Groups in Hospice Palliative Care

Patient and Family



Careteam



FC3. Ability to Facilitate Change

Hospice palliative care aims to help patients/families manage the challenges and opportunities they face during their changing illness and bereavement experiences. To fulfill that goal, caregivers must be skilled at maximizing openness and adaptability in the attitudes, knowledge, skills and behaviours of everyone involved in the therapeutic relationship. They must also have specific skills to assist patients and families through the transitions they experience during illness and bereavement.

Similarly, all aspects of organizational development and function, education, research and advocacy are also based on the effective application of change strategies.³⁶

References

URLs were last updated March 23, 2002.

- ²² Adapted from: Expert Working Group on Integrated Palliative Care for Persons with AIDS to Health and Welfare Canada Federal Centre for AIDS. Caring Together. Ottawa, ON: Health and Welfare Canada, December 1987: 29.
- ²³ Bioethics for Clinicians, Canadian Medical Association Journal. See <http://www.cma.ca/cmaj/series/bioethic.htm>.
- ²⁴ Baker RB, Caplan AL, Emanuel LL, Latham SR. The American Medical Ethics Revolution. Baltimore, MD: The Johns Hopkins University Press, 1999.
- ²⁵ Buckman R. How to Break Bad News: A Guide for Health Care Professionals. Baltimore, MD: The Johns Hopkins University Press, 1992: 65-97.
- ²⁶ Ferris FD, von Gunten CF, Emanuel LL. Knowledge: insufficient for change. Journal of Palliative Medicine 2001, 4(2): 145-7. See http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11441621&dopt=Abstract.
- ²⁷ The Ian Anderson Continuing Education Program in End-of-Life Care, <http://www.cme.utoronto.ca/endoflife/>.
- ²⁸ The Pallium Project, <http://www.pallium.ca/>.
- ²⁹ The Education for Physicians on End-of-life Care (EPEC) Project, <http://www.epec.net>.
- ³⁰ The End of Life Nursing Education Consortium (ELNEC) Project, <http://www.aacn.nche.edu/elnec/>.
- ³¹ The End of Life Physician Education Resource Center, <http://www.eperc.mcw.edu/>.
- ³² Tuckman B. Developmental Sequence in Small Groups. Psychological Bulletin, 1965; 63: 384-399.
- ³³ Tuckman B, Jensen M. Stages of Small Group Development. Group and Organizational Studies, 1977; 2: 419-427.
- ³⁴ McNamara C. Group Dynamics: Basic Nature of Groups and How They Work. St. Paul, MN: The Management Assistance Program for Nonprofits, 1999. See http://www.mapnp.org/library/grp_skill/theory/theory.htm.
- ³⁵ Hall P, Weaver L. Interdisciplinary Education and Teamwork: a Long and Winding Road. Medical Education 1002; 35: 867-875.
- ³⁶ von Gunten CF, Ferris FD, Portenoy RK, Glajchen M. Change in CAPCManual: How to Establish a Palliative Care Program. New York, NY: Center to Advance Palliative Care, 2001. See <http://www.capcmanual.info/content/development/change.html>.