Background

This section describes the rationale for a standardized approach to hospice palliative care, for a national model, and for the use of "norms" rather than "standards" of practice. It also describes the consensus process used to develop the model over the last 10 years.

Why a Standardized Approach to Hospice Palliative Care?

Canada's first hospice palliative care programs developed in the 1970s to respond to the needs of the dying. These programs were largely individual grass roots initiatives that have gradually evolved into a cohesive movement that aims to relieve suffering and improve quality of life for those who are living with or dying from an illness. Yet there continues to be considerable variability in the quality and availability of hospice palliative care. Although there are more than 600 programs across the country that deliver hospice palliative care, only a small proportion of Canadians living with a life-threatening illness have access to these programs. Many of the existing programs are not comprehensive, and are unable to address all of the issues faced by patients and families.

To ensure that all Canadians have access to consistent, high quality care that can relieve suffering and improve quality of life, Canada needs a more standardized approach to hospice palliative care. With this kind of approach, individual caregivers and organizations will be more consistent and effective at identifying patient and family issues, the care required to manage each issue, and the resources and functions needed to develop and manage hospice palliative care organizations.[2]

A standardized approach to hospice palliative care will help to:

- ensure all caregivers and staff are knowledgeable and skilled, and have the support they need to fulfill their roles

- reveal any gaps in care and encourage organizations to expand their services or develop partnerships with other healthcare providers to fill these gaps

- ensure each healthcare organization manages its activities, resources and functions in a manner consistent with its approach to care delivery.

While standardization encourages consistency, it doesn't imply uniformity. Organizations will continue to differ in the ways they develop and function, and in the policies, procedures, and data collection/documentation strategies they develop to guide their provision of hospice palliative care.
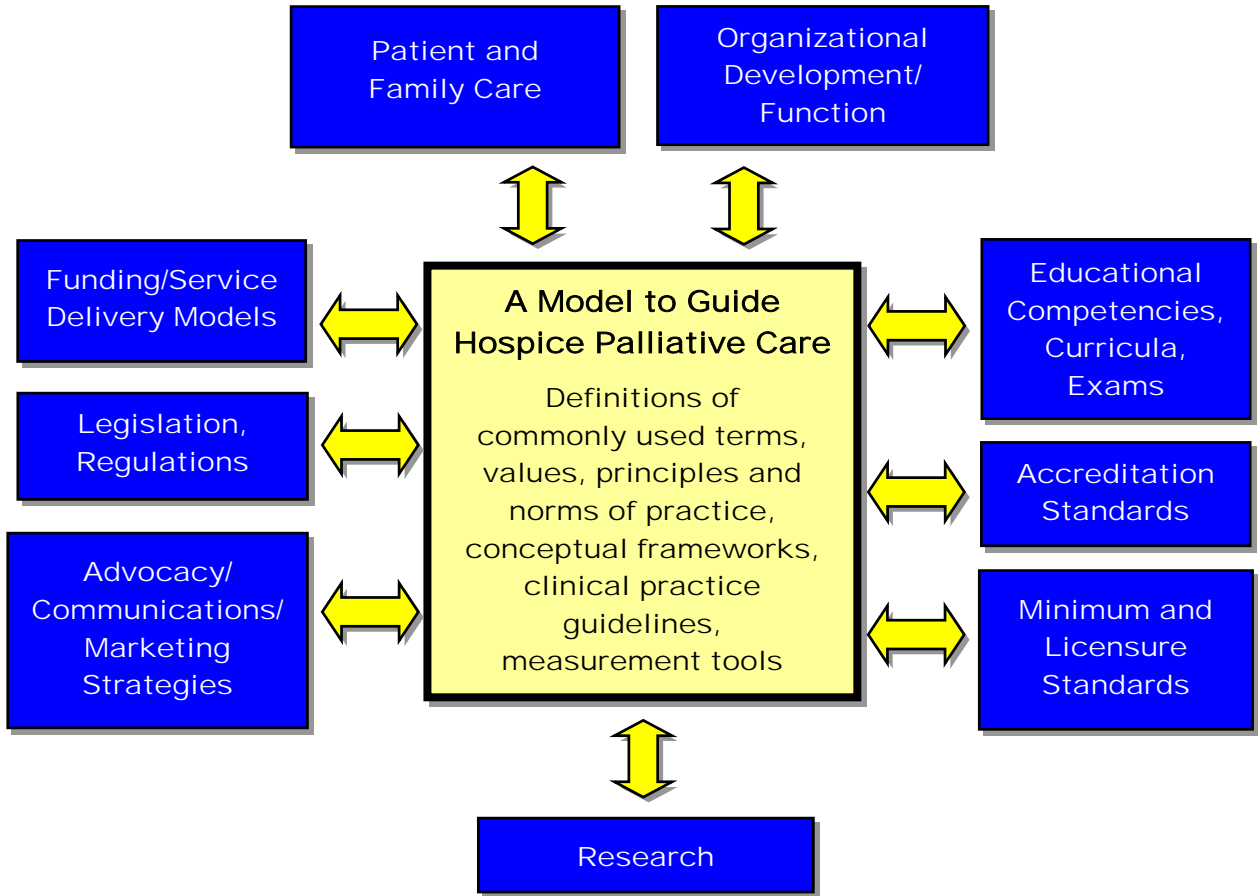
Why a National Model for Hospice Palliative Care?

A national model for hospice palliative care is a tool to guide all activities related to it. When developed in consultation with experts across the country, and based on patient and family issues/needs (as opposed to existing funding and service delivery models), it creates a shared vision and sets the stage for a consistent, standardized approach to patient and family care, organizational development, education and advocacy across the country.

The consensus-based model developed by the Canadian Hospice Palliative Care Association (CHPCA) presents a lexicon of commonly used terms, the values on which hospice palliative care is based, the principles and norms of practice, and the conceptual frameworks to guide each of the activities related to it. The model can be used to (see figure #1 on the next page):

- guide patient and family care provided by both primary and expert caregivers

- guide the development and function of hospice palliative care organizations

- develop core competencies, comprehensive curricula and examinations

- develop accreditation and minimum/licensure standards

- allow organizations to compare (benchmark) their practices to nationally accepted norms of practice, as well as against other hospice palliative care organizations

- guide research in hospice palliative care

- ensure consistency in advocacy, communication and marketing strategies.

- promote laws, regulations and policies that facilitate rather than obstruct the provision of hospice palliative care

- develop funding and service delivery strategies that will ensure access to hospice palliative care when needed.

Figure #1: Application of the Model to Guide Hospice Palliative Care

Within the broader health system, a national model for hospice palliative care will:

- increase the credibility and facilitate maturation of this relatively young specialty

- help integrate hospice palliative care into mainstream healthcare

- serve as a model for the development of similar strategies to change other aspects of mainstream healthcare.

The Process of Developing a National Consensus-based Model

Canada's hospice palliative care community has been working for a number of years to develop a more consistent approach to care. In 1981, Health and Welfare Canada published *Palliative Care Service Guidelines* (revised in 1989). In 1989, both the British Columbia Hospice/Palliative Care Association and the Metropolitan Toronto Palliative Care Council (MTPCC) started processes to develop more specific standards of practice. In 1991, the Ontario Palliative Care Association joined the MTPCC process. In 1993, the CHPCA consolidated all of these efforts into one national initiative to develop "norms of practice" that would:

- describe patient/family-centred hospice palliative care

- support the growth of current programs and guide developing programs

- provide a framework to evaluate the outcomes of hospice palliative care

- provide a foundation on which to build strategies to change national, provincial and regional healthcare policies, funding and service delivery systems.

In 1995, the CHPCA process received significant support from the Canadian Special Senate Committee on Euthanasia and Assisted Suicide report, *Of Life and Death*, which recommended that the development and implementation of national hospice palliative care guidelines continue.[3]

To develop accepted norms of practice that form the basis for a national model, the CHPCA Standards Committee led a nine-year consensus-building process that involved hundreds of participants. The three-phase process, which will be of interest to others trying to build a national consensus on principles and norms of practice, consisted of the following steps:

Phase 1 – Committee Consensus (1993-1995)

The CHPCA Standards Committee:

- reviewed and collated existing standards and available literature [4]

- worked towards, and achieved a committee consensus

- published Palliative Care: Towards a Consensus in Standardized Principles of Practice 1995.[5]

The consensus process was based on principles of group structure/ function: [1]

Forming: using provincial association representatives and champions to engage stakeholders to participate

Storming: acknowledging everyone will have different starting points and will need to express her/his opinion

Norming: providing structure and education to guide the process

Performing: using a sequential Delphi process [2] to reach consensus.

[1] *Tuckman B. Developmental Sequence in Small Groups. Psychological Bulletin, 1965; 63: 384-399.*

[2] *Delphi Technique. In: Nursing research. Polit DF, Hungler BP (eds). JB Lippincott, 1991, 356-7.*

Phase 2 – National Consensus (1995-2000)

The CHPCA Standards Committee:

- distributed more than 5,000 copies of *Palliative Care: Towards a Consensus in Standardized Principles of Practice* to hospice palliative care providers/organizations across Canada

- established a Revisions Workgroup to conduct a consultation/consensus-building process

- established criteria to define consensus (i.e., consensus was achieved when: 75% of the respondents agreed with the concept/wording of a given item; < 10% of the respondents had not responded to the given item; and there were not a lot of consistent comments to the contrary)

- asked each of the 11 provincial hospice palliative care associations to recruit participants and host one or more workshops (17 workshops were held between June 1997 and February 1998)

- analyzed the quantitative and qualitative data from the 706 participants

- determined that consensus had been reached on 70% of the items in the English version, but that the French version needed further review

- summarized the progress to date in *How Close are We to Consensus 1998* [6] (completing the Phase 2 consultation on the English version)

- asked l'Association Québécoise de Soins Palliatifs to facilitate further review of the French version

- received *Le Rapport Final* [7] from la comité des normes de pratique de l'Association Québécoise de Soins Palliatifs in 2000 (completing the consultation on the French version).

Phase 3 – National Consensus (2000-2001)

The CHPCA Standards Committee:

- integrated the outcomes from the English and French consultations, and created a single document based on both sets of norms of practice (the results of each consultation influenced the other)

- revised the 1995 principles document and published the *2001 Proposed Norms of Practice* [8]

- developed an online questionnaire and data collection tool which were posted on the CHPCA web site to gather feedback on the proposed norms of practice

- developed a team of champions to help disseminate the proposed norms, engage the hospice palliative care community in discussing them, and collect the feedback data

- analyzed the quantitative and qualitative data from 419 respondents

- determined that consensus had been reached on all of the items

- synthesized the experience and the feedback, and evolved the national model for hospice palliative care presented in this guide [9]

- had the model and this guide approved by the CHPCA Board of Directors (which includes the 11 provincial hospice palliative care associations in Canada).

Why Norms instead of Standards of Practice?

At the core of the model are "norms of practice." Norms are simple statements that present the "usual" or "average" practice for hospice palliative caregivers and organizations. Norms are less specific or rigid than standards (which are defined as measurable conditions or states used as a basis for assessing quality and quantity).

As the following diagram illustrates, norms of practice are different from minimum standards (which typically describe the "floor" or minimum level of care that is acceptable, e.g., the US Medicare Hospice Benefit Conditions of Participation[10]). Norms set a higher level to which organizations can and should aspire.

Figure #2: Normative vs. Minimum Standard of Practice
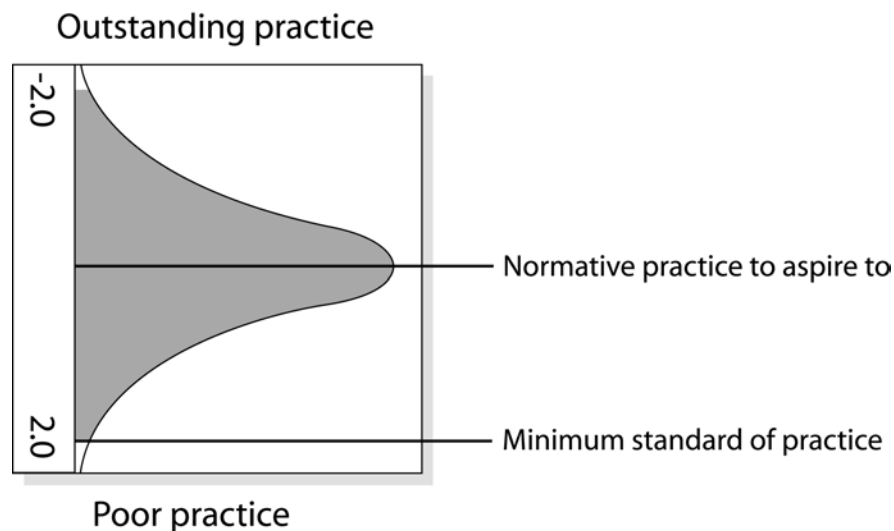
While norms are different from standards, organizations can use the norms to establish their own standards of practice, and to guide patient, family and public expectations. For example, the norm for response times is:

> "Requests for initial evaluation and ongoing follow-up are responded to within acceptable time frames."

Based on that norm, an organization will develop a more specific standard of practice that will establish the minimum requirements to be met at all times:

> "Requests for initial evaluation are responded to within 48 hours."

> "Requests for ongoing follow-up are responded to within 12 hours."

The model provides one or more norms of practice for each step in the process of providing care, and each aspect of an organization's function. The norms in this first iteration of the model are not as specific as some might expect. This is because, in the early stages of a consensus process, it is neither possible nor desirable to be specific. As organizations use the norms, they will test them and gather evidence that can be used to refine the norms to be more specific and reflect actual and desired levels of practice.

Projected Improvement in Practice

When organizations first start to use the model, there will most likely be considerable variability in current "normal" practice. With time it is anticipated that "normal" practice will improve and variability will diminish as organizations gain experience with the model. While most hospice palliative care organizations will aspire to the suggested norms of practice, there will always be organizations that vary from "normal" practice.

Figure #3: Projected Improvement in Practice
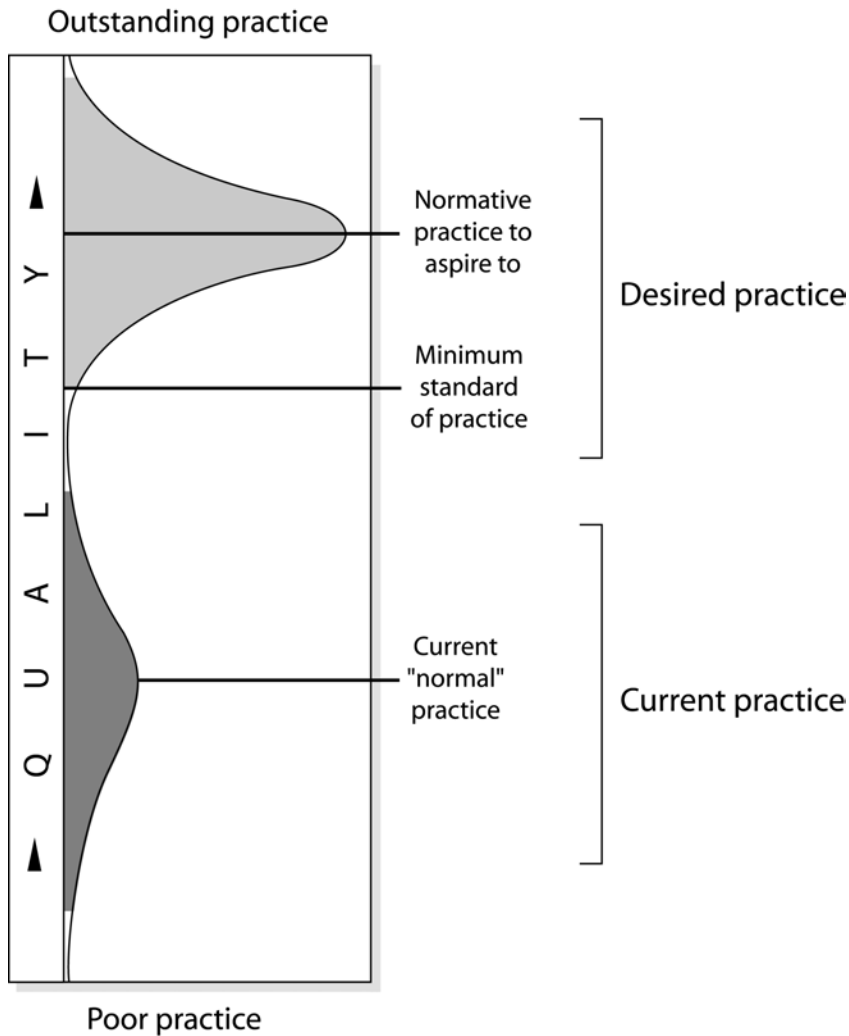
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