

V. Application of the Model

The consensus-based model presents the ideal of what hospice palliative care should be, independent of funding and service delivery models. It was developed to guide the delivery of patient and family care and the function of hospice palliative care organizations. The concepts can also be applied to all other aspects of hospice palliative care, including education, quality management research and advocacy. While the model was developed in Canada, with slight modification to local circumstances, it has broad international application.

This chapter describes briefly how the model can be applied:

- by both primary and expert clinicians to guide the process of providing hospice palliative care, the timing of referrals for consultation with hospice palliative care experts, and the development of standards of practice, policies and procedures, and standards for data collection/documentation
- by administrators to guide the process of developing an organization, standards of practice, policies and procedures and standards for data collection and documentation
- by careteam leaders to guide the process of developing individual patient/family careteams
- by quality managers to guide the development of a comprehensive quality management strategy
- by educators to guide the development of core competencies, curricula and examinations for primary and expert hospice palliative care providers
- by regulators, policy makers and funders to guide the review and development of laws, regulations, policies, funding, service delivery, and population data surveillance strategies
- by researchers to ensure that research focuses on the deficits in our knowledge and skills about hospice palliative care practice
- by consumer and provider advocates to guide the understanding of hospice palliative care services, the expectations of healthcare providers, and their advocacy efforts.

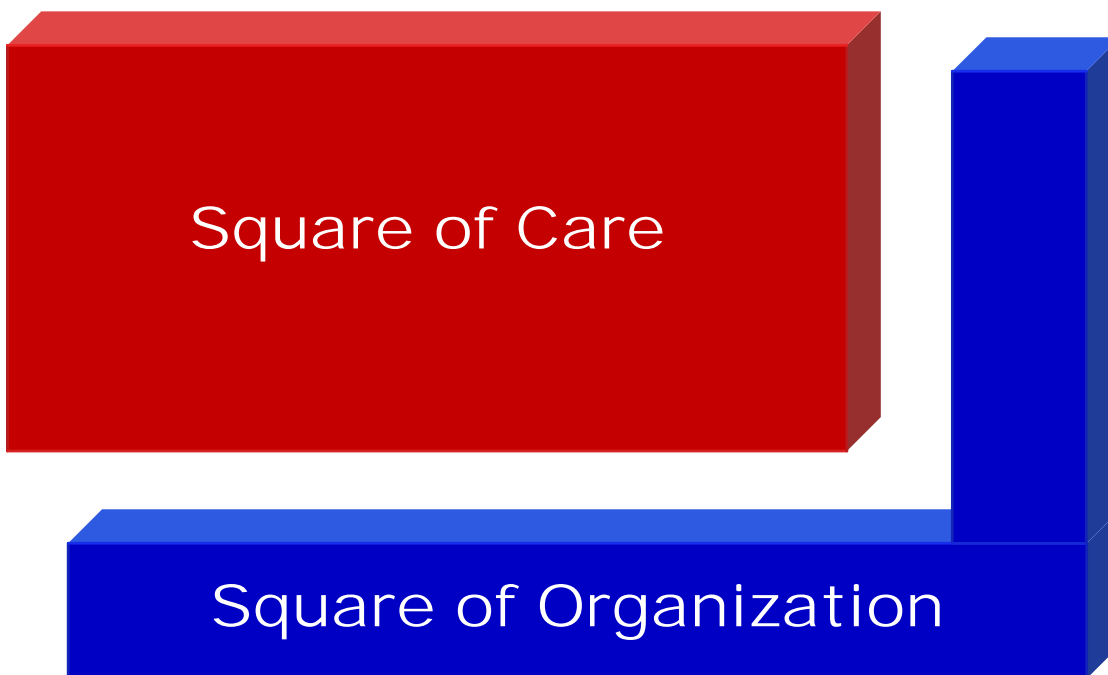
While hospice palliative care has grown out of “care for the dying”, the concepts can now be used to guide care at any point during an acute, chronic, or life-threatening illness, or bereavement.

Certain aspects of hospice palliative care – such as effective communication and decision-making, advance care planning, surrogate decision making, information about what to expect during an illness and what to expect from healthcare providers, and the management of symptoms, loss, grief and transitions – can also be used effectively with those who are at risk of developing an illness (e.g., people who are HIV-positive, those with genetics that put them at risk of developing a life-threatening illness, the elderly, and even people who are well but worried that they will develop an illness in the future).

The Integrated Square of Care and Organization

There are two main aspects of the CHPCA model to guide hospice palliative care: the delivery of patient and family care, and the development and function of an organization. Although for presentation purposes these have been separated in this monograph, the two are inextricably linked. They are guided by the same understanding of the illness and bereavement experiences, the same definitions, values, principles and foundational concepts. They are also interdependent. Clinicians cannot provide care without the resources and principal functions of an organization, and the organization cannot fulfill its mission or vision without a well-established process of providing care that addresses the issues commonly faced by patients and families. This interrelationship between patient and family care and hospice palliative care organizational function is illustrated by the integrated “Square of Care and Organization” in the figure below. In essence, the organizational resources and functions are present to “support” the clinical activities.

Figure #16: Interrelationship of the Square of Care and the Square of Organization



Adaptations of this tool can be used to guide all activities related to hospice palliative care. A simple version is shown in figure #17 on the next page.

Figure #17: The Square of Care and Organization

		Process of Providing Care							
		Assessment	Information Sharing	Decision-making	Care Planning	Care Delivery	Confirmation		
Common Issues	Disease Management							Patient and Family Care	Governance & Administration
	Physical								Planning
	Psychological								Operations
	Social								Quality Management
	Spiritual								Communications, Marketing
	Practical								
	End of life/ Death Management								
	Loss, Grief								
		Financial	Human	Informational	Physical	Community	Principal Functions		
Resources									

See figure #37 on page C2 at the center of this guide for the detailed “Square of Care and Organization.”

1. Applying the Model to Clinical Care

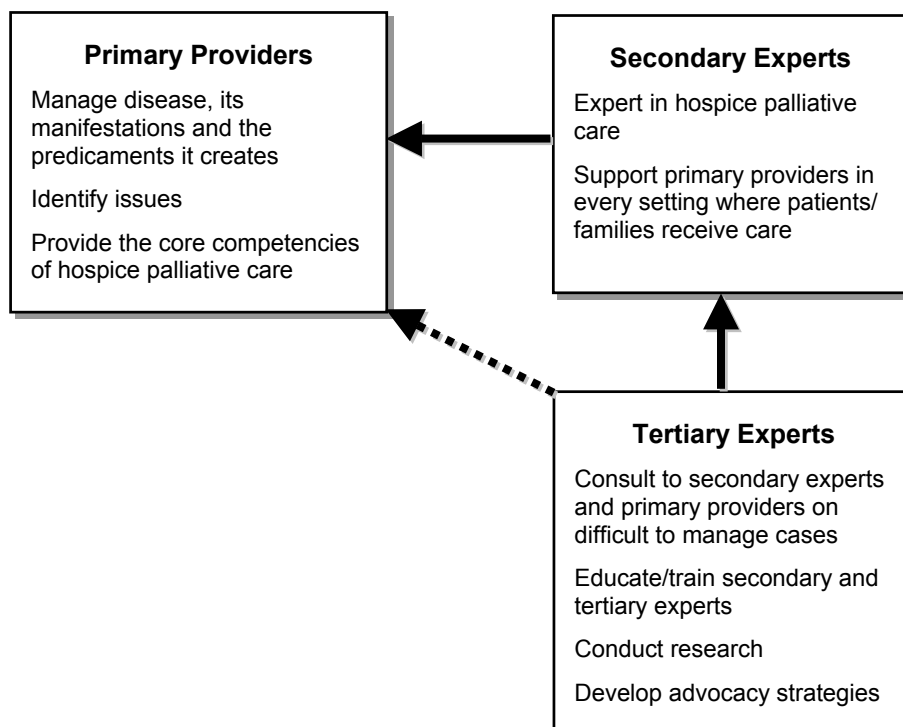
Providing Hospice Palliative Care

Because hospice palliative care issues occur throughout the illness and bereavement experiences, all clinicians (i.e., formal caregivers including volunteers) must be:

- competent at identifying the full range of issues that patients and families commonly face
- skilled at providing the core competencies of hospice palliative care using approaches that are based on widely-accepted preferred practice guidelines
- effective at assessing their outcomes
- appropriate with their documentation.

As in any other healthcare situation, when primary providers encounter care issues and situations beyond their level of confidence and expertise, or when their practice outcomes are not consistent with accepted norms of practice (i.e., those in this model), they must be able to seek help and support from hospice palliative care experts.³⁹ For this to be possible, interdisciplinary teams of secondary hospice palliative care experts must be readily accessible in every setting where patients and families receive care. In addition, these secondary hospice palliative care experts require access to tertiary experts in every major academic/population centre.

Figure #18: Provider Roles in Hospice Palliative Care



The Development of a Therapeutic Relationship

Hospice palliative care is based on the development of a therapeutic relationship between skilled caregivers and the patient/family. It is a creative process that aims to change the patient's and family's experience of illness and bereavement. It combines the art and science of the process of providing care with the knowledge and skills needed to deliver a wide range of therapeutic interventions.

Each relationship builds over a series of successive therapeutic encounters. Individual therapeutic encounters must occur with sufficient frequency to address the changes in the patient's/family's situation, and deliver the chosen therapies. For some patients, circumstances may require prolonged encounters or continuous care.

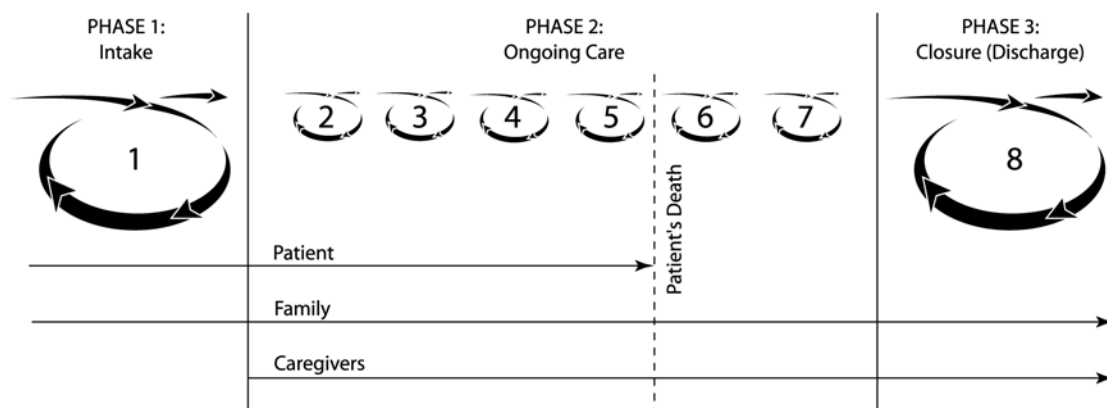
Development of an effective therapeutic relationship depends on formal caregivers being:

- skilled at effective communication (see page 21)
- skilled at facilitating careteam formation and function (see page 22)
- effective change agents (see page 23).

To develop a successful therapeutic relationship requires continuity of both the formal and informal caregivers throughout the process. Every time caregivers change, the process of developing a therapeutic relationship will start over and move through the stages of group development until the patient, family and caregivers are again performing effectively together.

Both primary and expert hospice palliative care providers will find the details of the six essential and several basic steps (see figure 10 on page 26) and the conceptual framework the "Square of Care" (see figure 11 on page 27), useful to guide any of their therapeutic encounters.

Figure #19: Successive Encounters During the Development of a Therapeutic Relationship



Note: the numbers in the figure only serve to highlight the sequence of encounters. Depending on the need for care, and the length of involvement, there may be more or fewer encounters over the duration of the therapeutic relationship.

Phases of a Therapeutic Relationship

The development of a therapeutic relationship can be thought of as having 3 phases: intake, ongoing care, and closure (discharge). Depending on the phase of the therapeutic relationship and who is present during a given therapeutic encounter, there will be variability in the specific content and approach to care for each essential step.

Assessment

During assessment, clinicians can use the list of domains and common issues to guide a functional inquiry and identify issues (see figure #7 on page 15). A validated screening tool, such as NEST,⁴⁰ can guide clinicians to domains in which there are active issues that require a more detailed history and examination. Clinicians must also look for issues that could become problems if they are not prevented, and opportunities for growth. If one or more issues are missed, they can compound and further complicate the patient/family situation. See figure #20 for variations in the approach to assessment during each phase of a therapeutic relationship.

Figure #20: Variation in Assessment by Phase of Relationship

Phase 1: Intake	Phase 2: Ongoing care	Phase 3: Closure (Discharge)
Collect patient/family characteristics/contact information Collect history of primary and secondary diseases, comorbidities and their treatments Establish prognosis Assess eligibility for admission (if there are entry criteria (e.g., Conditions of Participation, Medicare Hospice Benefit ⁴¹) Conduct a comprehensive functional inquiry to screen all domains for active and potential issues, and opportunities for growth Conduct a detailed history and examination of all identified issues Establish preferences patient/family have for the overall "process to provide care" Establish whether last will/named beneficiaries exist Establish preparedness to discuss end of life/ death Collect specific data, including: <ul style="list-style-type: none"> • cultural, personal, religious values, beliefs, practices • developmental state • disabilities • adverse events • allergies • adherence to past therapeutic interventions • dietary restrictions • personality 	Review patient/family characteristics Review the status of active issues, compare with previous status measures Screen for any new issues or opportunities for growth Conduct a detailed history and examination of all new issues Assess for adverse events, medication interactions Assess adherence to plan of care and therapeutic protocols	Review the status of active issues Specify closure/transfer data

Information-sharing

Communication is an essential part of the therapeutic relationship. It is always bidirectional. Figure #21 lists the different types of information shared during each phase of a therapeutic relationship.

Figure #21: Variation in Information Sharing by Phase of Relationship

Phase 1: Intake	Phase 2: Ongoing care	Phase 3: Closure (Discharge)
Establish patient/family's understanding of their illness/situation Establish limits of confidentiality Establish preferences patient has for "process to share information" Introduce the organization and the services it can offer Explain patient rights and responsibilities Share any pertinent information	Review understanding of illness/situation Review limits of confidentiality Review preferences for process to share information Share any pertinent information	Review understanding of illness/situation Share any pertinent information

When language is a barrier, formal caregivers have a responsibility to ensure the patient/family has access to effective translation to ensure clear communication and information sharing. Translation should be provided using people who understand both the concepts being conveyed, and the meaning of the words in both languages and cultures. If at all possible, clinicians should avoid using family members to translate, as they are often unskilled with medical terminology/concepts. In addition, asking a family member to translate may confuse her/his role as a family member with that of a healthcare provider.

Decision-making

Figure #22 lists the different types of decision-making during each phase of a therapeutic relationship.

Figure #22: Variation in Decision Making by Phase of Relationship

Phase 1: Intake	Phase 2: Ongoing care	Phase 3: Closure (Discharge)
Assess capacity to make decisions Establish goals for care Prioritize issues Offer therapeutic options Facilitate choosing treatments Obtain consent Establish who surrogate decision-maker will be Establish advance directives Explain approach to conflict resolution Strive to resolve any conflicts	Assess capacity to make decisions Review goals of care Review issue prioritization Review treatment choices Offer any new therapeutic options Facilitate choosing treatments Obtain consent Strive to resolve any conflicts	Assess capacity to make decisions Review acceptability of closure/discharge

Care Planning

Figure #23 lists the different types of care planning during each phase of a therapeutic relationship.

Figure #23: Variation in Care Planning by Phase of Relationship

Phase 1: Intake	Phase 2: Ongoing care	Phase 3: Closure (Discharge)
Choose setting of care Establish process to negotiate and develop plan of care Negotiate and develop the initial plan of care (IPOC)	Review appropriateness of setting of care Negotiate and develop, or review and update the continuous plan of care (CPOC)	Plan for transition Transfer plan of care to any ongoing healthcare providers (to ensure continuity)

Care Delivery

Figure #24 lists the different approaches to care delivery during each phase of a therapeutic relationship.

Figure #24: Variation in Care Delivery by Phase of Relationship

Phase 1: Intake	Phase 2: Ongoing care	Phase 3: Closure (Discharge)
Establish initial careteam: <ul style="list-style-type: none"> engage formal and informal caregivers establish who will lead, coordinate provide initial education, support initiate careteam communication tool Request initial consultations Establish setting of care Establish which services will be essential Provide initial patient/family/extended network education/support Deliver initial therapies Establish safety, storage, handling, disposal strategies Establish infection control procedures Dispose of any medications, wastes Report any errors	Continue careteam development, education and support Followup on any previous consultations Request new consultations Review setting of care Review essential services Provide ongoing patient/family/extended network education/support Deliver ongoing or new therapies Review safety, storage, handling, disposal strategies Review infection control procedures Dispose of any medications, wastes Review, report any errors	Adjourn and debrief careteam Close careteam communication tool Complete any consultations Provide final patient/family/extended network education/support Deliver final therapies Dispose of any medications, wastes Close safety, storage, handling, disposal strategies Report any errors

Confirmation

Figure #25 lists the different approaches to confirmation during each phase of a therapeutic relationship.

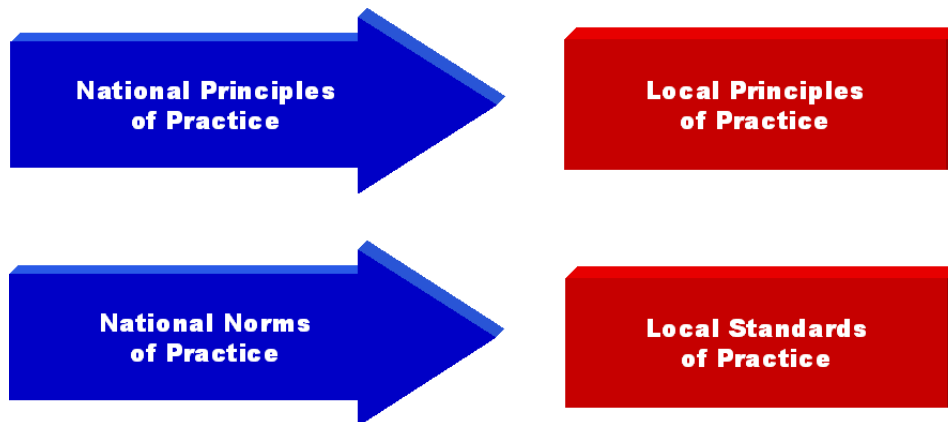
Figure #25: Variation in Confirmation by Phase of Relationship

Phase 1: Intake	Phase 2: Ongoing care	Phase 3: Closure (Discharge)
Establish understanding Assess patient/family/caregiver satisfaction Assess patient/family/caregiver perception of complexity, stress Query for any concerns, other issues, questions	Verify understanding Assess patient/family/caregiver satisfaction Assess patient/family/caregiver perception of complexity, stress Query for any concerns, other issues, questions	Verify understanding Assess patient/family/caregiver satisfaction Assess patient/family/caregiver perception of complexity, stress Query for any concerns, other issues, questions

Development of Principles and Standards of Practice

Clinicians and organizations can use the principles and norms of practice within the model to guide the development of local principles and standards of practice (see section III on page 25 and section IV on page 41). The process of reviewing, modifying and accepting these concepts will be as important as the approach to care they adopt.

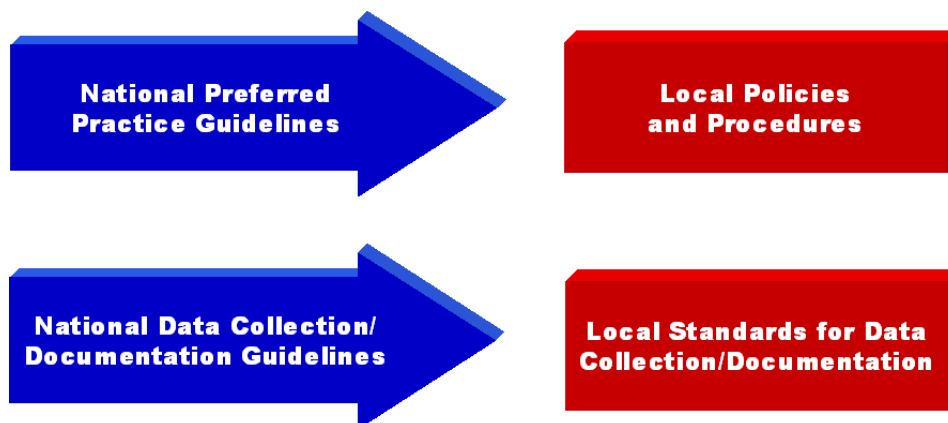
Figure #26: Development of Principles and Standards of Practice



Development of Policies and Procedures, Standards for Data Collection/Documentation

Combined with preferred practice and data collection/ documentation guidelines, clinicians can also use the model to guide the development of local policies and procedures, and standards for data collection/ documentation for each issue commonly faced by patients and families (for an example, see figure #29 on page 71).

Figure #27: Development of Policies and Procedures, Standards for Data Collection/Documentation



Other Clinical Applications

To be effective, clinicians must be appropriately educated and evaluated on an ongoing basis, and receive the support they need from colleagues and their organization. Through continuous application of the model, clinicians will develop a consistent approach to the process of providing care that:

- helps them develop reasonable expectations for prognosis and outcomes for each individual patient/family unit ^{42,43}
- minimizes the risk of errors ⁴⁴
- minimizes their occupational risk, overall sense of stress and the manifestations that come with it ⁴⁵
- reduces their risk of burnout/job turnover.

By combining the model for hospice palliative care with the funding and service delivery models in use in their jurisdiction, clinicians will be able to develop personal strategies for conducting therapeutic encounters, collecting clinically useful data, and documenting the patient/family issues and their therapeutic interventions in a manner that is consistent with widely-accepted practices, and minimizes the risk of reimbursement denials.

2. Applying the Model to Organizational Development and Function

Hospice palliative care organizations develop in one of two ways: as independent entities or as part of a larger host organization. They are always subject to existing funding and service delivery models. Their success is dependent on all participants being:

- skilled at effective communication (see page 21)
- skilled at group facilitation and dynamics (see page 22)
- effective change agents (see page 23).

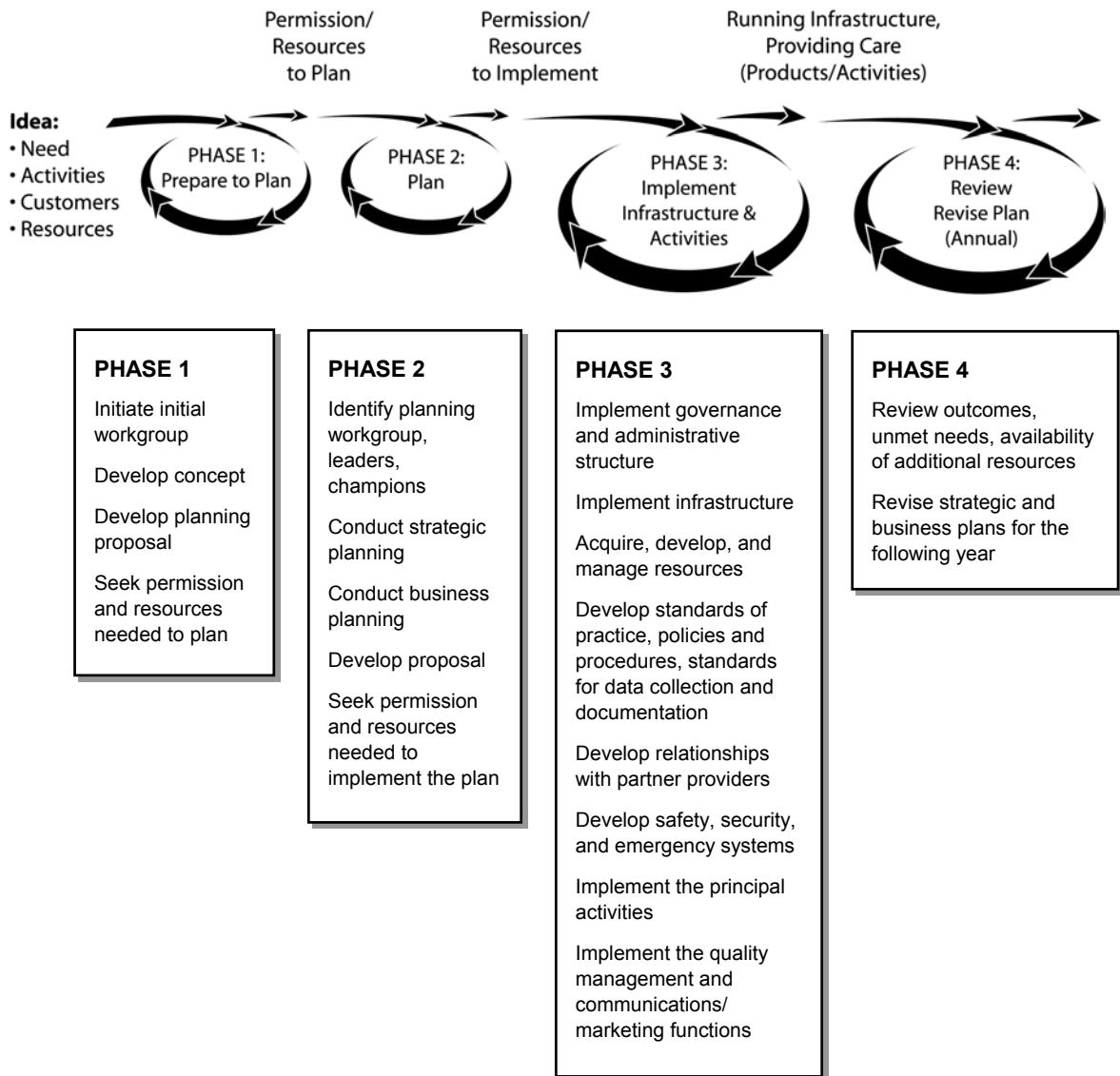
Initial Idea

Administrators and clinicians who want to develop a hospice palliative care organization will start with an idea of:

- the need within their community
- their principal activities or product lines (e.g., clinical services, education of primary providers and/or hospice palliative care experts, research and/or advocacy)
- their customers (e.g., the referring primary healthcare providers, host organization, patients and families)
- the resources required to operate their principal activities and maintain their organizational infrastructure (e.g., financial, human, informational, physical and community resources, see figure 13 on page 43).

Once the organizers have their initial idea, they can embark on the 4 phase planning process shown in figure #28 on the next page. The model outlined in this guide and the *CAPC Manual: Everything You Wanted To Know About Establishing a Palliative Care Program But Were Afraid to Ask*, will both be useful resources to guide this developmental process, see <http://www.capcmanual.info>.

Figure #28: Planning Process for a Hospice Palliative Care Organization



Phase 1: Prepare to Plan

During Phase 1, an organizing workgroup will develop their initial ideas into a planning proposal. This proposal will outline: the need, the concept for each of their principal activities, their customers and stakeholders, their planning process, and the resources required to complete the planning. The model to guide patient and family care (see section III on page 25) and organizational development and function (see section IV on page 41) can be used extensively to guide the development of these initial concepts.

Once the planning proposal is complete, the workgroup leaders and other champions will present the proposal to those who will provide resources and give permission for the full planning process (i.e., the administrators of the organization that will host the hospice palliative care organization, or the principal funders).

Phase 2: Plan the Organization

Once the organizers have the permission and resources needed to proceed with planning, they can embark on a full strategic and business planning process to define the new organization. To start the process, they will form a planning workgroup and identify leaders and key individuals who will contribute to the planning process and/or champion the plan once it is complete.

Strategic Planning

Strategic planning aims to define the organization, its product lines, and how it will be developed. Based on the concept developed in phase 1, the first steps in strategic planning will be to:

- identify key customers and stakeholders ⁴⁶
- conduct a needs assessment of the organization(s) who will host the new hospice palliative care organization and the community it will serve. ⁴⁷

This analysis will be used to justify the development of the new organization, guide its design, and identify other healthcare organizations that may become partners or competitors.

Define The Organization

Once the needs assessment is complete, the workgroup can start to define the organization, its principal activities, clinical services, and developmental strategy. A number of concepts within the model can be used to guide the definition of the organization:

- The values and principles on which hospice palliative care is based can be used to develop the organization's values and principles (see page 19)
- The model mission and vision statements can be used to guide the development of the organization's mission and vision statements (see page 42).

Define Its Principal Activities

Most new organizations will start by implementing a limited number of principal activities (e.g., a single clinical service that provides care in one setting, and education for a limited number of primary healthcare providers, see page 41). Once these have been implemented successfully, the range of activities can be expanded in subsequent years to meet the demonstrated need within the community.

Define Its Clinical Services

Organizers can use the detailed list of domains and issues associated with illness and bereavement (see figure #7 on page 15) and the “Square of Care” (see figure #11 on page 27) to decide the issues to be addressed and the therapies to be provided by the organization’s clinical services, and those to be provided by partner organizations (i.e., to avoid any gaps in the care available to patients and families).

Organizers will also need to decide what types of care they will provide, in what settings, using which service delivery models.

Potential Types of Care

Since the number of issues, their acuity, the duration of need, and the rapidity of the response required can vary considerably over the course of an illness and bereavement, planners must decide what types of care they will provide.

Acute care. At any time during the illness, from the outset to discharge, patients and families often experience a number of acute issues that require time-limited attention.

Chronic care. As the disease progresses, and the illness becomes life threatening, patients and families may experience an increasing number of chronic issues that require continuous custodial or skilled nursing care.

Respite care. At times, family caregivers may become fatigued and require respite relief to give them a break or vacation.

End-of-life care. As the patient approaches the end-of-life, the acuity of issues and the need for care can rise considerably, particularly in the last hours of life when everything can change over a few hours to days.

Bereavement care. For those who survive the patient’s death, the intensity of need during bereavement typically waxes and wanes as the individuals realize what has happened, and recognize the significance of the loss to their lives. With time it slowly diminishes as they rebuild their lives and establish the new family group.⁴⁸

Response times. Both standard and emergency response strategies will be needed for each of these types of care.

Potential Service Delivery Models

To complete the definition of their clinical activities, organizers will need to choose service delivery models and the settings where they will provide care.

Consultation/Primary Care Services: Hospice palliative care organizations frequently develop an interdisciplinary team of experts that provides a mix of consultative and primary care services in one or more settings where patients and families receive care (see the side box on this page). Primary healthcare providers can then access the team for:

1. a one time consultation with no ongoing followup
2. consultation with followup where the primary healthcare providers maintain overall responsibility for the patient's/family's care and the experts maintain a supporting role
3. consultation with followup where the experts assume overall responsibility and the original primary healthcare providers maintain a supporting role
4. consultation followed by assumption of the primary responsibility for the patient's/family's care (as the original primary providers stop being involved).

Setting of Care

Patient/family care can be provided in a variety of settings, including:

- acute care facilities (e.g., general beds, intensive care units, emergency rooms in hospitals)
- long-term care facilities
- the patient's home (e.g., own home, boarding house, correctional facilities, on the street)
- office or clinic
- daycare centre
- free-standing hospice palliative care facility.

Specialized Environments: To facilitate access to more intensive hospice palliative care around the clock, many organizations develop specialized environments that provide expertise and skilled care 24 hours a day, seven days a week, 365 days a year (24/7/365), and enhance the opportunity for family privacy and intimacy. While a specialized environment can be created "as needed" in the patient's environment, it is frequently more efficient for a hospice palliative care organization to have a number of beds it controls in one location, either within its own free-standing facility, or in a unit within an acute or long-term care facility.⁴⁹

Developmental Strategy

Finally, to complete strategic planning, the workgroup will need to establish goals and objectives, strategies and tactics, and the timelines and strategic decision points to develop the organization's infrastructure, and each of its principal activities.⁵⁰

Business Planning

Business planning describes the functions and resources required to deliver the organization's principal activities, and run its infrastructure. Once the strategic planning is well underway, the planning workgroup can use the "Square of Organization" and the associated principles and norms of practice to develop the organization's business plan ⁵¹ (see figure #14 on page 45 and pages 46-52).

Through business planning, the workgroup defines:

- the organization's governance and administrative structure, including leadership and accountability
- the plan to acquire and manage the needed financial, human, informational, physical and community resources (see figure #13 on page 43)
- the plan to implement and operate each of the principal activities, and the organization's infrastructure, including plans for the development of standards of practice, policies and procedures, and standards for data collection/ documentation (see pages 38 and 62)
- a quality management plan (see page 77)
- a communications/marketing plan (see page 86).

Sell the Proposal

Once the strategic and business plans are complete, they are combined into a proposal and presented to those who will provide resources and give permission to build the new organization (i.e., the administrators of the organization that will host the hospice palliative care organization, or the principal funders). It requires careful planning to orchestrate the presentation and approval process to achieve a successful outcome.

Phase 3: Implement and Run the Organization

Once the workgroup has the permission and resources needed to develop the organization, they can begin the process of implementing and running the new organization. They will need to:

- implement the governance and administrative structure, and select the leaders
- acquire, develop and manage all of the needed resources
- develop their standards of practice, policies and procedures, and standards for data collection and documentation
- develop their relationships with other partner providers to ensure that there is continuity of the plan of care, information and caregivers
- develop their safety, security and emergency systems
- implement each of the principal activities, and the quality management and communications/marketing functions
- ensure that all activities meet regulatory requirements for licensure/function.

A number of concepts within the model can be used to guide the operations of the organization. The process of reviewing, modifying and accepting these concepts will be as important as the approach to care adopted by the organization.

- The lexicon of commonly used terms can be used to develop definitions for the terms that will be used regularly within the organization (see appendices on page 91)
- The principles and norms of practice for patient and family care (see pages 28-37) can be used to guide the development of general and issue-specific standards of practice for each of the issues that will be addressed by the clinical services (see figure 26 on the next page)
- The principles and norms of practice for organizational function (see pages 46-52) can be used to guide the development of the general and resource-specific functions of the organization
- Preferred practice guidelines (see page 38) can be used to guide the development of issue-specific policies and procedures
- Data collection/documentation guidelines can be used to guide the development of issue-specific standards for data collection and documentation (see page 38 and 62).

Ultimately, organizers will need to develop tables that extend the “Square of Care” and detail the process of providing care for each issue commonly faced by patients and families. These tables will be similar to the tables in the 1995 Model ⁵² (for an example see figure #29 on the next page). Similar tables will be developed to extend the “Square of Organization” and detail the principal functions to acquire and manage the resources required to maintain the organization’s infrastructure and run its activities.

Figure #29: Sample Table of Standards of Practice, Policies and Procedures, Standards for Data Collection and Documentation for a Specific Issue

	Standards of Practice	Policies and Procedures	Standards for Data Collection and Documentation
Assessment	Standards of practice for assessment related to the issue	Policies and procedures to guide assessment of the issue	Status and context of the patient and family related to the issue Related expectations, needs, hopes, fears Etiologies Perceived benefits, burdens from previous therapies Adverse events
Information sharing	Standards of practice for information sharing related to the issue	Policies and procedures to guide information sharing related to the issue	Information discussed related to the issue Emotional reactions Understanding of the information shared related to the issue
Decision-making	Standards of practice for decision-making related to the issue	Policies and procedures to guide decision-making related to the issue	Goals of care related to the issue Priority of this issue Therapeutic options offered with their potential for benefit, risk, burden Treatment(s) chosen Advance directives related to the issue
Care Planning	Standards of practice for care planning related to the issue	Policies and procedures to guide care planning related to the issue	Setting of care Plan to deliver care related to the issue
Care Delivery	Standards of practice for care delivery related to the issue	Policies and procedures to guide care delivery related to the issue	Careteam activities, training and support related to the issue Consultation related to the issue Patient/family/extended network education and support related to the issue Therapies given with any effects experienced (benefits, adverse events) Errors related to the issue
Confirmation	Standards of practice for confirmation related to the issue	Policies and procedures to guide confirmation related to the issue	Understanding related to the issue Satisfaction related to the issue Perception of complexity and stress related to the issue Ability to provide and participate in the plan of care

Note: Examples of the standards for data collection and documentation have been included to illustrate the potential breadth of the data that might be collected for each issue. Specific guidelines will be needed for each issue to ensure usefulness and practicality.

Phase 4: Review the Organization Annually and Revise the Plan

At the end of each year, as part of its quality management activities, each organization will review:

- the outcomes of its principal activities and infrastructure
- the unmet needs within its host organization(s) and the community it serves
- the availability of additional resources.

Based on this analysis, each organization will repeat a variation of planning phases two to four and revise its strategic and business plans, standards of practice, policies and procedures, and standards for data collection/documentation for the coming year.

Organizational Labeling

Depending on their size and relationships, hospice palliative care organizations choose a variety of different labels or names for themselves. Some will call themselves 'services;' others will call themselves 'programs.'

Services tend to be part of a larger organization (e.g., a host organization or a program). They have one or more component activities. Most will not have their own governance structure.

Programs may be part of a larger host organization, or independent. They are usually involved in more than one component activity or service, and may or may not have their own governance structure.

In some jurisdictions, the label that an organization uses will be based on minimum or licensure standards. Depending on whether these standards were developed by an association or a regulatory body, compliance and the use of a given label may be voluntary or mandatory.

In its 1989 Palliative Care Services Guidelines, Health and Welfare Canada suggested a functional classification for palliative care programs.⁵³ From the outset, it was clear that one or two well-intended caregivers who provide a few aspects of hospice palliative care can only be considered to be a preliminary service. Today, a variation of this classification might still apply:

Level 0 - Preliminary Service: a service that provides only a few hospice palliative care services. Typically there are one or two experts, but not a full interdisciplinary team.

Level I - Core Clinical Program: a service or program that provides the full range of clinical services needed to address the issues commonly faced by patients and families throughout the illness and bereavement experiences. Care is provided by an interdisciplinary team that includes one or more clinically active, expert physicians, nurses, social workers/psychologists, chaplains, pharmacists and volunteers. Program functions include quality management and communications/marketing.

Level II - Complete Program: a service or program that integrates a full range of clinical services to provide care throughout the illness and bereavement experiences, education for primary healthcare providers, research and advocacy. Each of these activities are provided by an interdisciplinary team that includes one or more expert physicians, nurses, social workers/psychologists, chaplains, pharmacists and volunteers. Program functions include quality management and communications/marketing.

3. Applying the Model to Careteam and Regional Team Development and Function

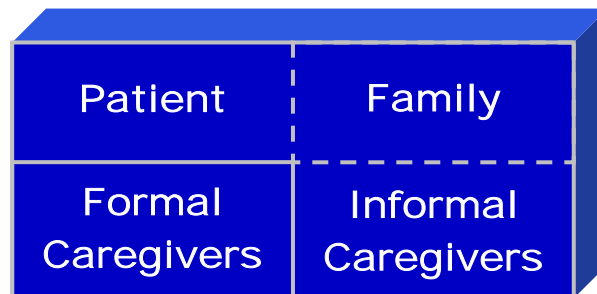
Careteams and regional teams are in essence “mini” organizations. Careteams take on the task of caring for an individual patient and family unit, in order to change their experience of illness and bereavement. Regional teams are functional units within hospice palliative care organizations designed to provide formal caregivers and oversight to multiple patient/family careteams within a given population/region/setting of care. To operate effectively, each team needs all of the same types of resources, functions and infrastructure as any larger organization.

As the following careteam example illustrates, all aspects of the model to guide organizational development and function can be applied to both careteam and regional team formation and function (see section IV on page 41).

Careteam Development and Function

As noted in section II of this guide, hospice palliative care is most effectively provided by interdisciplinary careteams, which form around individual patient/family units to provide care.

Figure #30: Patient/Family Careteam



Development of an effective careteam is dependent on the formal caregivers being:

- skilled at effective communication (see page 21)
- skilled at leading and facilitating careteam formation and function (see page 22)
- effective change agents (see page 23).

As with any other organization, a careteam develops through four phases (see figure #31 on page 76). However, because a careteam is a time-limited organization developed to meet the needs of a patient/family, it goes through one additional phase in its life cycle when its services are no longer required: adjournment.

Phase 1: Prepare to Plan

From the outset, an individual patient and family may need care for any number of issues (see figure #7 on page 15). The formal caregiver who assesses their needs on intake, discusses the potential for an interdisciplinary careteam with them as part of care planning, and seeks their permission to proceed.

Phase 2: Plan

Once permission is received, the formal caregiver will develop the plan for the careteam and its activities.

Strategic planning for any careteam is relatively straightforward. The customers are the patient and family. The stakeholders are the formal and informal caregivers, the patient's and family's extended network, the hospice palliative care organization, and any other healthcare or community organizations involved in their care. The needs assessment is conducted as part of the intake assessment and the ongoing process of providing care. The careteam's values and principles are based on those for hospice palliative care (see page 19). Its mission is to care for the patient and family, and its vision is developed from the patient's and family's goals for care. Its principal activity is to provide the type of care required in the care setting chosen during care planning.

Business planning is much more specific to individual patient and family situations, and can be guided by the "Square of Organization" (see page 45). Each careteam will be led by a designated formal caregiver who is skilled at careteam formation, understands how to manage careteam dynamics, and knows how to coordinate the process of providing care. An informal caregiver and/or the patient may assist with leadership.

Each careteam leader will plan for:

- the financial, human, informational, physical and community resources to support the careteams activities
- the formation, education, implementation, management and support of the careteam and its activities
- routine review of the careteam activities
- a communications strategy among careteam members.

Phase 3: Implement the Plan

When the plan of care is in place and the resources are available, the careteam leader(s) will implement the plan of care. Infrastructure and administrative support typically come from the hospice palliative care organization.

Resource acquisition and management: Most careteams use a mix of resources that come from the patient and family, the hospice palliative care organization, other parts of the healthcare system, and the community. Acquisition, development and management of each of these resources will take a considerable amount of the leaders' time. There will need to be:

- **Financial resources:** Sufficient financial resources to support the careteam's activities and the delivery of care
- **Human resources:** Enough caregivers who are competent and confident to deliver the needed care

Careteam formation: Wherever possible, careteams include a mix of formal and informal caregivers. Formal caregivers are chosen from the hospice palliative care organization's regional team for their skills required to deliver the plan of care. Most careteams will include one or more primary and/or expert physicians, nurses, social workers, chaplains, pharmacists and caregiving volunteers. Informal caregivers are typically family members and friends who wish to be involved. Other disciplines and consultants will join the team as needed. Careteam leaders must be careful to give everyone a role, but be selective in ensuring that those who provide direct patient care are both capable and properly motivated. It is also important to ensure family members are not distressed by their caregiving roles and have time to maintain their "family" roles.

Careteam education: Formal caregivers receive ongoing education and evaluation through the hospice palliative care organization. Informal caregivers must be taught the specific skills they need to do the tasks assigned to them.

Careteam support: Caregivers require ongoing self-care. Leaders must ensure team members have resources and opportunities to share their experiences/feelings.

- **Informational resources:** A data collection/documentation tool that provides a health record for the patient and a communication tool for the careteam; a schedule to manage the caregivers' hours and activities; and resource materials to supplement caregiver education and training
- **Physical resources:** Medical equipment, medications and supplies to provide care
- **Community resources:** Community resources to supplement the careteam's resources and activities.

Operations: When the caregivers and the resources are in place, the careteam will begin to provide care to the patient and family. All careteam activities will be guided by the hospice palliative care organization's standards of practice, policies and procedures, and standards for data collection and documentation.

Communications: To support the careteam's activities, an effective communication strategy will need to be developed and maintained by the leaders and the hospice palliative care organization.

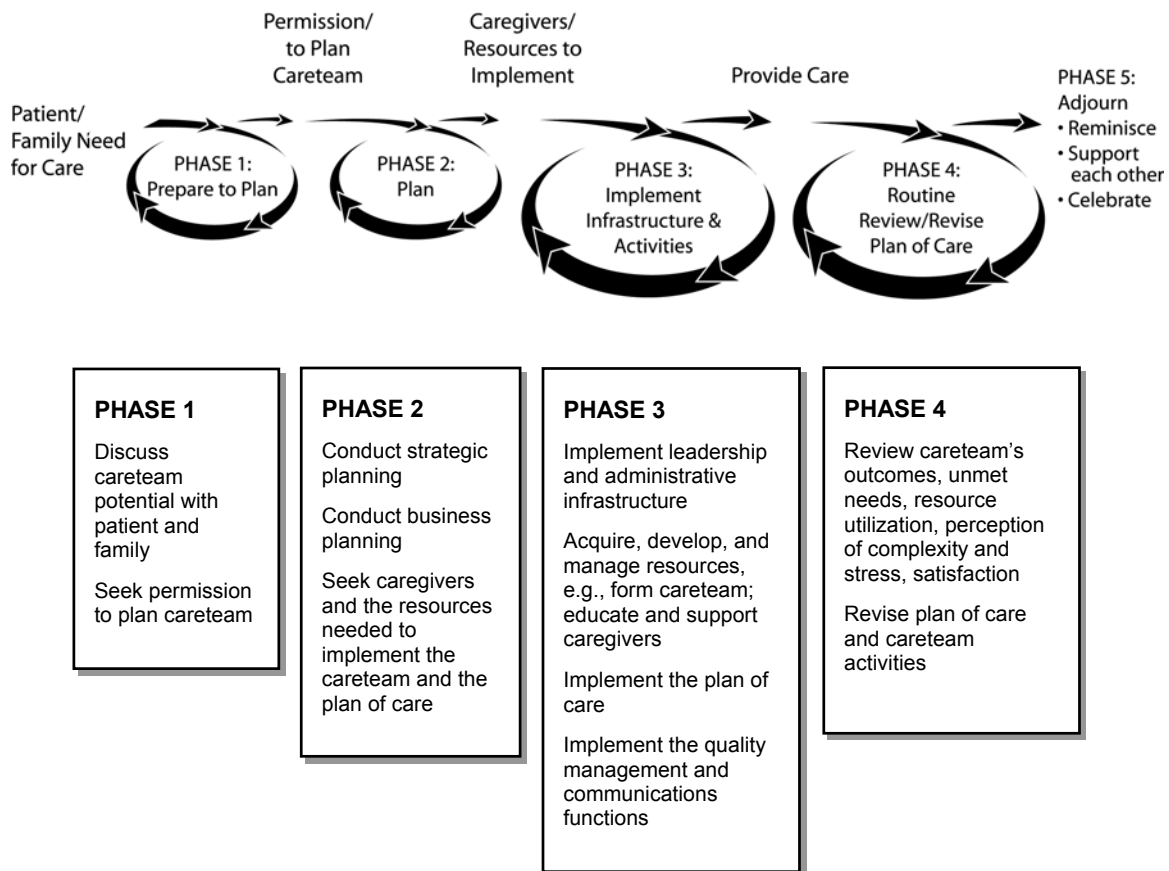
Phase 4: Review and Revise the Plan (Quality Management)

At regular intervals -- usually once a week -- formal caregivers and other key members of the hospice palliative care organization will review each careteam's activities to assess their for overall outcomes, unmet needs, resource utilization, perception of complexity and stress, and caregiver satisfaction. Changes are made to the plan of care and the careteam's activities as required.

Phase 5: Adjourn

When the patient and family no longer need the careteam, it must adjourn. To bring closure to the therapeutic relationship and the group's activities, it is important that the careteam meet as a whole one last time to reminisce, support each other, and celebrate their accomplishments. If the patient has died in the process, careteams will often integrate a memorial service to commemorate the person they have cared for.

Figure #31: The Life Cycle of a Careteam



4. Applying the Model to Quality Management

One of the goals of a national model is to provide an effective means to compare activities both within and between organizations. As all hospice palliative care activities aim to change the experience of illness and bereavement, assessing their effectiveness at meeting this goal must be an integral part of each organization's principal functions.

Quality managers can use this model to guide the development of a comprehensive quality management strategy to review both patient and family care, and organizational development and function.

Standards of Practice, Policies and Procedures, Standards for Data Collection/Documentation

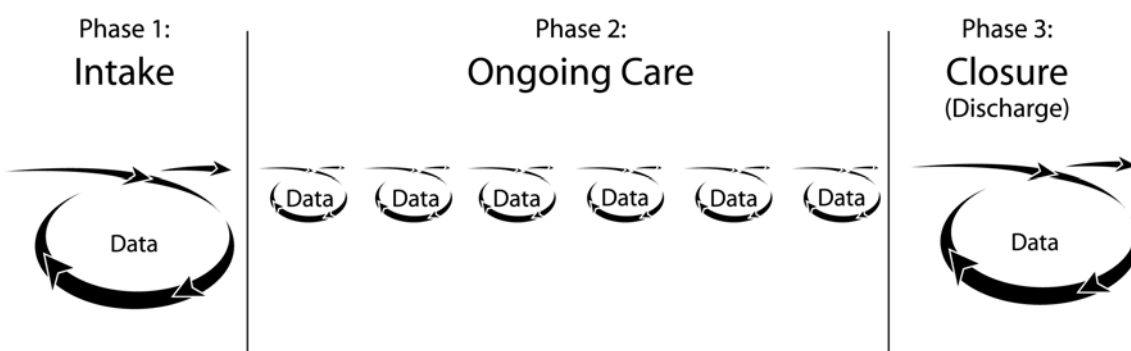
The model to guide hospice palliative care presents a conceptual framework, the "Square of Care," and principles and norms of practice for all aspects of patient and family care, and a conceptual framework, the "Square of Organization," and principles and norms of practice for all aspects of organizational development and function. When combined with preferred practice guidelines and data/documentation guidelines, the model can be used to guide the development of general and issue-specific standards of practice, policies and procedures, and standards for data collection and documentation in each hospice palliative care organization (see pages 38 and 62).

Outcome Assessment

During each therapeutic encounter, clinicians will collect the data required to document the status of each issue the patient and family face, and any action taken during the encounter. By comparing the status, perceived complexity and stress, and satisfaction data from successive therapeutic encounters, quality managers will be able to assess a variety of different outcomes and trends related to the organization's clinical activities (see figure #32 on the next page).

By collecting resource utilization and adverse events data, quality managers will be able to assess a variety of different outcomes and trends related to the organization's function.

Figure #32: Comparison of Data from Successive Therapeutic Encounters



Simple outcome comparisons can be made by comparing single data fields from successive encounters (e.g., the change in severity of the patient’s pain from one encounter to the next; or the caseload of the organization on a given day).

Complex outcome measures (or indicators) can be calculated from multiple data fields collected over several therapeutic encounters (e.g., the percent of patients whose pain was <5/10 on a visual analogue scale 48 hours after admission; or the average length of stay of patients with a cancer diagnosis who died while in the program).⁵⁴

Using the data and simple analytic techniques, quality managers will be able to assess the outcomes of care and program function from many different perspectives:

- each patient and family unit
- each careteam
- each regional team in the organization
- the organization
- the population served by the organization
- the population within a given region (i.e., population data surveillance)
- special interest groups.

Performance Improvement

Once an organization is fully functional, the quality review cycles will vary depending on the perspective and the issue under consideration (see figure #33 on the next page). For example:

Short cycle performance improvement strategies will review data on a daily, weekly or monthly basis with a view to making rapid improvements (e.g., Institute for Healthcare Improvement’s Plan-Do-Study-Act strategy for accelerating improvement⁵⁵)

Long cycle performance improvement strategies will review data on a quarterly, semi-annual, or annual basis (or longer) with a view to making long-term improvements (e.g., the phase 4 review of an organization discussed earlier in this section).

Figure #33: Quality Review Cycles

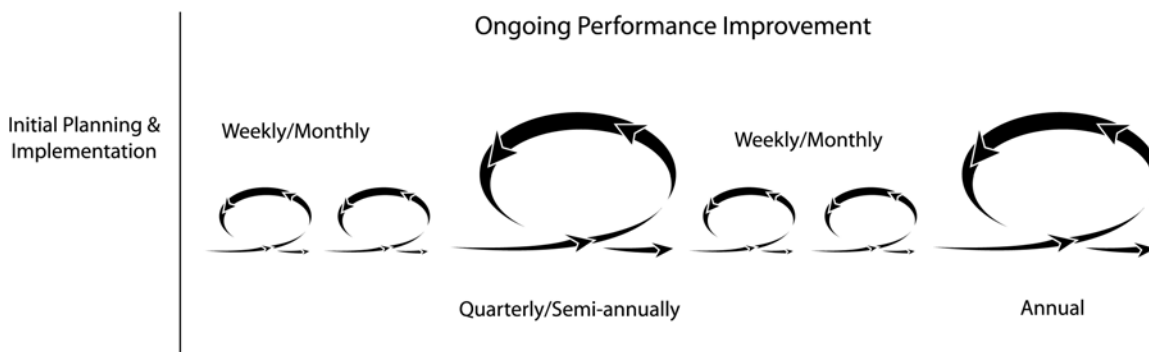


Figure #34: Review Frequency for Different Strategies

Perspective	Review Frequency
Clinical outcomes (status, actions, perception of complexity/stress, satisfaction)	
Individual patients and families	Day to day
Careteams	Weekly
Regional teams	Weekly, monthly, annually
Overall program	Monthly, annually
Population served	Annually
Resource utilization	Monthly, quarterly, annually
Adverse events/risk management	Monthly, quarterly, annually
Compliance	Monthly, quarterly, annually
Strategic and business plans	Annually
Standards of practice	Annually
Policies and procedures	Annually
Standards for data collection	Annually

To see how well the organization is functioning, comparisons can be made with:

- historical data
- the organization's standards of practice
- the nationally-accepted norms of practice within this model.

Accreditation

Accreditors will find the model provides frameworks, principles and norms of practice to guide the development of accreditation standards that can be used to assess both patient/family care, and organizational function.^{56,57,58,59} Although the model is specifically designed for hospice palliative care organizations, the accreditation standards and target outcomes should be the same for similar activities in any healthcare organization.

In addition to inter-organizational comparisons (benchmarking), the model's norms of practice can be used during an external review as another point of comparison (i.e., "the ideal to which organizations can aspire").

Standards of Professional Conduct

As all healthcare providers should be able to provide the core competencies of hospice palliative care, aspects of the model can be used to guide the development of Standards of Professional Conduct by professional associations and licensing bodies.

5. Applying the Model to Education

As all patients and families will experience issues within the domains of hospice palliative care, all healthcare providers must be competent at providing at least the core skills of hospice palliative care. To change patients' and families' experience of illness and bereavement, clinicians (including volunteers) must:

- have the attitudes and knowledge necessary to address hospice palliative care issues
- be skilled at the process of providing care related to each of these issues
- change their behaviour as they manage these issues.^{60,61}

Healthcare educators will be able to adapt the "Square of Care" and the principles and norms of practice for patient and family care to guide the development of core competencies, curricula (i.e. The Canadian Palliative Care Curriculum⁶²), and examination strategies for both primary and expert hospice palliative care providers from all disciplines (including volunteers). Educators will also be able to adapt the "Square of Organization" and the principles and norms of practice for organizational development and function to guide the development of educational strategies for administrators and quality managers.

The model will be particularly useful to guide:

- **The development of educational standards for hospice palliative care experts:**

Nurses

CHPCA Hospice Palliative Care Nursing Standards of Practice, 2002,⁶³ developed in collaboration with the Canadian Nurses Association⁶⁴

Nursing certification through the National Board for Certification of Hospice and Palliative Nurses in the U.S.⁶⁵

Physicians

Standards of Accreditation for a 1-year Program of Added Competence in Palliative Medicine, The Royal College of Physicians and Surgeons of Canada⁶⁶ and the College of Family Physicians of Canada⁶⁷

Initial voluntary program standards for fellowship training in palliative medicine in the U.S.,⁶⁸ supported by the American Board of Hospice and Palliative Medicine⁶⁹

Social Workers

Competency-based Education for Social Workers. Alexandria, VA: National Hospice and Palliative Care Organization, 2001. See item #820020 at

http://www.nhpco.org/store/category.cfm?category_id=77

- **Medical schools in Canada and the U.S.** that are now required to teach end-of-life care. According to the Liaison Committee on Medical Education in the U.S.: "Clinical instruction should cover all organ systems, and must include the important aspects of preventive, acute, chronic, continuing, rehabilitative, and end-of-life care."⁷⁰ This also applies to Canadian medical schools: "The Committee on the Accreditation of Canadian Medical Schools (CACMS) serves as a mechanism to ensure high standards on a national

basis, as well as meeting accreditation standards of our U.S. counterparts, the Liaison Committee for Medical Education (LCME)”⁷¹

- **Residency training programs in the U.S.** that are now required to teach pain management and end-of-life care, e.g., family medicine,⁷² internal medicine.⁷³ For example, the special educational requirements for general internal medicine and internal medicine subspecialty training include:

“Pain management: Each resident should receive instruction in the principles and practice of pain management, including symptom assessment and control”⁷³

“End-of-life care: Each resident should receive instruction in the principles of palliative care for terminally ill patients, including the role of the health-care team. Instruction should include psychosocial, cultural, and religious issues related to death and dying. It is desirable that residents participate in hospice and home care”⁷³

- **Continuing medical education programs** specializing in end-of-life care, hospice care, pain management and palliative care, including:

The Ian Anderson Continuing Education Program in End-of-Life Care⁷⁴

The Pallium Project⁷⁵

The Education for Physicians on End-of-life Care (EPEC) Project⁷⁶

The End-of-Life Nursing Education Consortium (ELNEC) Project⁷⁷

The End of Life Physician Education Resource Center⁷⁸

Provincial/state regulations mandating education in end-of-life care, such as California Bill AB 487 mandating 12 hours of physician education in pain management and the treatment of terminally ill and dying patients by December 31, 2006.⁷⁹

Hospice palliative care organizations proposing to develop “education” as one of their principal activities, will also find that the “Square of Organization” and the principles and norms of practice for organizational development and function can be used to guide the development of their educational activities. To date, specific norms of practice have not been developed to guide educational activities.

Note: Education of patients, families, and informal caregivers is part of care delivery (see page 34). Education of staff (e.g., formal caregivers) is part of the development of human resources (see page 44).

6. Applying the Model to Policy Development

An initial review of the impact of the 1995 Principles of Practice⁸⁰ demonstrated that even the first working document on national standards of practice can change approaches to care within organizations and across healthcare regions, as well as provincial and federal policy.⁸¹

Regulators, policy makers and funders will be able to use the new model's conceptual frameworks, the "Square of Care" and the "Square of Organization," to guide the review and improvement of existing laws, regulations and policies. Each law, regulation and policy will fit somewhere on the grids created by these frameworks. Queries might include:

- What existing laws, regulations and policies guide hospice palliative care practice and program development
- Do they create any barriers to providing patient/family care or developing effective hospice palliative care organizations
- Are there aspects of patient/family care and organization function that would benefit from new policy, regulation, or law?

The "Square of Care" and the "Square of Organization" will also be used to guide the review and improvement of existing funding and service delivery models. Queries might include:

- What resources are currently available to fund hospice palliative care activities
- What activities do they facilitate
- Are there gaps in the funding or service delivery models that create barriers to good patient/family care
- How should funding and/or service delivery models be changed to overcome those gaps?

As an example of the potential impact of review: when California realized that private healthcare insurers were not providing hospice care consistent with the U.S. Medicare Hospice Benefit, they created legislation that made it mandatory for "each health care service plan [to] include as a basic health care service, hospice care that at a minimum shall be equivalent to that provided pursuant to the federal Medicare program."⁸²

Population Data Surveillance Strategies

To understand how populations of patients receive hospice palliative care, policy makers will be able to use the norms of practice within the model to help develop national data collection and documentation guidelines. Once in widespread use, consistent data collection strategies will help policy makers and regulators develop population data surveillance strategies.

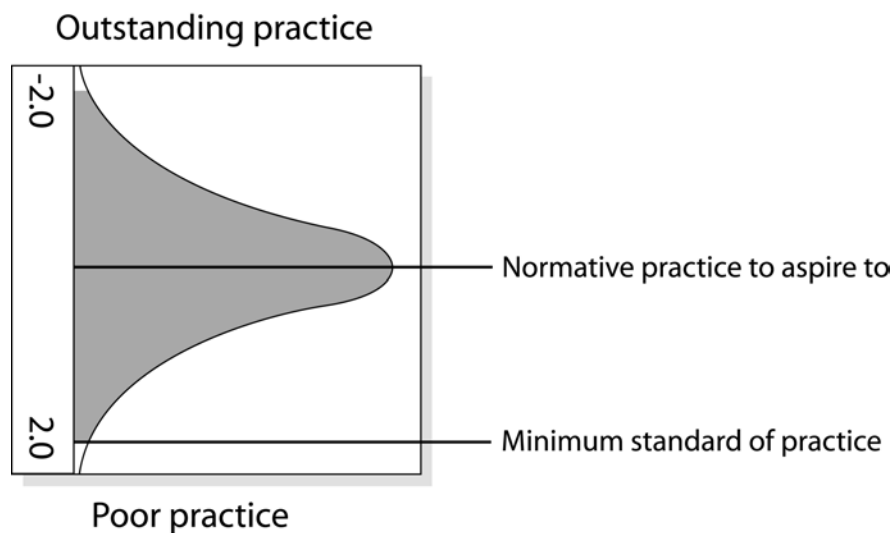
New Policy, Regulation, Law, Funding or Service Delivery Models

Policy makers will also be able to use the model to guide the development of new policy, regulation, and law, funding or service delivery models (e.g., provincial/state hospice palliative care policy and funding/service delivery strategies.) Their content should be consistent with the model's principles and norms of practice, and encourage the widespread implementation of high quality hospice palliative care.

Minimum/Licensure Standards of Practice

Minimum standards of practice are frequently developed by stakeholder associations to guide their members' practice, or by policy makers who wish to regulate an industry (e.g., the Conditions of Participation of the U.S. Medicare Hospice Benefit).⁸³ Minimum standards are different from norms of practice. They establish the "floor" or "minimum practice" that is acceptable to meet a given condition (i.e., labeling, licensure).

Figure #35: Minimum Standards of Practice



Compliance with "minimum standards" may be:

- voluntary if the "minimum" performance criterion is established as a guide (e.g., guidelines to define the labeling of hospice palliative care programs, such as the functional classification of a palliative care program presented in the 1989 Palliative Care Services Guidelines)⁸⁴
- mandatory if the "minimum" performance criterion is legislated or regulated, and labeling or licensure can be revoked if the conditions are not met (e.g., the Conditions of Participation of the U.S. Medicare Hospice Benefit).⁴¹

The model presented in this monograph might be used to guide the development of minimum/licensure standards. However, policy makers are reminded that the principles and norms of practice within the model present the ideal practice to which hospice palliative care providers and organizations can aspire. They do not represent current standards of practice.

While minimum or labeling standards may contribute to the development of hospice palliative care, policy makers are cautioned not to create licensure standards prematurely without data to support their usefulness, and careful analysis of the potential for secondary unintended consequences.

7. Applying the Model to Research

Researchers will be able to use the model to identify new research initiatives to advance both the delivery and organization of hospice palliative care. The grids of both the “Square of Care” and the “Square of Organization” can be used to map out the existing literature, identify gaps in knowledge, and suggest research priorities.

Administrators, clinicians and educators will be able to use this same review process to identify existing knowledge and skills that are not well integrated into clinical practice or organizational function. They can then develop strategies to disseminate the information to end-users and integrate it into routine practice.

Hospice palliative care organizations proposing to develop “research” as one of their principal activities, will also find that the “Square of Organization” and the principles and norms of practice for organizational development and function can be used to develop their research activities. To date, specific norms of practice have not been developed for research activities.

8. Applying the Model to Advocacy and Communications/ Marketing

Advocacy

A concerted advocacy effort by many organizations using the nationally-accepted model has the potential to have a significant impact and be a force for change. For example, the model could be used to:

- trigger the development of community associations and partnerships of hospice palliative care organizations and providers to deliver care and advocate for change
- guide advocacy aimed at changing organizational, regional, and national policy, and funding/service delivery models
- enhance consumer and provider awareness of all aspects of hospice palliative care.

The definition, values and guiding principles in section II (see pages 17-20) will help shift the understanding of hospice palliative care. Instead of being seen as “care for the dying,” hospice palliative care will be “care that aims to relieve suffering and improve quality of life throughout the illness experience and bereavement, so that patients and families can realize their full potential to live even when they are dying.”

The “Square of Care,” principles and norms of practice will help to change consumers’ expectations of their healthcare providers (i.e., the issues they can expect to have addressed, the process of providing care they can ask for, the approach to careteam function they can anticipate, when to access hospice palliative care services). Overall, it will enhance consumers’ confidence and encourage them to ask questions of their healthcare providers.

Hospice palliative care organizations proposing to develop “advocacy” as one of their principal activities, will also find that the “Square of Organization” and the principles and norms of practice for organizational development and function will help to develop their advocacy activities. To date, specific norms of practice have not been developed for guide advocacy activities.

Communications/Marketing

The model will serve as a cornerstone to guide communications and marketing. Having a nationally accepted model will make it easier to develop consistent messages that everyone can support, (e.g., Living Lessons, an innovative social marketing campaign that was based on the 1995 Principles of Practice).⁸⁵

Conclusion

The success of modern medicine has markedly changed the experience of illness and bereavement. Today, people are living for much longer with the multiple issues that are the manifestations, predicaments and opportunities presented by their underlying disease, conditions, or aging. In the process, they experience prolonged suffering, and considerable change to the quality of their lives. It affects not only the patient, but also their families, and the communities in which they live.

This monograph defines hospice palliative care and presents a model that includes conceptual frameworks, principles and norms of practice to guide all aspects of patient/family care, and organizational development and function. It is hoped that, through application of the model, all healthcare providers will become more effective at relieving suffering and improving quality of life. It is also hoped that, with time, there will be widespread application of hospice palliative care throughout the experience of illness and bereavement, “so that patients and families can realize their full potential to live even when they are dying.”

In the end, our society’s ability to realize its potential will be related to its success at relieving suffering. The health and compassion of our communities will be related to the degree of integration of hospice palliative care into all aspects of our healthcare system. For our patients, our families, our communities, and ultimately ourselves, isn’t it time to get going?

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- ⁸³ Conditions of Participation, Medicare Hospice Benefit, Code of Federal Regulations, Title 42, Chapter IV, Part 418, see http://www.access.gpo.gov/nara/cfr/waisidx_00/42cfr418_00.html.
- ⁸⁴ Subcommittee on Institutional Program Guidelines. Palliative-Care Services Guidelines. Ottawa, ON: Health and Welfare Canada, 1989, 5.
- ⁸⁵ Living Lessons, developed by the GlaxoSmithKline Foundation, see <http://www.living-lessons.org/>.