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# **The Team Approach to Hospice Palliative Care: Integration of Formal and Informal Care at End of Life**

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## Key Implications for Decision Makers

The purpose of this research was to develop an integrated team approach for hospice/palliative care in the community. Implementing an integrated model of care that brings together both the formal and informal caregivers will result in improved care for hospice palliative care clients and their families.

- The four key features to an integrated hospice/palliative care system are improving communication, having a central co-ordinator, building community awareness of hospice services, and increasing the number of services offered.
- For a model of care to be truly integrated, there needs to be a unity of purpose that focuses on the needs of the patients and their families and builds on effective partnerships between formal (for example, doctors and nurses) and informal (for example, volunteer agencies, family members) care providers.
- Services should be provided in a regional network.
- There are six key activities to implementing an integrated system:
  - create community networks that use multiple points of access, customize care, and ensure minimum standards;
  - establish a provincewide information system;
  - develop a dedicated body to mobilize/co-ordinate a community response at the local level;
  - create and use innovative collaborative models to develop healthcare professional teams;
  - promote links between nurse practitioners, palliative care physicians, trained volunteers, informal caregivers, and other personnel; and
  - examine new management models.
- The research provides a detailed 15-point plan that shows how to implement an integrated model of care. It covers the following areas:
  - provincial policy framework;
  - governance entity;
  - network development;
  - situational analysis;
  - ideal systems planning;
  - integration of partners;
  - communication strategy;
  - working relationships;
  - co-ordinated care;
  - access and entry points;
  - awareness;
  - education and training;
  - funding;
  - evaluation; and
  - culture and philosophy.

## **Executive Summary**

### **Introduction**

The purpose of the research was to develop an integrated team approach for hospice/palliative care in the community. The research was, and is, particularly timely given the changing nature of community-based care brought about by recent fiscal, demographic, and political imperatives, and the increasing awareness that Canadians prefer to die at home.

### **Background and Context**

More than 220,000 Canadians die each year, 75 percent of whom die in hospitals and long-term care facilities (Senate Subcommittee, 2000). The Senate subcommittee notes that, on average, each death potentially affects the well-being of five other people. People receive different treatment and support across the country. Seniors are less likely to want to die at home than younger people, and there is “considerably less access to palliative care” in rural areas compared to urban centers (Senate Subcommittee, 2000). A recent national survey conducted by Angus Reid, however, indicates that 51 percent of respondents would very likely use hospice care services if they had a terminally ill family member (Angus Reid, 1997).

While medical care is traditionally associated with acute-care settings, this is now changing. There are considerable benefits to integrating care among an inter-disciplinary team (Wright, 2001) and broadening hospital-based palliative programs into the community to more effectively address pain management and the psychological, social, and spiritual needs of both those dying in their homes and their family members (Early et al, 2000; Lycan and Glass, 2001, Ratner et al, 2001; Steinhauser et al, 2000; Thompson, 2000). This also requires improved co-ordination among formal providers (Lynn, 2000), and indeed the informal network of support in the community (Parent and Anderson, 2001).

While formal homecare services from community care access centres in Ontario have become more restrictive, there has been substantial growth in the contribution of informal volunteers through the 88 hospices of the Hospice Association of Ontario. These hospice agencies provide care and support in more than 400 communities. In the year 2000, for example, they co-ordinated more than 12,000 volunteers, operating almost entirely with private funding outside the publicly funded system.

Given the continuing constraints on the *formal* system and the substantial and rising commitment of *informal* volunteers, it is desirable to examine ways that the different modes can work together (and with families) to ensure people receive consistent access to a consistent array of services and supports for hospice/palliative care across the province. The findings from this research can greatly assist government, community care access centres, and hospice volunteer agencies develop an approach to improving the care and support for individuals who are dying at home and their families.

## **Approach**

The extensive consultation process involved a wide range of stakeholders including hospices, community care access centres, family caregivers, hospice volunteers, other key informants, and members of the palliative pain and symptom management network. The methods included mailed surveys, focus groups, e-surveys, e-delphi, interviews, case studies, and integrating workshop participation.

## **Findings**

Synthesis of the eight data collection phases revealed several necessary features required for a truly integrated model of hospice palliative care. Fundamentally, there needs to be a unity of purpose — one that focuses on patients/clients and their families that is developed and built upon effective collaborative partnerships among formal and informal providers. This team approach emphasizes a regional network of services and point of care teams that have a culture of respect and inclusiveness.

The eight core features of an integrated system are:

- unity of purpose;
- collaborative partnerships and relationships;
- access to comprehensive hospice palliative care services;
- communication structures;
- co-ordinated care;
- a governing body;
- training and education; and
- a formal evaluation plan.

## **How to Put the Findings to Real Use**

The culmination of the study is a detailed 15-point implementation plan that will assist current providers and caregivers to implement an integrated model of care. The plan covers the following areas:

1. building a provincial policy framework for palliative care;
2. identifying a governance entity;
3. establishing a local or regional network;
4. defining the state of current systems/processes in local area;
5. identifying future ideal systems and processes;
6. establishing tools to facilitate integration of regional network partners;
7. generating an effective communications strategy;
8. developing effective working relationships;
9. ensuring co-ordinated care;
10. facilitating access and establishing functional entry points;
11. increasing awareness of hospice and palliative care services as a specialty;
12. improving education and training strategies;
13. integrating funding and resources;
14. building strong evaluation strategies; and
15. establishing a culture and philosophy related to palliative care.

## **Conclusion**

This research initiative did not finish with the completion of the study. The dissemination of the findings is well-timed to coincide with the newly agreed upon charter for hospice palliative care and the formation of local area health networks in Ontario. Most specifically, the 15-point implementation plan will prove beneficial to decision makers at the macro, meso, and micro levels. We believe that hospice palliative care clients and their families will receive improved care through an improved understanding and implementation of an integrated model of care.

## Introduction

The purpose of the research was to develop an integrated team approach for hospice/palliative care in the community. The research was, and is, particularly timely given the changing nature of community-based care brought about by recent fiscal, demographic, and political imperatives, and the increasing awareness that Canadians prefer to die at home. The research was funded by the Canadian Health Services Research Foundation, the Ontario Ministry of Health and Long-Term Care, and Health Canada.

## Approach/Methodology

The research involved an extensive consultation process with a wide range of stakeholders including hospices, community care access centres, family caregivers, hospice volunteers, other key informants, and members of the Palliative Pain and Symptom Management Network. The multiple method approach enabled the triangulation of both data and methods. The methods included mailed surveys, focus groups, e-surveys, e-delphi, interviews, case studies, and integration workshop participation. They are shown in the table below.

*Table 1*  
*Methodology*

Stakeholder Group	E-survey	Mail-out survey	Focus group	Interviews	E-Delphi
Hospices (EDs) (n=31)				X	
CCACS (n=5)	X				
Palliative Pain and Symptom Management Network (n=4)	X				
Family caregivers (n=50)		X			
Hospice volunteers (n=105)		X			
Case studies (n=4)			X		X
Integration workshop participation					
Key informants					X

What follows in the remainder of the report is the synthesis of these findings.

## **Background and Context**

More than 220,000 Canadians die each year, 75 percent of whom die in hospitals and long-term care facilities. The Senate subcommittee notes that on average, each death potentially affects the well-being of five other people. People receive different treatment and support across the country. Seniors are less likely to want to die at home than younger people, and there is “considerably less access to palliative care” in rural areas compared to urban centers. A 1997 national survey conducted by Angus Reid, however, indicates that 51 percent of respondents would very likely use hospice care services if they had a terminally ill family member.

While medical care is traditionally associated with acute-care settings, this is now changing. There are considerable benefits to integrating care among an inter-disciplinary team and broadening hospital-based palliative programs into the community to more effectively address pain management and the psychological, social, and spiritual needs of both those dying in their homes and their family members. This also requires improved co-ordination among both formal providers and the informal network of support in the community.

While formal homecare services from community care access centres in Ontario have become more restrictive, there has been substantial growth in the contribution of ‘informal’ volunteers through the 88 hospices of the Hospice Association of Ontario. These hospice agencies provide care and support in more than 400 communities. In the year 2000, for example, they co-ordinated more than 12,000 volunteers, operating almost entirely from private funding outside of the publicly-funded system.

Given the continuing constraints on the *formal* system and the substantial and rising commitment of *informal* volunteers, it is desirable to examine ways that the different modes can work together (and with families) to ensure people receive consistent access to a consistent array of services and supports for hospice/palliative care across the province. The findings from this research can greatly assist government, community care access

centres, and hospice volunteer agencies to develop an approach to improving the care and support for individuals who are dying at home and their families.

In April 2004, a provincewide stakeholder consultation took place in Toronto to develop an “Ontario strategy” for providing quality end-of-life care. Three of the researchers were invited to participate in the two-day workshop. Among other things, integration was a major theme, and the participants acknowledged several areas of common ground. These are shown in Appendix 1.

Several strategic priorities were identified which followed from these common ground elements:

- Develop a policy framework
- Enhance accountability
- Increase awareness of hospice palliative care
- Create networks/integration

This fourth strategic priority relates directly to this research. Six key activities are recommended, and these are shown below with emphasis added to indicate the synergies with the current research:

- Create **community networks/partnerships that utilize multiple points of access**, customize care, and ensure minimum standards are met
- Establish a **provincewide common information system** for hospice palliative care
- Develop a **dedicated body to mobilize/co-ordinate** a community response at the local level (**co-ordination and communication among the people providing the care**)
- **Create/use innovative collaborative models to develop healthcare professional teams** across the hospice palliative care continuum

- **Promote linkages** between nurse practitioners and palliative care physicians, and engage other personnel such as trained volunteers and informal caregivers
- Examine **the creation of new models of management**

The two-day workshop produced agreement on a charter (see Appendix 2). This spring 2004 charter statement is especially notable given the divergent views that were observed prior to and at the beginning of the workshop, and in many ways represents a clear blueprint for a plan of action. There is a momentum within the province to better position hospice palliative care in the healthcare system. It is in this context that the results of this research project can be applied.

## **Results**

It is not possible to fully articulate the range of issues, gaps, and barriers in the limited space provided. We have instead opted to provide a summary listing of these in Appendix 3.

### ***Key Features of an Integrated Model***

Survey responses from hospice volunteers provided the following rankings when considering integrated care. The ideal system features included effective communication, central co-ordination, community awareness, and the ability to simply provide more services (Table 2).

**Table 2**  
**Ideal Integrated System Features**

<b>Ideal Integrated System Features</b>	<b>(n=102)</b>	<b>Percent</b>
<b>Communication</b> — all healthcare workers and volunteers working as a team	65	64%
One <b>central co-ordinator</b> is needed — one very aware control person of all services for one client	20	20%
<b>Community awareness</b> of hospice — physician awareness of hospice	11	11%
<b>More services needed</b> — no limits on where or when services are provided	10	10%
Better funding for hospices	8	8%
Education and better training of volunteers	7	7%
Volunteers should receive referrals earlier	5	5%
The clients/patients should direct their own care — they are at the center of the healthcare team	5	5%
Don't know	3	3%
More paid healthcare workers	1	1%
An integrated system does not exist	1	1%
The system is great as is	1	1%

Similarly, when asked to identify the factors currently contributing to an integrated system, the focus of the responses was on communication (Table 3).

**Table 3**  
**Factors Currently Contributing to an Integrated System**

<b>Factors Currently Contributing to an Integrated System</b>	<b>(n=49)</b>	<b>Percent</b>
<b>Communication</b> — volunteers are kept informed by supervisors	25	51%
<b>Dedication and experience of staff</b>	7	14%
<b>Hospice is in good contact with the hospital</b>	5	10%
<b>Co-operation of doctors and nurses</b>	5	10%
Patient-oriented care	4	8%
Training and ongoing education of volunteers	4	8%
Great hospice facilities	2	4%
Financial support	2	4%
Community support and interest	2	4%
Unknown	1	2%

Stakeholders interviewed in the study identified a number of key features of an integrated model for hospice palliative care. The most common feature identified was consistent **centralized** communication that is high quality, open, confidential, frequent, and between all parties; This should include standardized service agreements, protocols, practices, procedures, a common language and terminology between provider partners and shared with client and families, and the realization that more information is needed than what is shared at the time of the referral. Some commented that it would be ideal for hospices to have the same information as the original assessor or even more comprehensive

information. There should be strong connections with the general practitioner in the home as well as engagement in community ‘rounds’ in hospitals and tertiary care, and a common communication tool that everyone uses and respects.

There should also be **co-ordinated care**, with an easy and effective flow of clients from site to site (seamless transition); assistance for caregivers to co-ordinate services and informal supports (for example, visiting roster for family/friends; food drop-offs); a better ‘road map’ for clients/caregivers to understand the system (that is, who is coming, when, why); and customized (individual) care plans for clients through case management.

**Access to care** should be easy, equitable, and comprehensive (what some referred to as one-stop shopping) for services and information for clients, family caregivers, providers, and the general public within the respective communities of residence; 24/7 service; good transportation systems to support people dying in a rural/remote setting; and access to service regardless of diagnosis or financial means.

There should be a **formalized entry point** — a mechanism (central registry for all clients) linking all sectors, clients, and providers (access centre case managers, hospitals, hospices, palliative care units, physicians, and service providers). With such a system the key providers (some would say everyone) would have access to client information.

**A multidisciplinary proactive team approach with regular team meetings** is recommended to ensure that service is comprehensive in meeting clients’ needs across the care continuum (such as to process referrals, plan, develop programs). An interdisciplinary and multidisciplinary approach is desired — a true, integrated resource team, not an individual approach with recognition that everyone is part of the team and has something valuable to contribute. There should be an understanding — a real *philosophical ownership* — that the client belongs to the team. More physician involvement is desired, and there needs to be a removal of the ‘silo’ and ‘turf protection’ mentality with some ‘blurring’ of roles and a shared philosophy of hospice palliative care based on mutual respect and trust.

**Continuous education/training** is desired for all volunteers, formal providers, and family caregivers. This should include palliative care education, plus training in their own role and the role of others and the system as a whole. There should be specialized general practitioners and nurses who are educated in hospice palliative care or those who are willing to declare palliative care as a specialty and work to acquire the skills and experience. There should be 24/7 support and reassurance for family caregivers regarding their role and responsibility at hospital discharge and centralized educational resources/resource libraries and a research base.

It is almost a given to express a need for more funding, but in this instance the call is for **an integration of funding, resources, and system advocacy**. This would support education opportunities, with enough funds to be effective in offering all services required in local settings (including caregiver support or bereavement, end of life care at home, palliative care beds, and an adequate transportation system). There needs to be adequate funding for hospice staffing and administration to address operational needs; funded time (full time) for planning and identifying/developing resources; better funding for hospice program administration facilities (co-locating and virtual); additional physician support; and collaborative funding among formal and informal provider agencies for education and special projects.

There is a growing **awareness** that more needs to be stated as to what hospice palliative care can provide. This message (or these messages) should be directed to the general public, physicians, and professional providers through a focused marketing strategy, with well-publicized services and resources and an understanding of the system and how it works: knowing whom to call, for what, and when.

A **co-operative and collaborative governing body** that includes both hospital and community representatives; networks composed of committed, informed decision makers with the autonomous authority to make decisions would greatly assist in developing an integrated team approach. One regional palliative care organization could serve all

sectors in respective geographical areas. It may well be, in fact, that the term “regional” is discarded in favour of “local” to better recognize the fact that local has more direct meaning to stakeholders. In contrast, “regional” can imply something that is much larger than a community, for example, and may give the appearance of being too big and not able (actually and/or perceived) to be truly effective for integrating care at the very grassroots community level. Ideally, at least one person could be dedicated (and paid) to co-ordinate the administration of a local or regional palliative care program, and there should be joint planning and development of the local system. Formal, facilitated planning sessions with all providers should be ongoing.

There should be **client-focused care** that recognizes direction should be taken first from the client and the family caregiver, and the client/caregivers should not have to do all the work in seeking out services. Clients and families, not the system, are at the center of care, and there should be encouragement for them to take an active role in care and planning.

**Hospice volunteers need to be recognized as integral members** of the team to ensure continuity and consistency. There need to be respect and appreciation for the volunteer, and recognition of the volunteer’s role as client advocate. There needs to be support for volunteers and staff in dealing with death and dying (such as training, funding to send people to networking groups, conferences, etc.), flexibility on the part of formal providers to negotiate volunteer’s tasks, and flexibility on the part of volunteers and volunteer agencies in defining tasks in a non-rigid manner.

There were many other system features emphasized by interview participants. These included the capacity and engagement of **residential hospice care** as part of holistic palliative care service in every community, and the importance of **common health records** with a shared client information system (referral, assessment, consent, chart [in-home], minimized assessments). There need to be common data input, access to records, and the continual updating of information to integrate care across sectors.

A **holistic approach** is strongly supported (as opposed to the medical model approach) — one that treats the client as a whole person and includes the family caregiver as part of the treatment unit. The holistic approach recognizes the psychosocial component and a built environment that is supportive of client and families (such as a place to shower, eat, and sleep; no restriction on visiting hours, pets, or children; alternative therapies, healing gardens, or sundaes at 2 a.m.).

It was recognized that **adequate primary care in the home** is important. Some clients, it was noted, have to go to emergency for care since they do not have family physicians or access to experienced, specialized providers; generalist palliative care physicians who are educated in pain control; and providers who are aware of what is happening. More interventions, it was suggested, need to be provided at home.

**A good referral process that is timely** and includes referrals from all sectors (doctors, community care access centres, the Victorian Order of Nurses, funeral homes, clergy, and community agencies) is essential. If referrals are received with adequate time, this helps to build relationships, friendships, and longer-term partnerships. There needs to be the capacity to meaningfully **track activities in every sector**, based on common information systems, comparative databases, and common terminology, with an agreement as to what needs to be collected (and how and by whom). The result would be an increased ability to know what care is/will be required, who is best suited to provide it, and the ability to plan accordingly. There also needs to be recognition that ministry's definitions and guidelines for data collection and reporting activities should be incorporated into such developments.

**There should be appreciation and respect** for various essential roles and expertise required to provide comprehensive and integrated hospice palliative care. All roles should be defined to avoid duplication, but flexibility to blend roles should be possible when necessary. There needs to be mutual trust between informal and formal providers. Indeed, to enhance such relationships and interaction there should be a consistent person(s) in the role of **volunteer co-ordinator**. These individuals need the requisite skill set, experience

(direct experience in palliative care), enthusiasm, and perseverance to build the integrative service between and among the formal and informal sectors (many hospice agencies, for example, continually have to orient new staff and start over rather than moving forward to develop new services — one interview participant had three coordinators within one year).

With any model there needs to be **flexibility** and the ability to change direction if required. As one participant noted, “sometimes when things are formalized, flexibility is lost.” Finally, overriding any model is the need to constantly evaluate and re-evaluate the relevance of existing services (such as continuous quality improvement, program evaluations, organizational development, and so on) to encourage and support accountability, evidence-based decision-making, and a spirit of enquiry to foster ongoing improvement of care.

When identifying role and function among the various stakeholder groups, we asked study participants to identify who would play the key role in providing care and support. We used the “square of care” developed for the Canadian Palliative Care Association as the framework for this role and function definition.

### *Clusters of Key Features for Integrated Formal and Informal Care*

Given the range of themes identified by stakeholders, we clustered them under several distinct but inter-related clusters. These are useful not just for their insights, but also because they serve as the backdrop for closer examination or exemplar models of integration we identified and report on in the subsequent section.

- A Centralized Communication Strategy
- Working Relationships and a Team Approach
- Co-ordinated Care
- Access and a Functional Entry Point
- An Awareness of Hospice and Palliative Care as a Specialty Service
- Education and Training Strategy

- The Integration of Funding and Resources
- A Governing Body
- Evaluation Strategy
- Culture and Philosophy Related to Palliative Care
- Palliative Care as a Specialty

### ***Summary of Case Study Findings on Integrated Models***

#### **Introduction**

The program themes summarized here represent key features of integration used to guide the interview and additional themes that emerged during the focus groups. The key features and main theme areas were labeled as: Unity of Purpose; Culture of Respect/Inclusiveness/Innovation and Philosophy of Hospice and Palliative Care as a Specialized Program; Collaborative Partnerships and Relationships (sub-theme: Sense of Community Ownership); Centralized Communication Strategy; Working Relationships and a Team Approach; Co-ordinated Care; Access and a Functional Entry Point (sub-theme: Comprehensiveness of Services); Education and Training Strategy; Governing Body (sub-theme: Leadership and Shared Resources and Finding Ways to Fund); and Evaluation Strategy. A cross-cutting theme observed across all programs was the recognition that hospice palliative care is a specialty service and that the relationships between providers is an important enabler of integrating care delivery systems. Common strategies to achieve integration across the exemplar program models are summarized in each of these theme areas.

#### **Key Features of Integrated Hospice Palliative Care Delivery Systems**

- **Unity of Purpose**

The most prominent feature of each of the program models was the focus on the needs of the client and families rather than the needs of the organization. The need to make the experience of confronting the death of a family member easier and improve the quality of dying was the unifying purpose voiced by focus groups participants across each of program models that brought individuals from different roles and programs to form an integrated delivery system. This initial relationship, which developed to achieve the

common purpose, evolved into a fluid formalized network structure that had two main components: a co-ordinated team care delivery approach at the point of care and a network of organizations working together at the regional level to facilitate hospice palliative care planning and integration of all systems of care in a unified direction. Even though the organizational structure of each of the three program models varied and the participants varied according to role, it appeared that it was their unique perspectives, skills, or part of the care system that they represented that was important to achieving their purpose and was essential to creating a system of care that was integrated. Critical to this shared understanding was a philosophy that hospice and palliative care is a specialized program.

Each of the component parts of the system and each of its members inclusive of the informal service sector (that is, volunteers) were seen as valuable and contributing to the whole. Issues of turf or individual organizational identities or accountabilities did not enter into the discussions, creating an organized system of care that functioned like a virtual network even though many of the participants came from a different part of the system and were accountable to a different part of the healthcare system. A virtual network has been defined as follows: “Virtual integration refers to an arrangement in which healthcare organizations exist within a network of organizations working towards a common goal of providing care to a given population but without common ownership.” Each of the program models exhibited features of a virtual network. Different organizations involved in the network retained their own structure and identity but came together in a virtual network to achieve a seamless system of care around the patient and family to meet their needs. An important common feature was that each of the program models had integrated both hospice volunteer services and many other features of hospice services, such as residential hospice and day hospice, along with formal services such as community care access centres and specialist palliative care teams.

The strategies of how they achieved integration differed across programs, but it was evident that unity of purpose was central to their coming together and creating a network structure that worked for the local healthcare context. There was a sense of sophisticated

structure in each of the program networks that evolved from their common history of working together or was strategically developed to achieve their purpose. As an example, one of the informal care sector hospice-led services had used joint positions crossing traditional boundaries to deliver care in different sectors of the healthcare system, such as cancer clinics and homecare, and across tertiary hospitals and community hospitals. However, the formal care specialist service delivery model had developed a structural model to achieve integration of palliative medicine physicians with generic and specialist palliative homecare services. Common across the program models was that members from differing organizations had clearly identified roles, and each member understood the contribution that each individual member and/or organization provided in the network to achieve their purpose. Central to unity of purpose was recognition that hospice palliative care programs are a specialty service.

- **Culture of Respect/Inclusiveness and Innovation**

A common element across programs was their creation of a culture of respect for each other and inclusiveness. Turf issues did not enter into discussions and there was the sense of both informal and formal providers being valued for their contributions in making the experience of dying a little bit easier for patients and families. Another important theme that appeared to be common across programs was the creation of innovation. Programs just knew what had to be done and found a way to get on with it and work together to make it happen, rather than waiting for a “top down” directive to achieve integration. The programs described cultivating a culture of positivism with a strong belief in the possible. Creative ideas were encouraged and those ideas were acted upon and means sought to fulfill the idea. The programs found either the resources or the persons to leverage the idea. The environmental culture created within these programs fostered the ability of the hospice-led programs to attract volunteers in a kind of “build it and they will come” philosophy. The exemplar program models did not experience difficulty with obtaining volunteer time and commitment. There were multiple examples of programs that were developed because someone had the idea that it was the right thing to do. An interesting finding throughout the focus groups was that there was no reference to care sector or

organization, but rather to people being aware of each other's roles and always being there to support each other as a team delivering the care.

- **Collaborative Partnerships and Relationships**

The ability to come together as a network was enabled by the relationships that had been built over time between the members of the network and the need to achieve what they knew they could not achieve alone. More importantly, the network structure that developed from these relationships was continually sustained as a result of the evolved structure. The program models exhibited collaborative partnership and relationships at two levels of integration; namely, at the point of care and at the regional level. At the point of care, partnerships between members of organizations were developed in order to create a system of care around the patient and family. The program providers cultivated partnerships and relationships rather than leaving it to chance.

The members of the network also worked together to develop strategic direction at a regional level to identify unmet needs of patients and families and to find creative solutions as partners for addressing needs. It appeared that partnerships were enabled through what was described as a “collaborative attitude” and a sense that each of the members and/or organizations in the partnerships was interdependent and considered essential if patient and family needs were to be met. Formalized meetings were held to address regional planning issues for hospice palliative care. These meetings were viewed as critical to working together to resolve unmet needs but were also important to build relationships between individual members and organizations. Relationship was seen as critical to achieving the goals of the partnership. The key focus of the partnership centered on building services or programs based on needs of patients and families with less attention paid to organizational needs. The programs exhibited what has been previously described in the literature as collaboration, which is a step beyond co-operating and is described as an alliance among organizations that allows them to “go beyond their limited vision” to see what is possible.

- **Centralized Communication Strategy**

The exchange of information across all members of the team providing care to the patient and family was considered essential to achieving co-ordinated and consistent care. The use of technology, having clear and centralized mechanisms for information exchange, communication mechanisms and tools to support consistent care and clinical decision-making, and weekly and monthly regional planning meetings were all key features of information exchange across the exemplar program models.

- **Working Relationships and a Team Approach**

Each of the program models described team-based care delivery as an essential feature of their ability to achieve integrated and co-ordinated care. Team meetings did not occur on an ad hoc basis, but were structured to ensure weekly team meetings including all members of the team, if possible, for sharing of information and for the purposes of developing a plan of care. Weekly face-to-face team meetings were described as essential to the process of delivering team-based care and the development of working relationships that centered on the delivery of seamless point-of-care delivery. Face-to-face meetings enabled the team members to develop a plan of care to meet patient/family needs, but they also helped clarify roles and develop relationships among team members. Clarity of roles was particularly emphasized as a key element in achieving integrated care, avoiding duplication, and supporting team function. Respect for the unique contribution of each team member to patient/family care was highly valued. The focus of the team was not on the care that would be provided by different organizations or disciplines but instead centered on developing a system of support around the patient and family.

Volunteers were considered valuable members of the team across the program models, and the care they were able to provide within the scope of their role was built into the service allocation. The role of the volunteer and the extent of support provided to volunteer development varied with organizational structure. For instance, the emphasis on the role, support, and training of volunteers was more central in hospice-led programs, whereas in the specialist-led program the volunteers were integral to team-delivered care,

but their training and support was retained by the hospice organization. Hospice-led services had responsibility for training, supporting, and co-ordinating volunteer team functions and held monthly sessions to honour the contribution of their volunteers. It is important to differentiate that in one of the hospice-led programs, the hospice program served as the umbrella organization for both the informal care system components and the specialist palliative care provider component, with the exception of contracted services delivered by community care access centre.

Team leadership was viewed as essential to effective team functioning, and having a designated person assume this role was vital. However, team leadership was not specific and was identified according to the needs of patients and families. Team-based care across the homecare sector and hospital care sector was facilitated by the introduction of joint appointments, such as physicians who were the lead palliative care consultants for both the palliative home consult team and the palliative care units. In the hospice-led umbrella organization, co-ordinators had roles within the cancer care system and the hospice, and all members of the program crossed traditional sectoral boundaries to deliver hospice and palliative care services in organizations, such as long-term care facilities and hospitals.

All of the network partners acknowledged the need to actively work at team-building on an ongoing basis. One of the most important aspects of this was being exposed to each other on a regular basis and finding ways to ensure the team culture thrived, such as holding team meetings at times and places where as many team members as possible could attend. Team-building activities were seen as critical to effective team functioning. The team approach to care was viewed as contributing significantly to care co-ordination, timely access to resources, and continuity of care. Clarity of roles was important and considerable attention was paid to clarifying roles; in some cases roles were clearly defined in written role descriptions.

Clinical integration of the palliative medicine physician was considered essential to provide consultative support to primary care physicians and to ensure their time in

providing direct support to complex palliative care physicians. Adequate reimbursement of physicians was seen as critical to ensuring their involvement and to support their ability to provide training to other physicians and provide leadership. A model of care that supported physicians being cross-appointed in the community consult program and in the institution was an enabler for care integration.

- **Co-ordinated Care**

Having a designated person in the care co-ordinator position was considered essential across programs. In many situations, the case manager from the community care access centre assumed the role of care co-ordinator. However, each of the hospice-led programs also had co-ordinators who were responsible for co-ordinating services delivered from their organization. These co-ordinators worked in close partnership and collaboration with access centres' case managers to avoid duplication of efforts. Although case managers co-ordinated contracted services, and hospice co-ordinators co-ordinated the services of their individual agencies, it became seamless delivery at the point of care. In all of the programs, the palliative care knowledge and skill of the access centres' case managers and their role as palliative care case managers (smaller case-load of 50-60 patients) was viewed as critical to their ability to ensure timely co-ordination, access to services, and filling gaps in knowledge for community providers novice to palliative care patient populations. Co-ordination was a shared responsibility across individuals and organizations within the network, even though each individual program had its own internal system of co-ordination. Point-of-care co-ordination was shared among all co-ordinators with clarity as to whose role the allocation of services was from individual member organizations.

- **Access and a Functional Entry Point**

One point of entry was considered the ideal that was not yet achieved across all programs. For instance, in one program, although all patients requiring either residential care or inpatient tertiary palliative care were enrolled in the program, not all patients needing hospice palliative care services had equal access to the care. However, network partnerships and a team-based approach to care meant once patients were enrolled in any

of the network partner programs as palliative care patients, they had access to all of the services that partners in the network provided. One program had a very structured process for screening palliative care patients in the homecare program to ensure that patients did not fall into system gaps. In addition, this program had two points of entry, but all patients were enrolled in a comprehensive palliative homecare program once enrolled, which was part of the unique structure.

All of the programs had open access for palliative care patients of any type of disease or age; thus no barriers to entry were identified. Patients and families could be self-referred or referred by any member of the team; access was not limited to physician referral. In communities with multicultural populations, attempts were being made to establish cultural focus partnerships with informal care networks and to translate written materials about the hospice palliative care program for these informal groups and the overall community.

Volunteers were considered vital to improving access to the program. The volunteer's role in advocating for the program was considered to be a key success factor in improving public awareness of the program. Volunteers had structured roles in disseminating information about the program in both of the hospice-led programs, whereas in the specialist-led program all the team members had responsibilities for educating the public and other healthcare professionals about the program to improve access.

A very important finding in one of the hospice-led programs is that they did not differentiate between supportive care and cancer care; subsequently they were receiving referrals from the cancer care system much earlier in the disease. The hospice was seen as a supportive care service that provided care along the trajectory extending into the end-of-life phase and bereavement. Having nurses with roles that crossed usual boundaries between institutional care settings and the home structurally supported this approach. In addition, volunteers crossed the boundaries to follow patients referred to the program but also to initiate care for patients and families in all care settings, such as long-term care

facilities. Sharing resources was vital to this approach. For instance, the stipend for the palliative medical director was funded by the hospice, which supported that role in providing a portion of time to the cancer care setting. This boundary-spanning ability facilitated improved integration across the institutional and community care sectors and created opportunities to find creative ways to share resources to meet human resource shortages.

*Comprehensiveness of Services* – All of the programs described services as being available around the clock. In addition, the need for each of the programs to have all the needed services available to the patient as a basket of services was considered important. Some concerns were raised regarding the knowledge and skill level of some of the providers in caring for palliative care patients, since palliative care was not yet articulated as essential to some of the services on contract with the community care access centre. The ability to have all services accessible in one program was viewed as important, such as having daycare services under the same umbrella as residential hospice services and home volunteer visiting.

- **Education and Training Strategy**

There was a strong sense across programs to build community capacity for hospice and palliative care by advancing the knowledge and skills of all providers in delivering effective palliative care. Training resources were shared and education was viewed as another opportunity to build relationships between organizations and individual providers. The calibre of volunteer training was highly valued by both the volunteers and the professional providers who were part of the care team. The programs that were hospice-led had more than 300 volunteers in their programs, which was considered to be a reflection of how they were valued in the program and the calibre of training.

The need to have training within the local community, particularly for family physicians, was viewed as important to build local capacity of family physicians to deliver effective palliative care to their family practice populations and to build human resources for the networks related to the palliative medicine program. One program expressed a need for

advanced practice nurse practitioners skilled in palliative care who could provide care across programs, ensuring a high level of expertise and access to specialty care.

Interdisciplinary ongoing education was emphasized in each of the programs. The Ministry of Health and Long-Term Care's palliative care initiatives funding was used to support formalized interdisciplinary education programs that were used by all providers in the community. The network of organizations shared the planning of the programs. Ongoing education sessions such as regional grand rounds, seminars/conferences, and the Internet were seen as tools for promoting best practices and consistency of practice among providers, but also as an opportunity to strengthen relationships.

- **Governing Body**

Each of the programs had very different governance structures, with only the specialist-led program having an explicitly defined governance model with a signed legal agreement between two of the partners in the program. Other program models had traditional community board-based governance models, retained by each of the programs.

*Leadership and Program Champions* – Having a designated person to act as the program champion was considered an important feature of being able to work towards program goals and to work with multiple stakeholder groups. The vision of creating an organized system of care around the patient and family was a critical element of the leader's role. The leader also played a role as a champion in cultivating a cultural environment that fostered a willingness to work together and a strong sense of a “we” versus silo organization ownership of hospice palliative care. In addition, program champions in all parts of the care system, including informal systems such as church organizations, enabled program development and strengthened relationships.

*Find the Financial Resources to Make It Happen* – The community-based focus of all the programs was considered a key strength, since it promoted a “sense of community ownership” of the program. The community focus provides an opportunity for all members of the community to contribute in whatever way they can. In the two hospice-

led programs, cultivating the communities' sense of ownership of the hospice appeared to be an enabling feature of the program and a successful strategy for fundraising a portion of their operating expenses. Fundraised dollars were considered essential to program innovation and for addressing community palliative care needs. It was identified in the volunteer hospice program models that private funds allowed for more program flexibility and an improved sense of community ownership, whereas support from ministry was essential for base funding of operations.

The specialist-led program funding was re-allocated from existing budget sources to create the program model, with the exception of palliative medicine physicians' salaries, which were supported through pilot funding. This alternative payment plan for physicians was critical to their ability to offer a comprehensive interdisciplinary palliative care program in the community, with physician integration as an essential component in the care delivery process.

- **Evaluation Strategy**

All of the programs recognized the need to evaluate their programs; however, they were challenged to find the resources to evaluate and to develop the outcome measures that would capture the system of care, as well as the benefits of the program for individual patients and families. The programs recognized the difference that the program made in the lives of individual patients and families and within the region, but they expressed uncertainty as to how to measure this across the program. Many of the participants had personal experiences with the programs in caring for their own dying family members and spoke of not being able to manage without hospice. Other individuals spoke of difficulties they faced trying to access programs in other regions due to the level of fragmentation, in terms of attempting to access services that either did not exist, required additional registration, or had additional program entry eligibility criteria. At the point of care, the fragmentation of district nurses having to contact multiple providers who were not part of a team was described as very disruptive to achieving timely access to appropriate care and influenced the quality of care.

One program described having a continuous quality improvement evaluation strategy that had been developed, but there was a need to develop clinically based outcome measures beyond the number of home deaths in order to evaluate care. This was one area where it seemed there was not enough evaluation expertise or resources dedicated to evaluating program outcomes, both at a regional network level and at point-of-care.

### ***Barriers to Integrated Care Delivery Systems***

Program participants described the lack of a policy framework for palliative care and the lack of recognition of the specialized nature of hospice palliative care as two barriers to program development. In addition, inflexibility and budgetary restrictions of community care access centre service packages were seen as barriers to effective care provision, as was the inability to ensure provider expertise when contracting for services.

### **Summary**

In summary, the hospice palliative care programs that were involved in the focus groups had made significant progress in moving towards integrated care delivery systems using bottom-up innovation (since they did not have the support of a policy framework). The holistic people-related approach used was powerful in mobilizing the strengths of both the informal and formal partners. Collaborative partnerships appeared to be critical to integrating care at the point of care and working together as organizations in a network approach to plan together and build a unified service direction. It appeared that the relationships established between agencies and providers to meet their common goal were foundational to their ongoing development in achieving integrated care. However, these relationships did not just happen. Initial structures such as joint appointments and formal alliances using legal agreements were enablers. In addition, clearly established roles and clarity of the contribution of each service to the whole appeared essential. The programs exhibited most of the key features of integrated care identified in interviews with providers throughout the system. An important finding was that services worked across traditional organizational boundaries to develop integrated hospice palliative care services at the point of care and networks or organizations to support regional planning. The organizations involved in integrating care used many of the strengths observed in

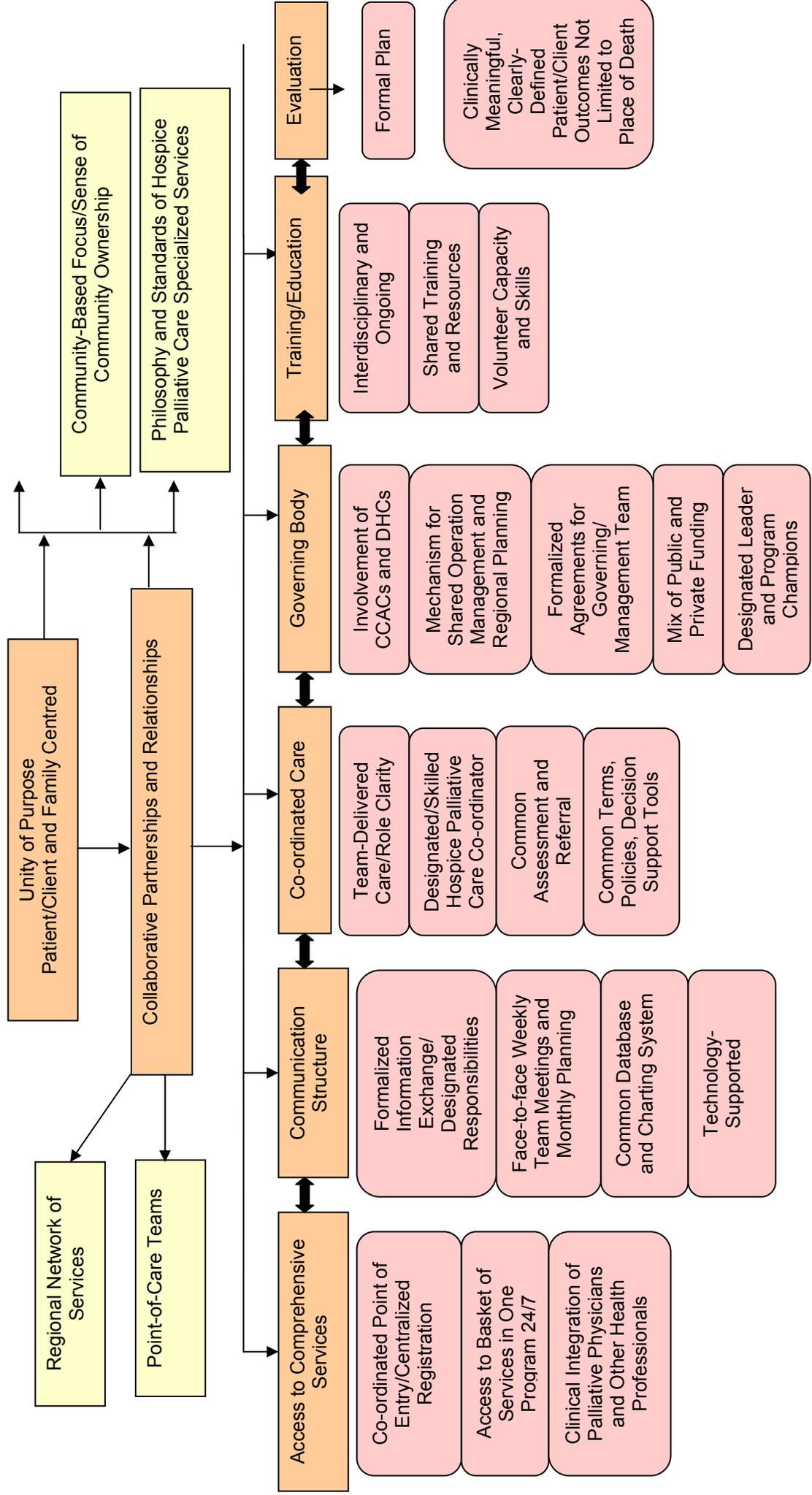
hospice palliative care, such as good communication, the holistic view of patient care, and collaborative working to improve the standards of care for patients and families needing such care.

### **Key Features of An Integrated Hospice Palliative Care Delivery System**

When we triangulated the findings from the different methods, we identified several key system features conducive to a team approach for integrated hospice palliative care in the community.

Throughout this section, the care delivery system will be referred to as the system or system. Throughout this section, the term team refers to an interdisciplinary, multi-agency, multi-sectoral group that includes all people involved in providing hospice palliative care. Members could include some or all of the following: client, caregiver, family, nurse (registered nurse, registered practical nurse, nurse practitioner), personal support worker, physician (family and specialist), volunteer, nutritionist, spiritual advisor/faith community, pharmacist, psychosocial counsellor or psychiatrist, social worker, therapist (physiotherapist, occupational therapist, speech and language pathologist), community care access centre case manager, hospice/day program staff, hospital palliative care unit staff, funeral director, lawyer.

The key features are shown in Figure 1 on the following page. Discussions of the variables are provided on the subsequent pages.



### ***Unity of Purpose***

This refers to the development of mutual goals and expected outcomes that are understood and common among all who provide care. Consideration for the person receiving care that begins with and is directed by the patient/client is the foremost underlying premise for ensuring that patient's/client's wishes and choice are promoted.

- A culture of respect, inclusiveness, and innovation
- Community-based focus and sense of community ownership
- Philosophy and standards of hospice palliative care as specialized services

### ***Collaborative Partnerships and Relationships***

This refers to the blending of roles, responsibilities, and the interaction necessary to build a network of support that releases organizational boundaries.

- Network of services in the region
- Point-of-care team approach

### ***Access to Comprehensive Hospice Palliative Care Services***

This focuses on those factors that increase the ability of those requiring care to receive a full range of services that take into consideration client/patient preference for location, provider, language, and cultural aspects.

- Co-ordinated point of entry/centralized registration
- Access to a basket of services 24/7 upon program entry
- Awareness/marketing and fundraising plan
- Clinical integration of physicians

### ***Communication Structure***

This refers to those factors that facilitate information/knowledge transfer and sharing between all people in the system.

- Formalized information exchange/designated responsibilities

- Face-to-face weekly team meetings and monthly network meetings
- Common database and charting/record system
- Technology-supported communication tools

### ***Co-ordinated Care***

This refers to the factors essential for ensuring care is provided in a manner that ensures harmony and synchronization across agencies and sectors.

- Team-delivered care/role clarity
- Designated/skilled hospice palliative care co-ordinator
- Common assessment and referral
- Common terms, policies, decision-support tools

### ***Governing Body***

This refers to the essential elements of the accountability, planning, and funding structure.

- Involvement of community care access centres and district health councils
- Mechanism for shared program delivery/management and regional planning
- Formalized agreements for governing/management team
- Mix of public and private funding
- Designated leader and program champions

### ***Training and Education***

These factors are important for ensuring that care is provided by those who have expertise and specialized palliative care skills and knowledge.

- Interdisciplinary training programs
- Ongoing education
- Shared training and resources

- Shared high-calibre training for volunteers

### ***Evaluation***

This refers to the assessment of factors necessary to ensure program accountability and success.

- Formal plan
- Patient/client-centred outcomes for evaluation not limited to population-based outcomes, that is, place of death

### **Implementing Integrated Hospice Palliative Care in the Community**

Building upon the model and input from the E-Delphi participants, we then developed central concrete activities that can contribute to developing an integrated model of hospice palliative care in the community. We begin with the model at the broader macro level and work through to the more detailed specific activities required at the point of care. The 15-point implementation plan is listed below (with details of each point provided in Appendix 4).

1. Build a provincial policy framework for palliative care
2. Identify a governance entity
3. Establish a local or regional network
4. Define state of current system/processes in local area
5. Identify future ideal system and processes
6. Establish tools to facilitate integration of regional network partners
7. Generate an effective communication strategy
8. Develop effective working relationships
9. Ensure co-ordinated care
10. Facilitate access and establish a functional entry point
11. Increase the awareness of hospice and palliative care services as a specialty
12. Improve education and training strategies
13. Integrate funding and resources
14. Build strong evaluation strategies
15. Establish a culture and philosophy related to palliative care

## **Conclusion**

The impact of the findings of this research did not end with the completion of the study. The dissemination of the findings is well-timed to coincide with the newly agreed upon charter for hospice palliative care and the formation of local area health networks in Ontario. Most specifically, the 15-point implementation plan will prove beneficial to decision makers at the macro, meso, and micro levels. It is our belief that hospice palliative care clients and their families will be receiving improved care through an improved understanding and implementation of an integrated model of care.

## **Additional Resources**

Canadian Hospice Palliative Care Association

<http://www.chpca.net/home.htm>

Health Canada

<http://www.hc-sc.gc.ca/english/care/palliative.html>

Health Canada Secretariat on Palliative and End-of-life Care  
Workshop Report, 2002 Winnipeg, Manitoba

[http://www.hc-sc.gc.ca/english/care/palliative\\_workshop.html](http://www.hc-sc.gc.ca/english/care/palliative_workshop.html)

National Hospice Palliative Care Associations

<http://www.nhpco.org/i4a/pages/index.cfm?pageid=3741>

Hospice Association of Ontario

<http://www.hospice.on.ca/>

## **Further Research (Gaps in Knowledge)**

1. How do we develop effective integrated models of hospice/palliative care?  
Approach: Develop predictors of effective models through interviews and surveys and then model using path analysis.
2. What does an integrated model cost to run compared with current delivery models? Approach: Conduct a cost analysis and incorporate some actual data with projected data, making assumptions on certain variables in the integrated model.
3. How do we evaluate the provision of hospice palliative care? Approach: Develop quality care indicators through consensus-building literature review and testing. Make user-friendly and applicable to a variety of different organizational contexts and at different levels of delivery — macro, meso, and micro.