



Palliative Care Services Decision- Making: Towards an Understanding of Healthcare Managers' Perspectives

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ABOUT THE PALLIUM PROJECT

The Pallium Project is a strategic initiative focused on facilitating improved access, enhanced quality and additional capacity for Hospice Palliative Care (HPC) within Canada's Primary Health Care Renewal process. In Phase II (2004-06) this has been achieved by focused public investments made possible by the Government of Canada's, Primary Health Care Transition Fund (PHCTF) and through extensive in-kind contributions of time, leadership, creativity and wisdom from many of Canada's most experienced HPC practitioners, scholars and leaders.

The concept guiding the Project is based on idea that *many hands make light work*. The Project functions as a Community of Practice (CoP). Communities of Practice are self-organized, deliberate collaborations of people who share common practices, interests and aims and want to advance their collective domain of knowledge and practice. The Project has evolved beyond its Phase I orientation (2001-2003) as an applied health human resource (HHR) research project in rural health and is currently a *focused capacity-building initiative*.

In late 2003, the Project was awarded \$4.3 million in Contribution Agreement funding from Health Canada's, National Envelope of Primary Health Care Transition Fund (PHCTF). Phase II focused on: 1) outreach education and continuing professional development (CPD), 2) knowledge management and workplace learning supports, 3) collaboration among providers, and 4) initiatives to strengthen service development and the ability of Canada's primary health care systems to respond to emerging demands for quality Hospice Palliative Care. Significant emphasis has been placed on improving supports to health delivery systems and community-based, voluntary-sector partners to improve local/regional capacity and inter-sectoral collaboration consistent with the stated objectives of Canada's Primary-Health Care renewal process.

ABOUT THE *KNOWLEDGE FOR ACTION* OCASSIONAL PAPER SERIES

The *Knowledge for Action* (KFA) occasional paper series was introduced in 2006 to provide Project stakeholders with early access to the results of commissioned work prior to peer-review publication, or work otherwise destined to become difficult to access "grey literature" (i.e., unpublished commercially, see www.greynet.org). The KFA series supports circulation of quality planning information as a practical example of *knowledge translation and exchange*. Practitioners have early access to information for service planning/evaluation and scholars receive the benefit of a formalized channel of early feedback to their community-oriented work prior to final publication in peer-reviewed literature.

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NOTICE ABOUT THIS MONOGRAPH

This occasional paper is a revised edition of a May 2006 monograph that was submitted as part of a commissioned health policy research study conducted and completed by the University of Calgary. This study has received a copy edit, has been reformatted for the *Knowledge For Action* occasional paper series and no material revisions have been made to the study team's original report.

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FOREWORD

In Summer 2002 and Spring 2003, during negotiations of a Letter of Intent (LoI) and an invited competitive proposal to the National Envelope of Health Canada's, Primary Health Care Transition Fund (PHCTF), the leadership group of The Pallium Project made a deliberate strategic choice to move beyond the Project's initial roots of health human resource (HHR), continuing professional development (CPD) and adopted a broader "strategic canvas" of system capacity-building as part of Canada's, Primary Health Care (PHC) renewal efforts.

The initial driver for this approach was rather simple and practical in intent. It was felt if the Project actively developed the knowledge and skills of primary-care professionals in rural western and northern Canada, without commensurate investments in the administrative, standards/quality and service design processes of health delivery systems, the Project would simply be fuelling additional dissatisfaction among primary-care professionals. That is, primary-care providers would know that they could be providing more effective palliative and end-of-life care services in their respective communities, but not necessarily be supported in those processes by their local delivery systems.

At the outset of Phase II (2004-2006), the Project had a clearly defined third thematic stream supporting service and system development. Early into the Phase II implementation process it was clear that there was considerable complexity around how to make change for patients and families in local delivery systems. The messages the Project leadership was receiving from front-line, program coordinator/service delivery leaders was that better care of those experiencing life-threatening and life-limiting illness was generally supported in principle at the executive- and governance-levels of delivery systems, but not consistently translating into suitably designed/resourced services at the local community-level.

In 2004, Dr. José Pereira (Pallium Project co-founder and project leader) felt strongly that the Project needed to engage academic expertise in health policy and systems to help better understand the phenomena of palliative and end-of-life care within delegated authority structures (i.e., regional health authorities, health regions, etc.) and in particular, both rural or mixed rural/urban (i.e., rurban) delegated authorities.

The dominant Canadian model of delegated-authority based, public service delivery¹ has many features of U.S.-style health maintenance organizations (HMOs). Few delegated authorities have well-integrated palliative and end-of-life care service delivery across hospital, home, hospice, long-term/continuing care and settings of marginalization (e.g., street, prison, First Nations reserves). In most instances delegated authorities have not integrated designated hospice setting delivery within their service mix to-date.

To help the Hospice Palliative Care (HPC) community and the Project leadership better understand how decision-making about palliative care service delivery decision making occurs within delegated authority delivery models, the Project commissioned the University of Calgary, Centre for Health and Policy Studies (CHaPS) to undertake an applied policy research study.

From a Project leadership perspective this was a very interesting study to collaborate on as arms-length advisors and navigators of context.

¹ Since the early 1990s, in many Canadian provinces, the constitutional authority for the delivery of health as delegated from the legislature of provinces through an Act of the Crown [i.e., law] and supporting regulations has been implemented through administrative structures with various operational brands such as Health Regions, Regional Health Authorities, District Health Authorities, Local Health Integration Networks, etc. In practice, delegated authority models look, act and feel analogous to many health maintenance organizations (HMOs). Delegated authorities generally provide a comprehensive and defined set of services to a defined population within a defined geographic/administrative catchment and are resourced with population health funded models.

That is, the CHaPS team brought robust applied research process and methodological expertise but were, at the outset, purposefully naïve about Hospice Palliative Care and the Canadian context. As they designed the study they approached the study content from an intentional position of curiosity as “the uninitiated” process experts. It was CHaPS research expertise combined with their content “newness” that made this engagement a particularly useful study for the Project leadership team. Several important insights are worth brief commentary although they are more generally discussed in the text.

First, despite being three years into national model introduction at the time of data collection, there was clear evidence at the delegated-authority level that virtually no health authority senior decision makers studied understood the Canadian model of Hospice Palliative Care as articulated in the CHPCA's *Model to Guide Hospice Palliative Care Based on National Principles and Norms of Practice*. The common language we see used is that of *Palliative Care*, most commonly associated with end-stage cancer care, and in some instances *End-of-Life Care*, with efforts to use language to differentiate/broaden the scope of disease management beyond an end-stage cancer connotation often associated with Palliative Care.

The current understanding of HPC among senior decision makers remains associated with the last days and weeks of life. This finding, if widespread among delegated authority executives, is perplexing because it suggests that the opportunities to more effectively manage decline associated with progressive chronic illness and imminent life-limiting illness remains “a lost opportunity to the system” for Population Health benefits that might otherwise accrue by better integrating the 2002 Hospice Palliative Care model elements within chronic disease prevention and management (CDPM) interventions and bereavement support. That is, broadening the focus on health authority service design to support longer dying processes and bereavement.

The rationale is to approach Hospice Palliative Care as a strategic health system resource which supports sustainability of public-funded health delivery systems by better responding earlier to the needs of not only the person who is dying, but also those family members (however family is practically conceived by the dying person) who are impacted by the dying experience, either through personal health impacts associated with family care giving and/or healthy processing of the loss, both pre- and post-death event.

Simply put, findings of many senior decision makers studied suggests current thinking and service design still generally conceived care of those with life-threatening and life-limiting illness as an end-stage, patient-centred service, thus missing important opportunities to support the health status of the broader family unit, whose members usually (although not exclusively) are populations served with the same RHA's service catchment. This is an important service design consideration as authorities are population-health formula funded, so they have the opportunity to pay a little now to support the family unit (also called “Person-Centred” care), or pay more later in increased chronic disease management and mental-health related costs.

The latter is particularly disconcerting from an economic development and workforce management perspective, because failure to design Hospice Palliative Care for family-focused care can predictably result in increased stress and distress which has a hidden but real economic cost in terms of workforce productivity. This is a matter of growing concern, particularly in western and northern Canada, where effective management of the available labour force has become an urgent and paramount concern in the current policy and economic context.

This study also highlights that there are significant gaps in objectively verifiable indicators about “normal” Hospice Palliative Care service performance. This was reflected in the field work

for this study when discussions about service evaluation were met with responses of concern about “evaluation against what criteria?” Parallel to this study process, community working groups of the Canadian Strategy on Palliative and End-of-Life Care were collaborating with Health Canada and the Canadian Council on Health Services Accreditation (CCHSA) for baseline accreditation criterion in some settings of care for which delegated-authorities are accountable.

It should be disconcerting that some executives report the tabling of “bouquets” (i.e., thank you notes from families) as a default proxy that “we must be doing a good job” in the absence of other measures which are more aligned with key aspects of the Norms of Practice, such as palliative assessment and safe/timely access to pain and symptom management at the community-level.

A somewhat disconcerting picture is also painted in a recognition among senior decision makers that delegated-authorities take “their marching orders” from provincial departments of health, consistent with the constitutional delegation of health service delivery for most Canadians to provincial governments, but largely lack comprehensive provincial Hospice Palliative Care policy frameworks from which to inform service delivery design.

As is noted in the limitations to this study, the delegated-authority subjects who participated in this study are among early leaders in western Canada. That is, participating RHAs self-selected to participate, with many others declining the invitation to participate in this study. So, the study frame for those participating in this study most likely reflects those RHAs who generally feel confident about their palliative care service capacity and were willing to discuss the study questions openly with the researchers.

There are promising early indications that delegated-authorities participating in this study do see provision of services associated with better care of the dying as an important accountability.

It is also somewhat disconcerting that the change drivers we see reported by the senior leaders tend to be solely from local champions within delivery systems and not from the public. The rationale for this is understandable, but not helpful and has been discussed extensively in other vehicles, including the 1995 and 2000 Senate of Canada sub-committee reports (i.e., see *Of Life and Death*).

There is an interesting observation in this study that “society only tolerates one change at a time.” I am not sure that I necessarily agree with this statement. I am increasingly of the view that our society and communities are complex social eco-systems, experiencing deep societal stress and distress from multiple sources and forces, with a natural disposition towards harmonious balance. The universality and irreversibility of dying as an inherent part of the human condition frames dying and death as a core aspect of that broader societal eco-system, with various social, economic, political and community/familial implications. Health service delivery is a key part of the mosaic to support life closure processes in our society.

The big questions that delegated authorities increasingly need to ask, in consultation with provincial governments and citizens, include:

- What should our role be in supporting those experiencing life-threatening and life-limiting illness to achieve optimal health status for all?
- What do we need to do to make that happen?
- Who pays/resources it?
- What supports are useful in those processes?
- How will we know we are doing things right and that these are the right things to do?

This study is an important developmental “snapshot” in an ongoing journey to better understand these kinds of key questions and it provides important insights for moving ahead.

Michael Aherne, M.Ed., CMC
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- Participants of the Pallium Project's, November 2004 Service Development Institute (SDI), who provided input into key questions, study design priorities and facilitated access to the field by furnishing the names of contacts within western and northern Canada health delivery organizations as prospective study participants.
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- Wendy Spragins, who contributed to the final editing and preparation of the report.
- The individuals across western Canada gave freely of their time to participate in one-on-one interviews for this study. It is to them that we are most indebted. Without their participation and insights there would have been no valuable data from the field.
- The Pallium Project, Phase II and Health Canada's, Primary Health Care Transition Fund.

We extend our heartfelt thanks to everyone listed here and to anyone who we may have forgotten. Whereas the study team retains full responsibility for errors or omissions, the ideas contained within this report are those expressed within the rich narrative data obtained from the interviews. Findings from this study should provide The Pallium Project and others involved in advancing the delivery of hospice palliative care with a better understanding of the opportunities and challenges facing health

regions/authorities who are working with their communities to implement palliative care programs across diverse regions. It is our hope that this increased understanding will, in turn, contribute to the realization of many visions of excellent patient and family-centered hospice palliative care.

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Executive Summary

"There are moral and ethical issues around death and dying and how much treatment is enough? The whole – when is the right time to die or is there a right time to die; and the withdrawal of mechanical devices to support life. And those will continue, I think, to be a challenge to society, not just to the team."

Introduction and Background

Since 2001, the Pallium Project has evolved as a strategic initiative focused on facilitating improved access, enhanced quality and additional capacity for hospice palliative care (HPC) within Canada's Primary Health Care (PHC) Renewal framework. A key lesson learned from earlier Pallium Project work is that education alone will not effect change; systems too must be ready to undergo some change to provide the milieu and support structures for optimal Hospice Palliative Care-related service delivery in the community. The study carried out and described here addresses the system readiness component.

The main purpose of this study was to develop a clearer understanding from the perspectives of senior decision-makers/managers of:

- their understanding of palliative care service delivery;
- their understanding of how their regional health authorities are providing palliative and end-of-life care to their constituents;
- the barriers and challenges to developing palliative care programs, including within remote, rural and urban contexts; and,
- opportunities within existing remote, rural and urban service delivery models to incorporate and improve palliative care service delivery (Pereira & Aherne, 2004).

Study Design and Participants

This exploratory, descriptive, qualitative study involved a series of in-depth key referent interviews with senior decision-makers/administrators across western Canada and a parallel series of interviews with "frontline" managers who had direct responsibility for palliative care service delivery. Seventeen participants from eight health regions across the four western Canadian provinces participated in these interviews. All the participating health regions served populations living in rural and remote as well as urban areas. Of these 17 interview participants, eight were senior decision-makers (at the vice-president or executive-director level), whose responsibilities included palliative care, and nine were direct managers of palliative care programs or 'local champions'.

Findings

Key findings from the interviews are summarized under eight emergent headings:

1. Senior decision-makers and direct managers or 'local champions' understanding of hospice palliative care service delivery

Hospice palliative care (HPC) was described by the majority of participants as a term that embodied a philosophy which encompassed an approach to palliative care that transcends settings and estimated time left to live. It was broadly defined as care required by patients to ease their approach to the end of life. HPC was described as based on a philosophy of care that was patient and family-centered and holistic (recognizing the physical, psychological, social, spiritual and practical dimensions of care). Some health regions/authorities are using the term 'end-of-life-care' to describe initiatives where the goal is to broaden the scope of palliative care beyond end-stage cancer care in a particular setting; that is, to move palliative care to a much earlier stage in the disease than the terminal or dying phase, and to all chronic diseases that will

eventually lead to death. Other health regions/authorities are continuing to use the term palliative care or hospice palliative to refer to initiatives that are broader in scope.

2. *Health regions/authorities 'models' of palliative care service delivery*

Senior decision-makers were able to describe in varying levels of detail a model of palliative care service delivery being provided in their respective health regions. All participants described their palliative care services being delivered in a variety of settings with nurses and physicians as the main caregivers. It was clear that there was not one model that could fit all contexts. Most programs were described as based on a philosophy of care that was patient and family-centered and holistic. Many participants spoke about pain control and symptom management as being important components of their programs and areas that required constant vigilance with respect to evolving best practice.

3. *Quality of palliative care programs*

Both senior decision-makers and direct managers discussed areas where they thought their region was doing well, providing examples as evidence. Examples included good reviews on accreditation reports; awards won by the region; and positive feedback from patients and families (often in the form of letters, cards and donations to the palliative care program). No one set of performance measures or quality indicators was mentioned consistently across regions. Rather, this area seemed to be in an early development stage in many regions. Participants emphasized the importance of adequate resources to the provision of quality palliative care. A number of factors contributed to the availability of resources and the quality of the palliative care services. These included the length of time the palliative care program had been in place; the length of time since

regionalization or re-organization of a health region; and the level of provincial resource allocation to healthcare services.

4. *Advancing palliative care service delivery: Networking and useful resources*

One of the strongest themes to emerge through this study was the importance of networking with others working in palliative care within and between health regions to advance the delivery of palliative care services. When asked what resources they had drawn upon when developing their palliative care service delivery, almost all of the participants cited people working in palliative care in other health regions as their major resource. In addition to networking with peers in other health regions working to advance palliative care service delivery, participants described other sources of valuable resources. These included:

- volunteer organizations with well-developed expertise or other resources including funding and education programs (e.g., hospice societies);
- provincial organizations (e.g., BC Cancer Agency, Alberta Cancer Board, Health Quality Council of Alberta);
- multi-province or national organizations specific to palliative care (e.g., The Pallium Project, Canadian Hospice Palliative Care Association); and,
- university-based researchers, to understand best practice.

External or system factors that were sometimes more indirect were used to leverage palliative care program development (e.g., provincial government initiatives such as policy on end-of-life directives and provincial health priorities that included palliative care).

5. *The challenges to palliative care service development and delivery*

The senior decision-makers and direct managers who participated in this study described some of the challenges they experienced in developing and delivering palliative care services. These included:

- providing palliative and end-of-life services in rural and remote areas;
- communication, particularly across large geographic areas and sectors;
- assessing the effectiveness of their palliative care programs, which was difficult in part due to a lack of palliative care performance measures;
- human resources – recruitment, retention and staff development;
- the integration of palliative care services with other health services; and,
- partnering with others to achieve an integrated palliative care program.

Many of the interview participants identified human resources issues as the predominant challenge for the future development of palliative care programs. Areas for improvement that were highlighted and that cut across regions included:

- provision of bereavement care for families as part of the palliative care service continuum; and,
- transcending traditional palliative care models based in oncology/end-stage cancer care settings to encompass broader concepts of palliative care including end-of-life care addressing a range of progressive illnesses.

6. *Opportunities within existing remote, rural and urban service delivery models to improve palliative care service delivery*

Opportunities to improve palliative care flowed directly from the challenges described by the participants. Participants identified a number of supports that would help them advance the delivery of palliative care in their respective health regions. These included:

- increased awareness and discussion at the societal level about moral and ethical considerations related to death and dying; and
- sound leadership and ‘champions’ at multiple levels in healthcare and related systems working to advance change on a number of fronts, including:
 - facilitating more public discussion about death and dying and the concept of a ‘good death’;
 - promoting palliative care as an integral component of a quality healthcare system;
 - palliative care policy development;
 - resource allocation to palliative care programs;
 - palliative care program design, implementation and evaluation;
 - developing palliative care service delivery models that are easily adapted to a variety of rural and remote contexts;
 - developing accompanying performance measures and indicators;
 - education of healthcare providers (undergraduate and continuing education opportunities);
 - working collaboratively with researchers to ensure that gaps in knowledge are addressed; and,
 - working with policy-makers to have input into policy, bring in new funding, etc.

7. *Organizational and system context, structures and processes that affect palliative care service development and delivery*

Manager and senior decision-maker participants shared their perspectives on a variety of organizational and system context, structure and process factors that can positively affect palliative care service development and delivery as follows:

- the visibility of palliative and end-of-life care within the organization;
- the existence of policies and strategic plans related to palliative care services;
- leadership and support for operationalizing the strategic plan;
- the strategic positioning of requests for additional resources for palliative care and aligning with other areas (e.g., chronic disease, home care) to leverage resources; and,
- sources of pressure to provide palliative care.

8. *Engaging stakeholders to deliver hospice palliative care services*

Direct managers and some senior decision-makers described engaging and working with stakeholders to deliver palliative and end-of-life care services to the populations they served. There were a number of strategies described by study participants that health regions/authorities used to engage stakeholders (including family physicians and community hospice care facilities) in their service planning and delivery. The following five strategies were described most frequently:

- Create opportunities for education and/or incentives for healthcare providers (often family physicians) and other stakeholders who were likely to become program champions or leaders in the field.

- Hold conferences, workshops or in-services that increase education and allow networking and exchange of information across sectors (cancer, chronic disease, volunteers, various healthcare providers).
- Create advisory or steering committees to guide program development within the health region – usually with multi-sectoral representation.
- Partner with others to provide services. Partnering was primarily discussed as working collaboratively with other health service areas or programs within a health region.
- Hold community consultations generally at the formative stages of palliative care program development.

Conclusion

Many of the senior decision-makers who participated in this study have a good conceptual understanding of palliative care; can describe at a high level how their health regions were delivering services to their respective populations; and, understand many of the challenges and opportunities facing them as they work to advance palliative care in their regional contexts.

Many times the direct managers, who are also often the local palliative care champions, have an incredible vision about what they want their palliative care programs to look like and are able to articulate this vision well. Their challenging role is to work within their respective, complex health systems and regional contexts to bring this vision to life.

Many, but not all, of the senior decision-makers could see this vision and often played both a supportive and a facilitative role in bringing the vision to life. That is, that a smooth continuum of high quality palliative care services was available and accessible; that these services were provided by well-trained and supported

healthcare providers; and, that the underlying program philosophy was patient and family-centered, holistic care. Continuing to build on what is known about effective knowledge exchange and managing change in healthcare organizations, including the potential of learning and innovating through communities of practice, can help translate more of these visions into reality.

"I think leadership is important. I mean you can have marvelous plans, but unless you can get a leader who can implement it, you're really up against it; so the right personality, knowledgeable, and then walking the talk. I think those are the important qualities; energy doesn't hurt either, and the ability to solve problems."

Key Messages

The health regions/authorities from across western Canada who participated in this study were at the stage of their palliative care program development where they were actively planning, implementing and evolving their palliative care programs. They likely represent better and emergent good practice in palliative care. Regions with no identified palliative care program did not participate in this study. The key messages below, then, reflect this.

Conceptualization: Thinking About It

- The terms most commonly used in practice settings by both senior and middle managers in the participating health regions to describe services provided to people with life-threatening and life-limiting illness are palliative care and end-of-life care.
- The concept and philosophical underpinnings of Hospice Palliative Care were understood by a few of the senior manager and most of the middle manager study participants, but the majority of these health region programs were not labeled 'hospice palliative care' programs.
- Hospice Palliative Care did not appear to be a term that was commonly used in practice perhaps because it is not a term recognized by people outside of the group of health professionals who are intimately involved in the hospice palliative care 'movement.'
- There is clearly an interest in moving palliative care beyond a focus on pain and other symptom management for people with cancer, although this will always remain an important component of palliative care programs. The approach that some health regions are using to expand the focus is to integrate the philosophy of palliative care into what they are calling End-of-Life Care initiatives which in turn are related to Chronic Disease Management initiatives.

Operationalization: Doing it

- The regions who participated in this study view palliative care as an important part of the continuum of healthcare services that they were responsible for delivering to their respective populations. Although there was ongoing planning in many health regions (often to integrate what had been palliative care programs in different health regions into one integrated program across a new larger health region), many health regions had completed their major strategic planning and were actively involved in implementing and continuously improving their programs.
- Palliative care programs, then, were often no longer being viewed as new initiatives, but had been integrated into health systems operations. Palliative care leaders and 'champions' required different kinds of skills to be able to take a strategic plan and conceptual model and operationalize it or put it into action.
- Framing palliative care program development as an organizational change or policy implementation initiative and providing 'local champions' with a variety of strategies that could be used to advance change on the ground might be a good way to go.
- It is apparent that there is no 'one-size-fits-all,' ideal palliative care service delivery model. There appears to be a relatively common conceptual model and philosophy that underpins them all, but how that model and philosophy are operationalized varies between contexts.
- Providing palliative care in rural health regions poses a particular challenge because of the diversity of context. Changing contexts (e.g., re-regionalization) pose unique challenges.

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- Partnering and collaboration with community groups and other stakeholders create both opportunities and challenges. Health regions and community organizations come to the table with different competencies, skills, resources and expectations. Health regions need to blend collaboration with stakeholders with fair business practices and other policies related to contracting. The growing literature in healthcare on partnership, collaboration and networking would be helpful in this regard.
- Client-centered care is described as a key philosophical component of palliative care, yet inviting the perspectives of patients and families into service planning, implementation and evaluation processes is an area that seems less well-developed. There was some realization that this is an area that required additional work.

Evaluation: Evaluating It

- Because people in practice are clearly at the stage where they are trying to implement comprehensive and coordinated palliative care programs that are client-centered and delivered in multiple settings, there is growing interest in evaluating whether the programs are being implemented successfully and whether they are achieving the intended results.
 - Managers providing leadership for palliative care in practice are looking for common indicators they can use to assess the value and effectiveness of their palliative care programs and ultimately whether their programs are meeting the needs of their populations.
 - The emphasis to date has been on utilization or process indicators rather than outcomes. Many palliative care program managers know the services are being well-utilized, but have comparatively little understanding of the effects that the services being provided are having on the patients and families.
 - How can we assess whether palliative care programs are succeeding in addressing the physical, psychological, social, spiritual and practical dimensions of care; and ultimately easing the approach to the end of life for patients and their families?
 - The development of evaluation frameworks including logic models that outline the intended processes and outcomes of palliative care programs, as well as indicators that could be used to assess their attainment, would be helpful to these leaders.

An Emerging Community of Practice (CoP)

- Networking with other people working on the ground is what is really valuable now. There is a desire to talk with people who have done it in similar contexts and who are just one step ahead. This prevents a constant 'reinventing of the wheel'.
 - The networking that people do at provincial and national palliative care conferences and educational sessions would appear to be equally if not more important than the formal sessions that are content-focused.
 - This developing network of practice reflects many features associated with an emerging community of practice as reflected in the literature on communities of practice (Wenger, 1998).
- Knowledge exchange and utilization, with a focus on the development of good collaborative relationships between researchers and palliative care practitioners, appear to be important at this point in the evolution of palliative care service delivery. An emphasis on this kind of knowledge exchange will help to ensure that recent research is used in practice and that practice issues and needs influence research agendas.

Introduction and Background

Since 2001, The Pallium Project has evolved as a strategic initiative focused on facilitating improved access, enhanced quality and additional capacity for Hospice Palliative Care (HPC) within Canada's Primary Healthcare Renewal framework. The Project is based on the idea that *many hands make light work*. It functions as a community of practice (CoP). Communities of Practice are self-organized, deliberate collaborations of people who share common practices, interests and aims and want to advance their specific domain of knowledge (Wenger, 1998).

As a CoP, The Pallium Project links a range of teaching-learning, service/policy development, knowledge management, change management and related collaborative initiatives on tangible short and medium term results which are essential building blocks for longer term sustainability in caring for those with life-threatening and life-limiting illness (Aherne & Pereira, 2005). Collaborators are committed to building on the vision of *Quality End-of-Life Care* for every person in Canada – a vision which assures comfort, dignity and peace of mind; reduces the burden of undue pain and suffering; and supports the health status of all caregivers and the bereaved.

The Pallium Project's initial focus was on improving palliative care in rural and remote areas (Pallium Project, Phase I). This focus has now broadened to embrace the Canadian model of Hospice Palliative Care which was released by the Canadian Hospice Palliative Care Association (CHPCA) in 2002 after a 10 year consensus-building process (Ferris et al., 2002), and includes Hospice Palliative Care service delivery settings associated with Primary Health Care. Respecting a commitment to implement the new Canadian model as part of its Primary Health Care Transition Fund Contribution Agreement with Health Canada (Pallium Project, Phase II), the Project recognizes that quality end-of-life care is required across a range of life-limiting illnesses including cancer; end-stage heart, lung and renal disease; and advanced degenerative neurological illnesses; as well as AIDS, etc.

The provinces studied and a summary of how their health services are administered are outlined in Table 1 below. The three northern Territories are partners in the Pallium Project (Phase II). Because health service delivery is generally achieved through a direct service delivery approach by each of the Territorial governments, and not delegated to health regions, they were not included as participants in the scope of this study.

Table 1: Health Services Administration in Western Canada

Province or territory	Health Services Administration ²
British Columbia	Responsibility of 5 regional health authorities (RHA's), which are further divided into service delivery areas, and one province-wide RHA
Alberta	Responsibility of 9 RHA's, plus the province-wide Alberta Cancer Board
Saskatchewan	Responsibility of 13 RHA's
Manitoba	Responsibility of 11 RHA's

A key lesson learned from the earlier Pallium Project work is that education alone will not effect change; systems too must be ready to undergo some change to provide the milieu and support structures for optimal Hospice Palliative Care related services. Supports required for the development of a Hospice Palliative Care service delivery system, then, must take a dual approach that involves both a service development component and a system readiness component. These two components are described briefly here:

1. Service development involves continued knowledge and skills development for those individuals directing the provision of care.
2. System readiness involves supporting decision-makers to make informed, prudent decisions about the value of Hospice Palliative Care responses and the inclusion

² Administration, for the purposes of this proposal, refers to responsibility for funding and delivering community and institutional health services within a region(s).

of palliative care service delivery in their health programs.

The study carried out and described here addresses the system readiness component. That senior decision-makers play a key role in the development of primary hospice palliative care service delivery was highlighted by participants attending workshops on Hospice Palliative Care service development in western Canada. These workshops, entitled *Putting Progress into Action* (held in June 2004 and Fall 2005 in Atlantic Canada), were delivered in partnership with the Canadian Hospice Palliative Care Association (CHPCA). Workshop participants identified key institutional and administrative-related barriers to hospice palliative care as follows:

- a lack of understanding by senior decision-makers about Hospice Palliative Care;
- a failure of senior decision-makers to recognize the needs of terminally-ill patients;
- an absence of sustainable funding for Hospice Palliative Care services; and,
- an absence or non-implementation of Hospice Palliative Care policy (Pereira & Aherne, 2004).

Project Intent and Scope

In the context described above, the Centre for Health and Policy Studies (CHAPS) at the University of Calgary was approached to provide assistance with this component of Pallium Project (Phase II). The purpose of this study was to develop a clearer understanding from the perspectives of senior decision-makers/managers of:

- their understanding of palliative care service delivery;
- their understanding of how their regional health authorities are providing palliative and end-of-life care to their constituents;

- the barriers and challenges to developing palliative care programs, including within remote, rural and rurban contexts; and,
- opportunities within existing remote, rural and rurban service delivery models to incorporate and improve palliative care service delivery (Pereira & Aherne, 2004).

A secondary intent was to explore any disconnect (pertaining to the four points outlined above) between senior decision-makers and frontline palliative care managers.

Project Significance

The results of this project will be used to inform the development of rural and rurban palliative care delivery in a way that recognizes the unique challenges faced by regional health authorities and other healthcare service providers, as well as the barriers to incorporating palliative care services in rural and rurban areas.

Study Design and Methods

This exploratory, descriptive, qualitative study involved a series of in-depth key referent interviews with senior decision-makers/administrators across western Canada and a parallel series of interviews with frontline managers who had direct responsibility for palliative care service delivery.

Interview participants

Interview participants included Executive Directors and Vice-Presidents (VP's) of health regions from the four western Canadian provinces. A parallel interview process was used. That is, wherever possible, two (or more) persons in each selected health region were interviewed – one a senior decision-maker and the other the regional palliative care coordinator/manager (a 'local champion'). This allowed for the exploration of any confluences and divergences of program development between these two levels as they related to hospice palliative care delivery.

A purposeful sampling strategy (Patton, 1990) was used to identify health regions and individuals to be targeted for participation in this interview process. That is, the health regions and potential interviewees were purposefully selected based on their ability to contribute meaningfully to the aim of this project. One particular type of purposeful sampling that was employed was Maximum Variation Sampling. The health regions from where the interview participants were drawn were purposely selected to obtain a maximum variation of perspectives. The criteria upon which maximum variation was sought were:

- the province within which the health region was located;
- the size of the rural and remote populations within the health region; and,
- the status of palliative care service delivery development within the health region.

A letter inviting participation in this study (see Appendix 1) was sent out by email to this purposeful sample of health regions/authorities from the four western provinces.

Data Collection

These interviews were exploratory with the discussion guided by a semi-structured interview guide (see Appendix 3). As is common in qualitative research, this interview guide did evolve somewhat as the interviews progressed particularly with respect to optimal wording of the questions, sub-questions and probes, as well as the ordering of the questions.

Fifteen interviews were conducted with 17 interview participants – eight with senior decision-makers (at the vice-president or executive director level) whose responsibilities included palliative care services and nine with direct managers of palliative care programs or 'local champions'. On two occasions, the senior decision-maker and direct manager(s) of the palliative care program chose to be interviewed together. The interviews were conducted between September 2005 and February 2006. Twelve of the 15 interviews were conducted over the phone. The interviews took approximately a one hour each to complete, with the actual interview time ranging from 45 minutes to 1.5 hours.

The characteristics of the interview participants are summarized in Table 2. In all, participants from eight health regions across the four western Canadian provinces participated in these interviews. All the participating health regions served populations living in rural and remote as well as urban areas. Five of the eight health regions were responsible for large geographic areas that included sizeable populations living in rural and remote areas. The other three were responsible for large urban tertiary care settings, plus rural areas (i.e., 'rurban' regions). Table 3 provides additional descriptive information on each of the participating health regions.

Table 2: Interview Participants

	MA	SK	AB	BC	Total
Interviews conducted	3	3	5	4	15
Interview participants	3	5	5	4	17
Senior decision-maker participants	1	2	3	2	8
Direct manager ('champion') participants	2	3	2	2	9
Participating health regions	2	2	2	2	8
Health regions that could be described as predominantly rural and remote	1	1	1	2	5

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Table 3: Participating Regional Health Authorities (Health Regions)

	Region 1	Region 2	Region 3	Region 4	Region 5	Region 6	Region 7	Region 8
Geographic considerations	A very large northern geographic region, much of which is remote	A large geographic region, with relatively homogeneous rural farming communities	A major Prairie urban centre	Accessibility of islands, ports, rural areas, some fly-in only access	Predominantly urban, but includes some rural. Responsible for tertiary & quaternary services for a large geographic area.	Geographically large (24 facilities are covered) but less description about urban issues. Predominantly rural.	Large geographic area	Large rural region that includes 80+ communities. Only one urban centre (not quite a city, but not totally rural).
Organizational context	Relatively new region, so service still somewhat fragmented as previous services are still being amalgamated	Relatively recent re-organization, trying to standardize service throughout	Regional program, integrated, community-based, serves about 500 clients at any one time, 1800 per year	Relatively recent re-organization of region. Considerable variation in the services provided across the region. CEO of region wants to move palliative care forward.	Relatively recent inclusion of rural services	Regionalized since 1999, some communities much earlier (e.g., since 1992)	Had 'integrated care' program (incl. volunteers, bereavement) and palliative care program since 1997	Relatively recent amalgamation of smaller regions into one larger region
Administrative responsibilities for hospice palliative care	Executive Director, Home and Community Care, Special projects coordinator	Regional VP with responsibility for palliative care, two palliative care coordinators (PCC) to assess referrals and oversee the Regional program	VP, two program directors, team manager, 3 clinical nurse specialists – 24 hour care, 24 hour accessibility, social worker	Executive director of end-of-life initiative, Director of palliative care with co-medical director	Executive Director responsible for end of life initiative & palliative care, as well as Senior's health, Director hospice palliative care, Medical director hospice palliative care	Housed under Cancer Care Team PCC position created in 2000	Director of Palliative Care Services	Palliative Care Program Leader reports to Vice President Medical

Data Management and Analysis

The interviews were audio-taped and transcribed with both the signed and verbal consent of the informants. As well, notes were taken during each interview as backup for the tape. Neither the names of the interviewees nor the names of their organizations are included in this report in order to protect the anonymity of the interview participants. A qualitative analysis method, Constant Comparative Analysis, was used to identify common themes that emerged within and across the interviews (Glazer & Strauss, 1967; Strauss & Corbin, 1994). Constant Comparative Analysis involves comparing the data to each emerging category and then integrating these categories and their properties into broader themes (Glazer & Strauss, 1967). Qualitative analysis software (QSR – N6) was used to assist with data management and analysis (Meadows & Dodendorf, 1999).

Ethical Considerations

This project was conducted in an ethical manner. It was made clear to potential participants that their participation was entirely voluntary. Written and verbal consent was obtained from all interview participants prior to beginning the interview. This project received expedited ethical approval from the University of Calgary's, Conjoint Health Research Ethics Board. The consent form is included as Appendix 2.

Strengths and Limitations

This qualitative study had both strengths and limitations. A few of the notable ones are described here. An aspect of this study that contained both strengths and limitations was the variation of the sample of interview participants. As was described in the methods section, the intent of this strategy was to purposely select interviewees in order to obtain a maximum variety of perspectives across a few

key dimensions. We intended to achieve this by interviewing participants from health regions/authorities from all four western provinces and by purposively inviting participation from regions that had different combinations of urban, rural and remote populations and were at different stages in their palliative care service delivery development. Strengths were that the interview participants brought perspectives from eight health regions (two from each of the four western provinces) that served quite different populations with respect to the urban and rural and remote mix. A limitation was that the interview participants all came from health regions that could be characterized as having emerging or established good palliative care service delivery. We had no success in entering the field in those health regions that had little or no organized palliative care service delivery.

The rigor of a qualitative study can be assessed by examining trustworthiness (Lincoln & Guba, 1985; Krefting, 1991; Sandelowski, 1993). Another strength of this qualitative study was the strategies used to increase the trustworthiness of the findings. The specific strategies used were reflexivity, member checking and peer review. Analysis of the data being collected began as soon as the initial interview was completed. Reflective memoing was done at the end of each interview and throughout the analytic process. Two analysts (one of whom also conducted the interviews) conducted the preliminary analysis of the data and discussed the emerging findings. The members of the research team contributed during the middle and latter stages of the analysis, bringing a rich diversity and practical expertise to the analytic process. A draft version of the study findings was sent out to all study participants inviting their feedback and this feedback was incorporated into the final draft.

Findings

The findings from the interviews conducted with 17 participants are described below under eight emergent headings.

1. Senior decision-makers and direct managers or 'local champions' understanding of Hospice Palliative Care- informed service delivery

Defining hospice palliative care

Hospice palliative care (HPC) was described by the majority of participants as a term that embodied a philosophy which encompassed an approach to palliative care that transcended setting and estimated time left to live. It was broadly defined as care required by patients to ease their approach to the end-of-life. HPC was described as based on a philosophy of care that was patient and family-centered and holistic (recognizing the physical, psychological, social, spiritual and practical dimensions of care). The way hospice palliative care was defined by participants resonated with the definition of hospice palliative care included in the Canadian Hospice Palliative Care Association's (CHPCA), *Model to guide Hospice Palliative Care based on national principles and norms of practice* (Ferris, et al., 2002) which describes HPC as aiming to 'relieve suffering and improve the quality of living and dying'. (p. 17)

I understand hospice palliative to be a particular philosophical perspective about the delivery of palliative care that involves...well, I know in our initiative, how I use the term is essentially trying to build a hospice philosophy or a palliative care services without the walls of the hospice. That is how I use the term.

All of the participants who worked directly in palliative care were familiar with and described the term appropriately, whereas this was not true of all the senior decision-maker participants. For example, one participant literally described Hospice Palliative Care as care provided in a freestanding hospice.

Participants working directly in palliative care felt that hospice palliative care was not a term commonly used in practice outside of that small circle of people who were active in the hospice palliative care movement. Those working in palliative care clinical services used their terms quite selectively when working with others (i.e., other healthcare providers not working in palliative care and patients – choosing their language carefully, providing definitions if necessary and so on). In practice, the term *Palliative Care* was much more commonly used than Hospice Palliative Care.

One concern expressed was that the use of the term Hospice Palliative Care can perpetuate the view that palliative care is a bed, in that people in the health system who are not intimately involved in the delivery of palliative care can misinterpret the term to mean palliative care provided in a hospice. There was recognition too, however, that palliative care beds in a variety of settings (including hospices) are an important component of a comprehensive palliative care program. There are people who are dying who require access to the kinds of supports provided in a hospice or tertiary palliative care setting. Having palliative care beds ensures that people are not being cared for in less appropriate settings, such as the emergency room or a typical acute care bed.

At what stage palliative care should begin in an illness trajectory was purposely defined flexibly by the majority of the participants with the majority responding that palliative care should begin when the patient and/or their healthcare provider (e.g., family doctor or nurse specialist) request it. A few participants gave a broad timeline (e.g., 'usually less than 6 months), but no hard timelines were noted in the data. There was recognition that psychosocial needs or circumstances might have accelerated a patient's transition to palliative care earlier than when only biophysical needs were considered.

Well, hospice care for palliative reasons is care of individuals at the end point in their life where they no longer require active intervention in the management of their clinical care, but support and treatment of symptoms or their care as they approach the end of life. Usually less than six months, some less than three months. There are some longer term hospices where people may live in them for say up to a year, but in those instances their social situations might not allow them to live independently, but they can still make decisions and they need more of an environmental support. So I think there is sort of the shorter term and the longer term hospice care models.

Other terms being used

Some health regions/authorities are using the term 'end-of-life-care' to describe initiatives where the goal is to broaden the scope of palliative care beyond end-stage cancer care in a particular setting; that is, to move palliative care to a much earlier stage in the disease than the terminal or dying phase, and to all chronic diseases that will eventually lead to death. Other health regions/authorities are continuing to use the term palliative care or hospice palliative care to refer to initiatives that are broader in scope. To illustrate, a typical response to this question was:

What my intent is, is that we will move more to using either hospice palliative care, as a single term, or we will move to end of life. Because really the resources required for all individuals who are dying are not significantly different.

Regardless of what term is used and how broadly HPC is defined conceptually, at the operational level, the majority of patients and families receiving palliative care services are cancer patients who have short life expectancies. One participant commented that this was primarily because of the reality of a limited amount of resources allocated to palliative care.

Managers vs. senior decision-makers

The only difference noted between groups was that managers seemed more aware that terms like 'hospice' or 'palliative' were not uniformly defined and were more concerned that their use of the terms be well-defined if talking with other healthcare providers or, when working with patients, would vary their use of the terms to match the language or understanding of the patients. For example, one manager said:

My colleague and I wanted to get pictures made that said, 'Palliative care is not a bed.' And we still struggle with that. There is the belief, especially from many institutions that when you refer to palliative care, you are referring to a bed.

2. Health regions/authorities 'models' of palliative care service delivery

All participants were able to describe in varying levels of detail a model of palliative care service delivery being provided in their respective health regions. There were some differences between direct managers and senior decision-makers in how they described their health region/ authority's model of palliative care. Senior decision-makers were able to provide an overview of their palliative care program that included a description of the types of healthcare professionals involved in providing palliative care and the range of settings in which this care was provided, as well as where the palliative care program fit into the spectrum of services offered by the health region/authority. Direct managers of palliative care tended to go into more operational details about their programs (e.g., the number of FTE's assigned to the palliative care program and admission criteria for the palliative care program).

All participants described their palliative care services being delivered in a variety of settings with nurses and physicians as the main caregivers. Some of the models of care described, particularly those within health

regions covering large geographic areas that were predominantly rural and remote, relied on frontline staff in a variety of settings to provide direct palliative care with support from palliative care teams playing an expert consulting role. One senior decision-maker described this as a shared care model.

...we believe that all of our staff, nurses, physicians, everybody should have the basic ability or some basic understanding of palliative care...and the consultants that we have are to support the primary caregivers, not replace them...We can't provide specialists for every community. We have to rely on the people that are there to be generalists.

In other programs patients would be assigned to a specialized palliative care home care program. It was clear that there was not one model that could fit all contexts. Most programs were described as based on a philosophy of care that was patient and family-centered and holistic. Many managers spoke about pain control and symptom management as being important components of their programs and an area that required constant vigilance with respect to evolving best practice.

Tertiary palliative care units were described as providing highly specialized care for those patients with the most complex needs, with an emphasis on pain control and symptom management. One area described by some participants as being weak was the bereavement component of their program for family members following the death of their loved one. Key characteristics of the models of palliative care service delivery described by the participants are summarized in Table 4.

Table 4: Palliative Care Model Characteristics

Model Characteristics (as described by participants)	Region 1	Region 2	Region 3	Region 4	Region 5	Region 6	Region 7	Region 8
Model description	Not stand alone, integrated, consultative model with consult available for local service providers 24/7				Specialty palliative care provided in a number of settings. Consultant services to support primary care providers in rural settings (home or hospital).	Early in home patient support, some support and education with home care nurse, limited follow up support in institutions by PCC ³	Moving to 'end-of-life' care model (i.e., to include chronic disease beyond cancer). Includes grief and bereavement (since 1988).	Have two broad levels of care, primary and secondary (consultant nurses and Drs. to support primary care providers). Refer only incredibly complex cases to tertiary palliative care unit in [large city].
Care settings	Cross sector - mental health, acute care, residential facilities, home care nursing	PCC's work with to support palliative care in community - long term facilities, private homes, acute care -anywhere in the Region - 24 hour care not available through home care	In home as much as possible (private, seniors' residences), 2 palliative care units (30 & 15 beds) – 1 in acute care, 1 in long term care, cross sectoral- includes dialysis, cancer	Hospice buildings in various sites, teams to support palliative care in homes	Hospice beds or wings within acute care or long term care settings, includes a tertiary care unit, majority of care is in-home support	2 PCC's – one covers 14 facilities, the other covers 10	PCC, Designated trained team for hospice beds, advanced interdisciplinary team with a broad range of care providers (e.g., occupational or music therapist, social worker), 0.5 Medical Director (physician)	Provided in acute care, long term care, and home settings in many small communities (80+) across a large geographic region

³ PCC = Palliative Care Consultant

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Model Characteristics	Region 1	Region 2	Region 3	Region 4	Region 5	Region 6	Region 7	Region 8
Care providers	Physicians with palliative care skills as program champions, palliative care nursing consultants working with local service providers (e.g., family physicians, home care nurses) to support front line clinical care	Staff in the relevant part of the community – some staff members have extra palliative training		Community physicians with specialized training, multidisciplinary palliative response team that works closely with home care, educators and resource nurses, rely on trained volunteers to supplement care in rural/remote areas	For rural areas have 0.5 physicians specialist and 1.0 clinical nurse specialist, also a telehealth coordinator	2 PCC's – one covers 14 facilities, the other covers 10	PCC, Designated trained team for hospice beds, advanced interdisciplinary team with a broad range of care providers (e.g., occupational or music therapist, social worker), 0.5 Medical Director (physician)	Primary care providers across the Region have been provided with additional training. PCC's provide education sessions, as well as do specialty consults. Volunteers &/or palliative councils in small towns run bereavement programs.
Partnerships/Integration	Provincial Cancer Care, Primary Health Care Models, Chronic Disease (diabetes, chronic heart failure)			Moving to end-of-life care & partnering with chronic disease. Work closely with volunteer hospice society.	Moving to 'end-of-life' and partnering with chronic disease	Work closely with palliative care providers in another region to develop care manuals to assist with education & support (home care, institutions, family Drs.)	Work with chronic disease management, work with smaller institutions to support and/or provide HPC, provide education to multiple levels of providers, work with charitable organizations	Partnerships with family Drs. Collaborating with: Pallium project, Pharmaceutical co's, Victoria Hospice Association, Capital Health Region, Alberta Cancer Board.

3. Quality of their palliative care program

Where they are doing well

All participants discussed areas where they thought their region was doing well, providing examples as evidence. Examples included good reviews on accreditation; awards won by a region; and positive acknowledgement by patients and families (often in the form of letters, cards and donations to the palliative care program). As one senior decision-maker noted, 'we get a lot of thank you letters and stuff like that, so it seems to be working.'

Performance 'measures' and quality indicators

No one or set of performance measure(s) or quality indicator(s) was mentioned consistently across regions. Rather, this area seemed to be in the stages of relatively early development in many regions. This was particularly true with respect to the development of indicators to assess quality-of-care. Some regions looked to other regions and compared themselves to them informally (e.g., 'I would say we are one of the two benchmark programs in Canada.') and/or more formally used other regions' indicators as templates to develop their own. For example, after naming various health regions the respondent had consulted or researched, one participant said:

I will be looking at benchmarking against things like how many tertiary level hospice palliative care beds are available? What are the staffing models that they have? How many hours of care is supplied in those units? Looking at the percentage of secondary resources, like specialized long term care beds. What is the staffing model there? What is the turnover and length of stay? So of those numeric indicators as first benchmarks, I would like to move to quality benchmarks, but we first need to get our continuum in line to do that.

One quality indicator for palliative care programs discussed was the extent of

networking within the region (i.e., how well those providing palliative care within the region could link well with others providing palliative care within the region, or sometimes outside of the region) and how well the palliative care services were integrated with other forms of healthcare within the region. The latter was sometimes referred to indirectly (i.e., lack of integration was seen as an area where improvement was needed). Sample quotes that illustrate this point are:

I think, on the whole, we have a pretty robust program. It's still young; it's about three years old, and I think they have established a team. In fact, they won an Interdisciplinary Team Award from the College of Registered Nurses of [province] this year. So I think that speaks to the interdisciplinary nature of the work...we've got an integrated model, which I think not all places have.

Well, one of the biggest problems has been the disparities...lack of integration with other programs, such as cancer care. We weren't integrated with them. We're still working toward that...And not only just cancer care, but say the AIDS group, the renal group, and really places where people would be surfacing with palliative care services. But we need to all be integrated.

One senior decision-maker described ideal palliative care as being patient-centered:

I think it should be patient-centered; meaning that what the patient wants is important, so you know that the care that is delivered is based on what the patient and their family want – rather than [being based on] the procedures and policies of the institution.

Managers vs. senior decision-makers

Some differences were noted between senior decision-makers and frontline managers in the discussion of indicators of quality palliative care. Senior decision-makers tended to speak

more of system level indicators (e.g., awards, accreditation). When asked about the quality of their palliative care program or services, managers often explicitly described the excellence of service provided by frontline staff or workers or compared themselves more informally to other programs. This was not a strong or consistent difference, but it seems fitting that the groups' outlooks may differ in this regard. Senior decision-makers may look to external evidence of quality – to make a strong case for funding in juxtaposition to, or competition with, other programs, etc. Managers are closer to frontline staff and may still be actively providing care, and are frequently reminded of the importance of this aspect of the work.

We do an annual evaluation and our evaluations have been very, very good. In the accreditation process we got particular mention for our palliative care service... They stated in the summary that palliative care was highly regarded throughout the Region. (senior decision-maker)

I think we do fairly well. When I talk to my colleagues across Canada, and have had the opportunity to do that on several occasions when we've come together. We're pretty lucky in [province] because we have a really extensive home care program. We have things like 24 hour care and we have 24 hour accessibility to palliative care nurses. They go out to the home. Where I don't see that in a lot of the other provinces. That is a big plus; just the kind of resources we have. We are funded pretty well; palliative care is supported as a real priority in this province. (manager)

Participants recognized the importance of adequate resources to the quality of provision of palliative care. Examples were given by those who felt they were well-resourced and those who felt they were under-resourced in terms of funding, leadership and support for the

program; adequately trained, skilled staff; and connectedness with researchers. A number of factors seemed to contribute to the availability of resources and the quality of the palliative care services. These included the length of time the palliative care program had been in place; the length of time since regionalization or re-organization of the health region; and, the level of provincial resource allocation to healthcare services.

It appeared that the longer palliative care had been part of the continuum of services delivered by a health region and the longer the region had been in its current structure, the more likely the participants were to talk about adequate resources and the ability to provide quality services. However, 'length of time' is only indirectly referred to in the data (i.e., there isn't a formal quantitative measure of 'years in current structure' or 'years of palliative care program within the region', etc). Length of time is indicated only qualitatively by description of the region or program.

Regionalization of health services was described as a positive contributing factor to the integration of palliative care services across a range of healthcare settings (e.g., home, continuing care, free-standing hospices, acute care, tertiary care, etc.) by some of the study participants. Senior managers were more likely to view regionalization as a positive contributing factor than frontline managers, but there were some exceptions here. The participants also described aspects of their palliative care programs where they felt there was room for improvement. These are discussed under challenges on pages 29-33.

4. Advancing palliative care service delivery: Networking and useful resources

Networking as a strategy

One of the strongest themes to emerge through this study was the importance of networking with others working in palliative care within and between health regions to advance the delivery of palliative care services. When asked what resources they had drawn upon when developing their palliative care service delivery, almost all of the participants cited people working in palliative care in other health regions as their major resource. All participants spoke of the importance of networking in palliative care as a resource or as a means to build resources. Sometimes they worked together to build resources.

So we have a palliative care manual in the Region that we have developed over time...And one of the pieces we have is pain and symptom management. We look at it about every two years, and we've done this venture pretty well jointly with a gal from another Region, who has a palliative care doctor in her Region. So she reviewed it for us, but it is basically a collection of information from the Pallium program. From doctors that we've met and that we've had through the Pallium. And from going to different in-services [education].

Sometimes they just found out who their contacts would be for more informal sharing of the "in's" and "out's" of operationalizing programs, potentially doing research further down the road. Participants spoke about connecting with other palliative care programs across the country to share knowledge and experience in operationalizing programs from guidelines or theoretical models of care, and connecting with other regions that were dealing with similar issues (e.g., the challenges of providing care in rural and/or remote areas within a health region). A few participants spoke about connecting with University-based

researchers both to influence the direction of future research in this area and to obtain information about 'best practice' in palliative care service delivery and related performance 'measures'.

I have certainly connected with some of the other individuals in similar roles to mine in BC. And have had some discussions with some folk in Alberta. I am waiting to meet with [individual]. I had hoped to meet with her this past weekend at the National Conference, but she wasn't there. So I'm beginning to make connections with individuals, but I have the great benefit of living in a community that has [a university]. [And a history of working] with researchers in various disciplines around issues for seniors and issues in health care in general.

The importance of networking also came up implicitly in the context of providing physicians with extra training in palliative care. One senior decision-maker described the 'formal training' provided to physicians as being just a start – that they were under no illusions that a one-month training program would turn a family physician into a palliative care expert. An important outcome was that the Family Physician consultants had made contacts and they felt free to phone them back for advice.

Local networking was also described as an important strategy for developing an integrated region-wide palliative care program, and that this was particularly important when working to integrate palliative care programs that had been operating as separate programs within health regions that had been amalgamated into one larger region. One of the participants described the relationship building and team building required to operationalize an integrated region-wide palliative care program as very time consuming, but important.

The strategies participants described using to advance palliative care service delivery in their respective health regions included:

- obtaining leadership support for palliative care at upper management levels (e.g., CEO of the region) to encourage adequate resources and/or innovation (e.g., physician education programs or partnering with home care or chronic disease initiatives); and,
- identifying and supporting program champion(s) passionate about palliative care who are strategically ready for opportunities to move palliative care initiatives forward and well-placed to act on them.

And we constantly align everything we do with that [regional priorities]; we also make sure in our planning that we align everything with what is the Region's health plan; what is the province's agenda – very strategic. You know that whining thing doesn't work, it doesn't work...the motherhood and pie thing, everyone can do that; so we try to be very, very strategic. But I firmly believe stars aligned as well, in terms of key people here.

Lesser-resourced regions had local champions who often paid, at their own expense, to increase their education and skills and then shared their knowledge with others locally.

These strategies resonate with what is known about how change is advanced in healthcare organizations, a topic addressed in the *Discussion* section of this paper.

Other sources of valuable resources

In addition to networking with peers in other health regions working to advance palliative care service delivery, participants described other sources of valuable resources. These included:

- volunteer organizations that may have well-developed expertise or other resources including funding and education programs (e.g., Victoria Hospice Society);

- provincial organizations (e.g., BC Cancer Agency, Alberta Cancer Board, Health Quality Council of Alberta);
- multi-province or national organizations specific to palliative care (e.g., The Pallium Project, Canadian Hospice Palliative Care Association); and,
- University-based researchers, to understand best practice.

Networking was used to strengthen the position of palliative care – networking wherever possible to build the case for palliative care, gain or maintain funding – talking to champions or leaders to influence local (regional) policy. It was also important to work collaboratively with local communities so that donations and fundraisers got allocated in such a way as to have the most positive impact on people living in the community who might require palliative care.

I have a feeling that if I came up with a really good idea, and there was support for that idea, we're around the kinds of tables that decisions get made, people nod their heads and say, 'Yeah, that is a really good idea.' It could happen. As opposed to other places, where even if it was a really good idea, and even if there was support for that idea, it might not happen...While in [name of Region], I think there is a feeling that it can happen. If you've got support, if the people who make decisions see that it's something that needs to happen, it seems like in the last few years, the resources can fall into place. And I think that makes a huge difference.

I think this is a growing area and it's a relatively small and specialized area in the overall picture where linkages across the country are good and helpful. So I think as a resource that does help our leaders. I think the interaction with the hospice and palliative care voluntary agencies is good. Yeah, they have been advocates and they also have found their niches in terms of whether

it's supporting bereavement processes, whether it's training, whether it's doing some voluntary work. I think that those are all useful and supportive ways to support a formal program. And I think that, because of the nature of the program and the fact that in Canada it is relatively new and relatively small that the national focus has been particularly-so the leadership from the political level and Senator Carstairs, the ability to communicate with the people and the need that people have to network, because there is not a critical mass in this province. I think those are all important.

There were a few specific resources that were mentioned by a number of the participants as being particularly helpful. These included the palliative care programs within Fraser Health Region in lower mainland B.C., and the Victoria Hospice Society (VHS). The Calgary and Capital health regions in Alberta were also mentioned by participants. All regions tended to be mentioned most by other health regions within the same province, but there was also plenty of evidence of inter-provincial networking taking place. Names of individuals arose within the data, but no single individual stood out as being particularly important; rather, a number of champions were identified.

Enabling contextual factors

External or system factors that were described by some participants as facilitating the development of palliative care programs; that is, they were used as resources to facilitate or further program development. For example, provincial government initiatives (e.g., policies on end-of-life directives; provincial reports on quality of care within long term or residential care facilities; provincial health priorities that included palliative care, etc.) were mentioned as factors that increased the profile or importance of, or the resources allocated to, a health region's palliative care service delivery.

Some of it comes from the provincial table. You know, this is what is going on, but we get notified if things change in the End-of-Life Directive and that kind of stuff. So the legislation piece we are notified of, that we need to keep up with it. And then just being out there in the palliative world, we find out who has changed the definition and that kind of stuff. But we attend different in-services; we just have to make sure that we keep up on what is going on.

Senator Sharon Carstairs served as Minister with Special Responsibility for Palliative Care from 2001 – 2003. The work done by Senator Carstairs, while serving as Government Leader in the Senate in Prime Minister Jean Chretien's Cabinet, was described as contributing to an enabling context for program development. This was described most directly by study participants in Manitoba, Senator Carstairs' home province. Policy and legislation, then, can be a catalyst that energizes and supports change on the ground, although policy in and of itself cannot create the change.

How people network

Participants described the variety of ways in which they networked including connecting with others at conferences or meetings; establishing regular meeting opportunities with people working in palliative care in other health regions (through teleconferences or email list serves); and personally knowing key players in other regions and drawing on their experiences.

We do have a good little network among administrators; we have a list of names and contact numbers for all of us. So that if we have a particular question, we will phone each other and say, 'What do you hear about this and what do you hear about that?'

There is a group of us that have like an administrative email group. [Members are] from Winnipeg, Fraser Health, Vancouver, Edmonton, Saskatoon, Regina. So we all use that in terms of are any of you doing this? How are you doing

that? And then in particular, because the most similar, we work a lot with Capital Health; the palliative care program there. We really try to meet at least once a year. If we are tackling an issue, we are always: 'How are you guys doing? What did you do with this?'

Managers vs. senior decision-makers

Some differences were noted between senior decision-makers and frontline managers with respect to the kind of networking that they described as being most useful. Senior decision-makers were more likely to discuss networking at the meso-level (e.g., networking with cancer care and chronic disease streams within the region or province) or macro-levels (e.g., networking across provinces or using provincial initiatives as system factors to build resources for palliative care).

Senior managers were also more likely to be networking generally across regions and across provinces as these were the circles they travelled in. Senior decision-makers were more focused on policy and creating organizational structures and processes that could enable effective palliative care service delivery. They were also more likely to be looking at contextual factors that they could use to leverage additional resources for palliative care.

Frontline managers were more likely to concentrate their discussion on micro- or individual-level resources to further program development within a region. They would describe, for example, the importance of education to increase skills or provide examples of themselves or other program champions using their own resources to build expertise within a region. Also, although frontline managers have less opportunity to do networking at the meso- and macro-levels described above, they clearly did value and sought out opportunities to connect with frontline managers in other regions and in other provinces who were actively involved in program development.

5. The challenges to palliative care service development and delivery

Providing palliative and end-of-life services in rural and remote areas

A challenge consistently noted by participants was the provision of adequate, integrated services to those in rural and/or remote areas within health regions. For those in rural regions, the challenge of providing consistent services across the region was heightened compared to those in predominantly rural areas. That may be because of an apparent inequitable access to services associated with palliative care for people living in rural and/or remote areas compared to those living in urban areas within the same health region. These participants expressed concern about the need to provide adequate and similar levels of services to patients in rural and/or remote areas.

We have challenges with our rural areas, particularly in the north... where the population is quite small and quite widely dispersed across a geographic area that is challenging. Some of the areas are fly in only, for example. We certainly have those kinds of challenges. So we have resources and services available in most communities for individuals to die in their own homes. We have some residential or community service beds for individuals who are palliative in some of our smaller communities...We haven't yet developed that resource in the south....I'm charged with developing a continuum of service across the Region. Recognizing the challenges with rural and urban issues, as well as the fact that...we will be becoming extremely multicultural here.

Communication was described as an ongoing challenge by managers responsible for operationalizing palliative care program development across large geographic health regions and particularly in those regions that had more recently been formed by bringing together a number of smaller regions.

Communicating across sectors was also described as challenging. One participant, for example, spoke about how healthcare region staff were not aware of an excellent volunteer-provided bereavement program being offered in their community.

Models of palliative and end-of-life care delivery designed to meet the unique challenges inherent in rural and remote contexts were not readily apparent in the data. Most participants (i.e., most health regions represented) were in the early stages of finding solutions to addressing the needs of their populations living in rural or remote areas. They were either in awareness, discussion or planning stages rather than at the stage of implementation and evaluation of solutions. There were a couple of notable exceptions, however. In these regions, the model that was being trialled and seemed to be working well was having the bulk of palliative care services being provided by primary-care providers and volunteers (unpaid care providers) in communities. Both these paid and unpaid care providers were supported by palliative care consultants who generally played two major roles – providing support and direct care when required, often in more complex situations, and providing ongoing education opportunities and training for the frontline providers.

Lack of palliative care performance measures

A number of the participants talked about their lack of knowledge about appropriate indicators that could be used to assess the value and effectiveness of palliative care. For example:

- How does one assess or measure quality of care and service?
- What are appropriate staff levels and mix in different settings?
- What does an evaluation framework for a palliative care program look like?

- Should an assessment of satisfaction with services obtain the perspectives of the palliative patient and/or the family?

None of these participants described doing ongoing evaluations of the quality of their palliative care programs as seen through the patients' eyes. Only one of the participating health regions described routinely collecting satisfaction data from families as part of their evaluation process. A few participants described how they were trying to find or develop indicators by looking at the research literature, talking with researchers and/or connecting with other palliative care programs. The participants did not describe a set of standards commonly known and used apart from accreditation or clinical practice guidelines.

Recruitment, retention and staff development

Another area described as challenging by many of the participants was the recruitment, retention and development of knowledgeable, skilled staff and physicians. The resources required for the education and training of healthcare providers was an area still described by some participants as challenging. Comparing health regions, there was a wide variety of experiences regarding staff development. Some regions paid their staff to acquire this education elsewhere and some provided it in-house.

A number of the participants in this study described using their own resources to take advantage of additional education and training in palliative care. The need for ongoing support of healthcare providers working within palliative care seemed to be an area that was recognized, but not necessarily well-addressed. The ability and willingness of health regions to invest in additional education and training for their palliative care providers and to provide good supports for their staff affected their ability to recruit and retain knowledgeable and skilled people. Contextual factors affected how

health regions tackled this particular challenge as this quote illustrates:

One of the biggest challenges we have is actually being able to engage the resources to support this whole initiative moving forward. So recruitment with the right expertise and knowledge is a challenge. So I think that one of the areas we have to focus on is developing the capacity from within, rather than depending on bringing in someone from the outside. That is one area. I think the other area that is a significant challenge is because of the size of our organization we have to try and ensure that we meet expectations of the clients that we're serving, but in a way where it's reasonable within the limited resources that we have. And to ensure that people do have access to these resources, but in the appropriate settings as well.

Recruiting and retaining Family Physicians to support palliative care service delivery in rural and remote areas could also be challenging, particularly the retaining piece. Sometimes there are structural barriers (inherent in provincial fee payment structures) to paying family physicians as palliative care consultants. One participant described successfully advocating to get a provincial-level policy changed so that their physicians could be paid for their consulting.

There were differences across western Canada with respect to strategies used to recruit, retain and train healthcare providers. These included:

- Provider differences – It appeared that some regions will pay for physicians, but not registered nurses, to attain skills.
- Palliative care program differences – Regions which had developed solid palliative care programs and therefore had a solid base of resources were able to provide more in-house education, increasing their ability to attract and retain highly skilled providers.

- Location differences – It was easier to attract skilled healthcare providers to work in some rural and remote geographical settings than others because of factors that affect quality of life such as climate, travel distances, opportunities for employment for other family members, etc.
- Funding differences – Better resourced regions could afford to provide more opportunities for their staff or hire highly skilled staff.

Many of the interview participants identified human resources issues as the predominant challenge for the future development of palliative care.

Integration of palliative care services

Participants spoke about the integration of palliative care with other health services (e.g., family physicians, chronic disease, home care, long term or residential care, volunteer services or organizations) and the challenges of various forms of 'partnership' or 'collaboration' to share care. Examples of the kinds of collaboration described included teaming up with home care or residential care, or extending collaboration to chronic disease areas such as the renal program. Collaboration is positive because it can increase resources and strengthen positions, etc., but it also poses challenges. This suggests the importance of further developing shared care models, but also being aware that there are both opportunities and pitfalls.

We get into these matrix relationships, which are good and bad...But sometimes they are complicated and it's hard to know who is really in charge and where does the buck stop? But they sometimes allow things to get started in a way that they wouldn't be able to get started. We had two clinical nurse specialists in [region] that work with Home Care and they technically report to Home Care. But they also report, somewhat to us, so there is a bit of dual reporting. Although

their primary reporting mechanism is to Home Care. It's allowed us to have a palliative presence at the advanced practice nurse level in Home Care. Though sometimes the relationship is a bit challenging, in terms of who is responsible for what?

So it's really shared care, partnerships, projects, seed money, those kinds of things.... That has been a challenge, because they are not a homogeneous group.

The budget has grown and I think what we've tried to do is not go back with an argument that palliative care needs to grow and grow. But we've juxtaposed it to resources that already existed. So where there were beds already in hospital and where there was already palliative care, we call them palliative care. Where we've been able to close hospital beds and open a different facility, we've done that and in the home care program, often people in palliative care were already on the home care program. So we have tried to make those liaisons so we don't have every year a big blood bath about how many people can die at home. We have a very large home care program here, and so we use the dollars within that program and then we direct them.

Under the topic of integration, additional issues arose as follows:

- the integration of palliative care services across an entire region with a goal of being able to provide some reasonable level of consistent service to people across a health region;
- the development of integrated, interdisciplinary teams to provide an appropriate continuum of care to individual patients;
- the integration of pre-existing palliative care services in health regions that have been relatively recently formed or re-organized; and,

- the integration of urban and rural/remote palliative care services across a single health region.

The importance of paying attention to historical and other contextual issues when trying to integrate palliative and end-of-life care services across a region was recognized by a number of participants as this next quote illustrates:

....it's trying to be helpful, without sounding like...we're imposing on them, because rural communities are sensitive, social structures that do an awful lot of things very well. And we need to make sure that we're being helpful, without trying to impose a model of care, which may not be appropriate.

Other challenges and areas for improvement

Other challenges and/or areas for improvement described by the participants (both the direct managers and more senior decision-makers) that cut across regions included:

- the need for care for those with life-threatening and life-limiting illness is growing, but resources (especially skilled staff) are not;
- the sheer volume of work for those already working in settings that offer palliative and end-of-life care services;
- the provision of bereavement care for families as part of the palliative care service continuum;
- vulnerability to funding cuts as care for those experiencing an expected death is comparatively small and low-profile;
- inconsistent definitions of palliative and end-of-life care even within a health region and across healthcare providers and patients; and,
 - transcending traditional palliative care models which are based in oncology/end-stage cancer care settings

to encompass broader concepts of palliative care including end-of-life care addressing a range of progressive illnesses.

So I think those are the two major challenges. How does hospice fit into the range of services; and, how much of that is going to be publicly funded? And then how do we move people, as quickly as possible, out of acute care and into a palliative care situation where we think that overall, their level of care can be different and hopefully, better from a palliative point of view. So those are our biggest challenges. There are moral and ethical issues around death and dying and how much treatment is enough? The whole - when is the right time to die or is there a right time to die; and the withdrawal of mechanical devices to support life. And those will continue, I think, to be a challenge to society, not just to the team.

6. Opportunities within existing remote, rural and urban service delivery models to improve palliative care service delivery

The opportunities to improve palliative care flowed directly from the challenges described by the participants. A number of the participants seemed more comfortable describing the challenges more as opportunities for improvement and many (although not all) were optimistic about the future of palliative care. Those participants who were less optimistic described the ongoing lack of discussion at a broad societal level about death and dying in comparison with the interest and discussion in curative medical breakthroughs and medical miracles. Participants identified a number of supports that would help them advance the delivery of palliative care in their respective health regions. These included:

- Increased awareness and discussion at the societal level about moral and ethical considerations related to death and dying such as:

- the right to die, society's responsibilities to maintain life, provide comfort in dying, etc.; and,
- the appropriate balance between levels of funding for palliative care and funding for treating illness and improving, maintaining or promoting health.

It's as important a quality issue as all of those things, is to step back and say, 'We know everyone is going to die. What would we like to have people say about the dying experience in our Region?' and I would hope that most people would say, 'We would want people to say that people in our Region go through end-of-life and the dying process well-supported, with comfort care and able to make the choices that they want and live as well as they can, up until that point.'

- Sound leadership and 'champions' at multiple levels in healthcare and related systems working to advance change on a number of fronts including:
 - facilitating more public discussion about death and dying and the concept of a 'good death';
 - promoting palliative care as an integral component of a quality healthcare system;
 - palliative care policy development;
 - resource allocation to palliative and end-of-life care services;
 - palliative care program design, implementation and evaluation;
 - developing palliative care models that are easily adapted to a variety of rural and remote contexts;
 - developing accompanying performance measures and indicators;
 - education of healthcare providers (undergraduate and continuing education opportunities);
 - working collaboratively with researchers to ensure that gaps in knowledge are addressed; and,
 - working with policy-makers to have input into policy, bring in new funding, etc.

I think we've been very fortunate here in having for the past 30 years, individuals who have provided leadership in palliative care in different forms...One might ask why it took 30 years for a program to evolve? We have done some of that work in home care in the past, but I think we are providing a higher quality of service, now that we're able to meld palliative care practitioners with the home care program. So I think external leaders, locally and then working with other practitioners and society at large to clarify and agree upon what kind of end-of-life care is important.

And I think leadership is important. I mean you can have marvelous plans, but unless you can get a leader who can implement it, you're really up against it. [This senior decision-maker described the following leadership qualities as important]...so the right personality, knowledgeable, and then walking the talk. I think those are the important qualities; energy doesn't hurt either, and the ability to solve problems.

7. Organizational and system context, structures and processes that affect palliative care service development and delivery

Manager and senior decision-maker participants shared their perspectives on a variety of organizational and system context, structure and process factors that affect palliative care services development and delivery. Their views are described under five headings related to the questions that were asked during the interviews to guide this part of the discussions.

'Visibility' of palliative and end-of-life care within the organization

A general trend was that the visibility of palliative and end-of-life care seemed to be growing relatively recently (within the past few years) although there was some variation across regions. The presence of palliative and end-of-life care on the health region/authority org chart or within policy or planning documents was not

described as a reliable indicator of visibility. Those participants who verified that palliative and end-of-life care was visible on organization charts alluded to recent inclusion or inclusion as a very small subsection within other portfolios.

Participants noted that, if palliative and end-of-life care has been operationalized and the focus is on ongoing quality improvement rather than the initial planning, it may not be highly visible (e.g., not on agendas, not highlighted in plans, etc.). For the majority of participants, indicators included the amount of discussion about palliative care at regional or provincial levels, within the community, and in the media; or external recognition such as funding, accreditation, awards, etc. Increased visibility becomes a driver for societal awareness and ultimately citizen engagement.

Our visibility is very high. We got funding back in '96, when there were how many billion dollar cutbacks? So there has been passion and commitment at our Board level, and there has been passion and commitment at our senior exec level...there was support at those strategic levels ...one key person....So I think some of it [support for palliative care] was life experience and knowing there is a differently, plus honestly, as well, this was a way for hospice beds and good palliative and hospice care was also a way to deal with acute care capacity, right?

Planning and policy development

Participants were asked two questions about their health region/authority's policies and planning related to palliative and end-of-life care services. They were asked whether they had a strategic plan specific to HPC or palliative care and whether palliative care was included in their overall region/authority's strategic plan. The trends here are closely linked to the findings on visibility in that regional planning or policy for palliative care plans is often subsumed within the plans for the portfolio that houses palliative and end-of-life care or within the

overall plan for the region. There were some health regions/authorities, however, that were doing major planning in the area of palliative and end-of-life care and either had strategic plans specific to palliative care and end-of-life care and/or they were developing these plans.

There appeared to be a number of contributing factors to the status of palliative care planning in health regions/authorities including the length of time palliative and end-of-life care programs/services had been an identifiable service entity within the region, and the length of time a region had been in its current structure. Some stability in the environment appeared to be a key enabler of palliative care service delivery development. The longer time an identifiable palliative or end-of-life care service entity or region had been in existence, the more likely participants were to place palliative care and end-of-life care 'strategic planning' within the overall health region strategic plan. There were some, but slight differences in senior decision-makers' and managers' discussions about planning. Senior decision-makers tended to speak more about the steps they had taken to create a strategic plan – one that ensured they were well-placed within the region or province.

We did all the work and we got the buy-in, and then the executives, the Board, committed resources towards its implementation.

We have a lot of support. And I think the other reason is we've always had a plan; we've been always very clear, here is our vision, here's our service delivery model, here's our principles, here's our strategic plan. And we constantly align everything we do with that; we also make sure in our planning that we align everything with what is the Region's health plan? What is the province's agenda?

The discussion at the manager level tended to place more emphasis on the programmatic aspects of planning and/or including their staff in 'strategic' planning.

And that is more of a strategic plan. I think, ideally, and what we have done a couple of times in the past, is I have taken our team, our whole team and sat down together and said, 'Okay, as a team, what do we want to do and what are our priorities and what do we see as our strengths and weaknesses?'

Everything we could absolutely think of went into palliative care. We have a palliative care policy; we have a purpose; we have content. We describe the program right down through bereavement and grief to educational support and materials.

Other participants commented about the work required to move beyond the strategic planning process to operationalizing the plan. An underlying theme that emerged from this data was that a good strategic plan did not necessarily equate to a good operating program. This movement from the conceptual to the operational required a different set of skills. As one senior decision-maker commented, 'we were concerned that we had a good program on paper, but not in fact.'

Operational responsibility for palliative care

Most health regions/authorities participating in this study had a palliative care manager or coordinator with direct operational responsibility for palliative and end-of-life care services. One region/authority had a council overseeing this rather than an individual. These individuals with operational responsibility had varied amounts of input into decision-making (putting their plans, ideas forward), but little actual decision-making power. Some of the health regions/authorities participating in this study were primarily still in the planning stage of development for their regional palliative care programs, so operational responsibility for the programs would be expected to evolve.

Resource allocation

Senior decision-maker participants provided the majority of the information collected on the resource allocation processes being used in their respective health regions/authorities. The predominant emergent themes here are that:

- senior decision-makers gather information primarily from the managerial level to make their case for resource requests; and,
- senior decision-makers often use a carefully calculated approach to when they will ask for an increase in resources, either by choosing which years they might ask and/or aligning themselves with another area (e.g., home care).

So we have tried to make those liaisons so we don't have every year a big blood bath about how many people can die at home. We have a very large home care program here, and so we use the dollars within that program and then we direct them. We provide the input from the home care program to direct and case manage. So we've tried to build onto the existing resources and I think that there is a lot of sympathy and empathy for good palliative care. And it hasn't been that difficult to defend if I have the information I need to defend the program. So we've had, I mean I would say a very large increase in the funding available for palliative care, over the last three years. And my strategy is to continue to work with those other programs to minimize fighting and increase allocation.

You don't come all the time, and again, when you come, you have your ducks in order.

Some of the senior decision-maker participants talked about specific criteria or processes used for decision-making (e.g., Programmatic Budgeting and Marginal Analysis - PBMA). Others talked about sitting around the table and discussing and comparing needs across programs. In contrast, manager participants

tended to defer this question to the senior decision-maker, although some would discuss the level at which they had input into the process (usually managers passed information to the senior decision-maker justifying resource requests). How decisions get made is clearly not transparent as the quotes below illustrate:

But I don't sit at that table, so I'm not sure how the decisions get made.

I don't know. [Senior decision maker] would probably be able to answer that question better.

Patient or family input and/or program evaluation findings were notable in their absence as criteria used to inform palliative care resource allocation decisions. Some participants acknowledged this absence.

One of the components of the strategic plan is to undertake some evaluation... I think we should have done, but we haven't done any evaluations yet, but it is part of the process that we are working on at the moment...it's an important part that we have neglected, quite honestly.

When asked directly, participants stated that accreditation results were used in resource allocation decision-making, but this was not raised spontaneously as a criterion to justify resource allocation to palliative and end-of-life care services. Some participants discussed providing administrative data to senior decision-makers to inform resource allocation decision-making processes.

In the context of resource allocation, participants were asked directly if they could approximate the percentage of the overall health region/authority's budget that was allocated to palliative care. None of the participants were able to answer this question. A few participants were able to provide dollar amounts for a palliative care program. Many of the participants stressed that the amount of funding

allocated to palliative care would be impossible to determine precisely as palliative and end-of-life service provision happens across multiple settings and through multiple services (i.e., not just through the budget allocated to a palliative care program).

Sources of pressure to provide palliative care

There were no major sources of pressure identified routinely by participants and few differences between groups were identified. An emergent theme was that participants described pressure primarily coming from those people most intimately affected by death and dying, 'people in the field', palliative care service providers working for or with the health region/authority (e.g., hospices, community physicians) and palliative care patients and their families. There was not much pressure coming from the general public to provide better palliative care. Pressure, especially when discussed in terms of 'the public' or 'community', was equated with 'support for palliative care'. A number of participants described how well-supported the palliative care program was by patients and families. An indicator of this support was the number of donations that the palliative care programs received.

I don't sense a pressure....If anywhere, the pressure comes more from us internally towards government than the other way around....Generally we get fairly positive press. Yeah, most of the time.

I mostly feel pressure from the team, who feel we should do more and better. I think that we've made a big improvement in caring for people at home when they are dying. So right now, I wouldn't say there is a high level of pressure to expand the program, but I think that it's because we're primarily responding to the needs and doing it pretty well; that doesn't mean we can't make more improvements.

A few participants described contextual factors as a source of pressure. Examples included aging of the population, the provincial policy environment and the Canadian Senate reports *On Life and Death* and *Update Of Life and Death* (Senate of Canada, 1995, 2000). The latter was described by a participant from the home province of the Senator chair of the committee who wrote the report. The policy environment was a key structural enabler that could positively impact regional palliative care practice. For example, direct managers of palliative care programs described it being easier to convince senior management to allocate additional resources to palliative care programs if palliative care service delivery was recognized by the provincial government as part of the continuum of healthcare services expected to be delivered to the population.

8. Engaging stakeholders to deliver palliative care services

Study participants described engaging and working with stakeholders to deliver palliative and end-of-life care services to the populations they served. The participants often described the health regions as leading and directing palliative care service planning initiatives although, until quite recently, most palliative care services were provided in the community by the voluntary sector. Care provided in a free standing, independently-governed hospice setting was not part of the continuum of healthcare services funded by some provinces although there was often some partial funding provided.

There were a number of strategies described by study participants that health regions/authorities used to engage stakeholders in their service planning and delivery, including family physicians and community hospice care facilities. The five key strategies described were to:

1. Create opportunities for education and/or incentives for healthcare providers (often family physicians) and other stakeholders who are likely to become program champions or leaders in the field to increase skills in caring for those with life-limiting illness.

Because we are geographically, a large Region, but population wise, we are very small, we get to know most of the physicians particularly well, and as you get to know the physicians, you get to know their interests, their areas of desire. And so we were able to pick out sort of two and approach them and say, 'This is something we would like you to participate with us on. Are you interested? We do have some resources and we recognize how busy you are, and we will try and make your life as easy as possible.' So we spent a lot of time working with physicians to support them to join us in this process. And that has paid dividends.

We've come up with payment schemes for the physicians so they are guaranteed payment; try to support their education needs, anything we can do to support the program...I've authorized payment for internet resources, one for each of them [family physician palliative care consultants]. You know, internet subscriptions.

2. Hold conferences, workshops or in-services that increase education and allow networking and exchange of information across sectors (cancer, chronic disease, volunteers, various healthcare providers). Some of these are regularly scheduled events; some are one-time.

We do an annual palliative day care conference, which we get over 350 people from the Region. That is all we do from all over: home care, continuing care, community care, acute care. Well the conference is around what is our best practice. Updates on best practice, timely topics, those kinds of things. We offer a two day, every

other month, a palliative care education course for interested healthcare professionals.

3. Create advisory or steering committees to guide program development within the health region, usually with multi-sectoral representation.

We amalgamated the steering committee. Then re-formed it and it's a pretty high level steering committee...In many cases, you want hands on people, but I wanted the Region to be very clear on the palliative process. And that is why we wanted the VP's on board to start with. At a more mature committee level, we might move back into staff nurses, social workers, and that kind of thing. Now most of the committee members are at a Director level.

4. Partner with others to provide services (this is partially discussed in other points described in previous sections (e.g., networking, planning and resource allocation above). Partnering was primarily discussed as working collaboratively with other health service areas or programs within a health region (e.g., participants discussed partnering with long term or residential care services or with chronic disease programs, etc.).

One of the things that we recognized very strongly in the North is the fact that we, as an organization, should not be the sole providers of everything that we try and do here. We need to work with very successful, small organizations and partnerships, for them to be part of this whole process. So we recognize the importance of these small, voluntary groups that do wonderful work on a day-to-day basis. And how do we support them to build on the work we also want to do as well? So it's very much a partnership with these small organizations.

I think we could probably never provide enough professional staff to deal with all the issues. We need community support.

5. Hold community consultations generally at the formative stages of palliative care program development. Community was usually represented by healthcare providers groups (nurses, physicians), disease specific groups (e.g., cancer, chronic diseases), and non-profit or volunteer organizations with palliative care interests (e.g., local hospice society).

My intention is to hold a strategic planning workshop for a wide group of individuals, probably in the next month and a half. It would include the clinical individuals currently working in our hospice palliative care areas. It would include our partners. So Home and Community Care, and in the rural areas, I certainly want to include some of the individuals who informally provide palliative care; like the physicians. And I certainly will be including partners from our chronic disease management initiatives, etc. Seniors Health... The universities...so some research, clinical experts. I would like to include some families of individuals who have experienced the death of their loved ones, both at home and in an acute setting. So we've got the perspective of the consumer and the service.

Although community consultation is often discussed in the data, it seems 'community' more often represents healthcare providers, volunteer organizations or other specific disease or service areas. Inclusion of patients or family caregivers as 'stakeholders' or 'partners' was seldom raised. Ongoing effort to engage and partner with physicians was seen both as a way to serve families and learn about the needs of patients and families. That is, physicians were viewed as being able to 'represent' the needs of patients and families in planning processes. Only one-time consultation with patients/families was discussed and resources were directed accordingly. This is well-illustrated in the following quote:

When I spoke with the physician or when I spoke with the sponsors, we felt that in order to make a Regional program work, we needed to partner with the physicians. Because they are providing a lot of the frontline care with patients and families...So we partnered with them and we organized compensation so that they would take part in the planning, and they would get an opportunity to review these policies and how the program worked. And they would be the ones connecting with their colleagues, and taking it out to medical advisory committees, etc. With respect to patients and families, [health region/authority] conducted what we called a community consultation process.

Regular and ongoing program evaluation could be one means of engaging patients and families as stakeholders within settings that offer palliative and end-of-life care, but few participants discussed this as a built in part of the process. One region discussed ongoing evaluation of service in the form of questionnaires sent to families a few months after the patient's death. Often the discussion of patients'/families' input into evaluation was simply absent.

The first thing we have been wanting to do and we've had it ready to go and we're just waiting for some commitment for someone to analyze the data. We are going to do a patient satisfaction [survey]. And we do have an active quality committee. So that is part of what that committee is charged with doing. That evaluation. So we're looking at a number of different indicators; we don't have one large evaluation. Like you would think of an evaluation tool. What we are doing is a number of indicators that we're tracking right now, and we're looking at things like home death rates, for example. Length of stay in the in-patient beds, satisfaction and several others that I can't quite remember. But we look at those each quarter and we look from year to year to see where we're at within those.

Other participants made statements that indicated the importance of patient input to palliative care, but it is not clear how this input was obtained and then used.

You do need to have people advocating for themselves and their family; it's a matter of how well we receive that information and incorporate that. We do need to be able to do that.

Issues For Further Discussion

The regions participating in this study clearly view palliative care as part of the continuum of services they are responsible for providing to their populations. Comprehensive, patient and family-centered palliative care programs are clearly becoming part of the operational world. This means that palliative care champions who in the past have had to focus on advocating for the inclusion of palliative care are requiring a different set of skills to work in this world. This, in part, requires a shift in focus from conceptualization to operationalization and evaluation.

There appears to be increasingly widespread understanding across western Canada of the need for services to address the needs of people with life-threatening and life-limiting illnesses. There are well-developed conceptual models that outline and describe the key components of palliative care such as the *Model to guide Hospice Palliative Care based on national principles and norms of practice*, that was developed by the Canadian Hospice Palliative Care Association (2002). There are also enabling policy environments in many health authorities that support the advance of palliative care service development. Health professionals involved in this service development are faced with operationalizing the conceptual models and implementing regional policy. These are new challenges requiring knowledge and skills in policy implementation specifically and organizational change generally.

Some of the successes and challenges faced by service delivery leaders in their efforts to implement services to address the needs of those experiencing a progressive chronic illness and expected death were described throughout the Findings section of this report. We discuss some of these in this section in the context of emerging knowledge in the area of healthcare organizational change. The first four topics discussed here are broad categories of

competencies that need to be developed to support improved palliative care practices – knowledge exchange and use; organizational change; evaluation; and, patient and family involvement in program planning and evaluation. Two additional challenges concerning aspects of palliative care development that were highlighted consistently by respondents are also discussed.

1. Knowledge exchange and utilization in palliative care

Hospice Palliative Care is at the stage of development where knowledge exchange and utilization is an important issue. A few of the study participants described developing relationships with university researchers so as to get access to current information on best practices in palliative care as well as performance measurement. They also had an interest in collaborating on research in palliative care and/or influencing the type of research being conducted by academic researchers.

We know that communities of practice can be a good mechanism for facilitating knowledge exchange and utilization. The field of palliative care is an emerging community of practice. Wenger (1998) describes a Community of Practice as a group of people who share an interest in a domain of human endeavour and engage in a process of collective learning that creates bonds between them. We know that learning results from interactions between people in the field (practitioners) rather than from the more traditional process whereby a teacher provides knowledge to a learner. Communities of practice can be a driving force for knowledge exchange as they emphasize informal learning processes like storytelling, mentoring and coaching.

The informal networking between people who are working in the health regions/authorities to advance palliative care and the desire to go to palliative care conferences to connect with

others facing similar challenges and/or working in similar settings emerged as an important theme in this study. This is an important time to be considering how this community can continue to be nurtured with an emphasis on enabling these connections between people in the field.

The Pallium Project has long recognized the centrality of learning in building long-term system capacity, noting that changing health service delivery environments demands rethinking of the knowledge and skills leaders require to influence desired change. A broader understanding of where and how learning takes place is essential for enhancing the quality of patient care. The people involved in The Pallium Project describe themselves as an innovative, inter-sectoral community of practice (Aherne & Periera, 2005). As contemporary HPC is an emerging field, the Project's approach to quality assurance is to rely on best practice where it exists, to use clinical consensus where it does not, and to invite collegial participation and peer review (Aherne & Pereira, 2005). This work is enabled through a Community of Practice model.

2. Healthcare organizational change

The strategies that senior decision-makers and direct managers described using to advance program development in their respective regions resonated with what we know about how change can be advanced in healthcare organizations. These strategies included:

- looking out for windows of opportunity and capitalizing on them to obtain additional resources for palliative care;
- seeking out and celebrating small wins; and,
- forming strategic alliances with internal and external stakeholders to advance palliative care service delivery.

We know from recent research in healthcare organizational change that, while it may be generally true that organizations find it difficult to change because of their commitment to existing ways of doing business, clearly there are examples where change is managed successfully. Normative, practitioner-oriented models focus on processes for managing change successfully. Rather than dealing with overall patterns of change, they suggest that there are particular elements or processes that have attention paid to and that they can be found by examining exemplary changes. What are these elements?

They fall into three categories – precipitating, directing and enabling. If we think of an organization facing change, first of all there has to be something that precipitates the need for change. But for change to happen two other elements have to be in place. One is the direction for change to go – people in an organization may feel themselves being encouraged to change, but change into what? And the other element follows on from this. Change may be pressing. We may know what we want to change to. But do we have the attributes that enable us to get there? So any change has to be precipitated, directed and enabled (Greenwood & Hinings, 1996). The development and support of communities of practice can enable learning and change in and across health organizations. In communities of practice the practice-based knowledge of health professionals is co-created, valued and broadly shared (Aherne & Pereira, 2005; Wenger, 1998).

For change to occur in an organization there have to be people who have values committed to bending the frame. There has to be a value commitment to doing things differently – to the new archetype. Anyone responsible for managing change has to be able to assess how far this commitment exists and whereabouts in the organization it is to be found. Of course, a fairly usual situation is that, while there will be

some people committed to new organizational forms, there will be others who are committed to the status quo; that is, a competitive situation (Seo & Creed, 2002).

If palliative care practitioners are to successfully implement or operationalize the new conceptual models and build the decision-making and policy environments necessary to sustain improvement, then learning to change will be a high priority for regional health authorities. Communities of Practice approaches are one tool to enable this learning.

3. Evaluating palliative care services

Many Hospice Palliative Care services have been provided through the voluntary sector for a considerable time, and has only comparatively recently, been formally considered part of the provincially funded healthcare delivery system. Health regions/authorities in this study are clearly at the stage where they are positioning for comprehensive and coordinated palliative care programming that is patient and family-centered and delivered in multiple settings. Palliative care programs, then, are at a stage in their development where there is growing interest in evaluating whether they are being implemented successfully and whether they are achieving intended results or outcomes.

Managers providing leadership for palliative care in practice are searching for common indicators they can use to assess the value and effectiveness of their palliative care programs and ultimately whether their programs are meeting the needs of their populations. The expressed interest in the development of performance indicators and measures is likely related to this state of development of palliative care programs in the context of a healthcare culture that puts a high priority on the 'measurement' of success. The emphasis to date has been on utilization or process indicators rather than outcomes. Many palliative care program managers, then, are able to assess that

the services are well-utilized, but have comparatively little understanding of how to assess the impact palliative care is having on patients and families. How can we assess whether palliative care programs are succeeding in addressing the physical, psychological, social, spiritual and practical dimensions of care; and ultimately easing the approach to the end of life for patients and their families?

The development of performance measures for palliative care is in its infancy. According to a recent systematic review (Adair et al., 2006) done on performance measures in healthcare, the entire field of performance measurement in healthcare is in the early stages of development. This is an area, then, where future applied research would be valuable. The development of evaluation frameworks including logic models that outline the intended processes and outcomes of palliative care programs, as well as indicators that could be used to assess their attainment, would be helpful.

4. Patient and family involvement

There is little indication that patients/families in receipt of palliative care services have been active participants in service planning, delivery and evaluation associated with palliative and end-of-life services. They were most frequently described as grateful service recipients as was evidenced by the volume of thank you cards and gifts including sizeable donations to palliative care programs. Patient and family-centered care is inherent in the conceptual models of hospice palliative care as is illustrated by having the patient and family placed at the center of the model. The integration of the patient perspective into the planning and evaluation of services and into the processes of care at the individual care level, then, is essential. If patients' and families' experiences and expressed needs shape the development and delivery of palliative care services, then their perspectives should be routinely sought and incorporated.

Patients and families who are currently involved with palliative care services and those families who have had involvement in the past can be invited to share their perspectives at multiple times and in a variety of ways including:

- At the program planning and development stage through:
 - participating in needs assessments (e.g., collecting patient and family perspectives through surveys, focus groups and/or town hall meetings);
 - sitting as members of service planning committees; and,
 - participating in the development of evaluation plans (e.g., in the development of evaluation frameworks or logic models).
- At the program evaluation stage through:
 - ongoing quality improvement initiatives (e.g., sitting as members of quality improvement committees, completing satisfaction surveys); and,
 - formative, process and outcome evaluations (e.g., sitting as members of evaluation committees, completing satisfaction surveys, describing experiences with the services in focus groups and/or in in-depth interviews).

Patient and family-centered care was acknowledged by many participants as a central component of the underlying philosophy of palliative care. An important element of patient and family-centered care is the involvement of patients and families in their own care, through:

- actively participating to the degree they are able to and wish to in their own care or their family member's care;
- being invited to share their perspectives and wishes on an ongoing basis; and,
- having access to the information they want on their illness and their care.

5. Differences between rural and remote in comparison with large urban contexts, about the kind of palliative care service delivery model that will work best

The underlying philosophy of Hospice Palliative Care and the conceptualization of the ideal service model may be agreed upon across settings. How this model actually gets operationalized varies between contexts and most certainly between rural and remote in comparison with major urban settings. There is discussion of the challenges of providing care in remote and/or difficult to access areas and a sense within the data that the issues may be similar in some ways to provision of care in rural areas that are not remote, but not quite enough data on this to clearly differentiate the differences and similarities.

The development across the country of primary care initiatives ('Networks') that have as a goal 'increased access to high quality services in an environment of scarce resources' may be one way forward here. In Alberta, palliative care is one of the 16 core services that must be included in the 'comprehensive' list of services these networks are responsible for providing. The development of stronger linkages between existing palliative care programs and primary care/family practice clinics has been identified as the way to provide this service.

Unfortunately these regionally-based palliative care programs are not always available. There are opportunities, however, for these networks to use the added provincial funding for identified priorities like this which may be used for education and human resources. One model being advanced suggests that, rather than dividing work by diseases (e.g., the chronic disease approach like asthma and diabetes clinics, palliative and geriatric programs), it will be necessary for us to divide work by multiple providers within a team. In rural settings, the limiting factors are things like distance, limited

human resources/expertise and the generalist approach that needs to be applied to everything. This newfound support for innovative service delivery models that utilize multidisciplinary teams, computerized information support to enhance continuity and follow-up, and new partnerships with other community resources may be an opportunity to advance Hospice Palliative Care in rural and remote areas that traditionally have not been able to access organized regional palliative services.

Partnering and collaboration with community groups and other stakeholders creates both opportunities and challenges. Health regions and community organizations come to the table with different competencies, skills, resources and expectations. Health regions need to blend collaboration with stakeholders with fair business practices and other policies related to contracting. The growing literature in healthcare on partnership, collaboration and networking would be helpful in this regard. It is important to 'dance with the community', working with community leaders to develop palliative care service delivery models that will work in and across a variety of often unique contexts that comprise large health regions.

6. Broadening the scope of palliative care

The historical development of palliative care has been closely tied to cancer care (Downing & Wainwright, 2006). Much of the expertise around palliative care that the study participants described was related to pain control and symptom management. For example, pain control and symptom management appeared to be the main reasons why a patient would be referred from their home community to a tertiary palliative care centre. Also, much of the professional development or education for health professionals actively working in palliative care outside of major urban centers was described as 'keeping up-to-date' on the latest best practices in pain control and symptom management.

As the philosophy of palliative care is extended to people facing life-limiting illnesses other than cancer through such initiatives as chronic disease management, hospice palliative care and end-of-life care, it is likely that this emphasis on pain control and symptom management will become comparatively less, recognizing that this will always be an important component of palliative care. As was described in the findings, many of the participants described palliative care broadly and holistically, clearly viewing it as more than end-stage cancer care.

In the context of Downing and Wainwright's (2006) 'Blurred Edge Model' of palliative care where four main foci are described (various diseases, stages of illness, ages of patients and locations in which care is provided), these participants generally described their palliative care programs quite broadly across three of the four foci. The exception was age. The age of the patients was rarely explicitly discussed. Palliative care for children, for example, was rarely mentioned and, in many health regions/authorities, seemed to fall under the responsibility of pediatrics or child health rather than a regional palliative care program.

There was usually a difference, however, between how palliative care was defined conceptually and how a palliative care program actually operates. For example, regarding stage of illness and disease, operationally the scope of the palliative program was fairly narrow – people who were at a very advanced stage of their disease and dying, with the majority of patients dying of cancer-related illness. This was not true of location, however, as most of the palliative care programs described encompassed service provision in a variety of locations (e.g., peoples' homes, long term care facilities, hospices, acute care hospital beds, palliative units in hospitals).

There was no single label that managers used to describe programs that went beyond a narrower

conceptualization of palliative care as end-stage cancer care; that is, included care at an earlier stage in the illness process or included care of people with diseases other than cancer. Some health regions/authorities were implementing a broader conceptualization of palliative care by moving their palliative care programs under something they were calling end-of-life care. Others were engaged in promoting the implementation of the hospice palliative care model developed under the auspices of the Canadian Hospice Palliative Care Association (CHPCA). Those managers who were actively involved in implementing this broader conceptualization still often used the term palliative care for their programs and services. Again, this finding is supported by Downing and Wainwright (2006).

Conclusion

Many of the senior decision-makers who participated in this study have a good conceptual understanding of palliative care; can describe at a high level how their health regions were delivering services to their respective populations; and, understand many of the challenges and opportunities facing them as they work to advance palliative care in their regional contexts. Many times the direct managers, who are also often the local palliative care champions, have an incredible vision about what they want their palliative care programs to look like and are able to articulate this vision well. Their challenging role is to work within their respective, complex health systems and regional contexts to bring this vision to life.

Many, but not all, of the senior decision-makers, could see this vision and often played both a

supportive and a facilitative role in bringing the vision to life. That is, that a smooth continuum of high-quality palliative care services was available and accessible; that these services were provided by well-trained and supported healthcare providers; and, that the underlying program philosophy was patient and family-centered, holistic care. Continuing to build on what is known about effective knowledge exchange and managing change in healthcare organizations, including the potential of learning and innovating through communities of practice, can help translate more of these visions into reality.

Finally, there are a few topic areas that were discussed rarely and in very little depth in the context of this study that should not be lost as palliative care service planning and delivery is advanced. These topic areas, when mentioned by participants, were described as being particularly challenging. They include palliative care for children and their families; palliative care for Aboriginal and First Nations people; and, cultural sensitivity in the provision of palliative care.

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**Palliative Care Service Delivery Decision-Making
Towards an Understanding of Healthcare Managers' Perspectives**

Appendix 1

Invitation Letter to Prospective Key Informant Interviewees



FACULTY OF | UNIVERSITY OF
MEDICINE | CALGARY

Centre for Health and Policy Studies

August 5, 2005

Health Sciences Centre
3330 Hospital Drive NW
Calgary, AB, Canada T2N 4N1

T: 403.210-9324

F: 403.210-3818

E: alcasebe@ucalgary.ca

Dear...

Re: Participation in a key referent interview

We are writing to formally request your participation in an interview for the study entitled: *Palliative Care Service Delivery Decision-making - Towards an Understanding of Healthcare Managers' Perspectives*. These interviews are being conducted, as part of a project being undertaken by CHAPS (Centre for Health and Policy Studies at the U of C) for the Pallium Project.

The purpose of this study is to develop a clearer understanding, from the perspectives of senior decision-makers and managers, of:

- how governments and regional health authorities are providing palliative and end-of-life care to their populations;
- the barriers and challenges to developing palliative care programs, particularly in remote, rural and 'rurban' contexts; and,
- the opportunities within existing service delivery models to incorporate and improve palliative care service delivery.

Work done under the auspices of the Pallium Project has informed the development of issues that we would like to explore in interviews with senior decision-makers and managers. The interview questions have been framed so as to stimulate a free-ranging discussion about managers' experiences in planning and delivering palliative care services. Key referents from a sample of health regions across Western Canada have been selected to participate in an interview. You are one of these people.

**Palliative Care Service Delivery Decision-Making
Towards an Understanding of Healthcare Managers' Perspectives**

The results of this study will be used to inform the development of rural and 'rurban' palliative care delivery in the future, in a way that recognizes the unique challenges faced by health regions and builds on what works. These study results will be shared with participating health regions.

Someone from the Centre for Health and Policy Studies will be contacting you about participating in an over-the-phone interview. We expect that this interview will take no more than one hour of your time. If you agree to participate in an interview, we will be asking that you sign and return (by fax) the enclosed consent form. This consent form contains additional information about this study and explains the safeguards put in place to ensure your confidential participation. If after reading over the letter and consent form you have any questions about this project, please don't hesitate to contact either Gail MacKean or myself at (403) 210-8565. Thank you in advance for your willingness to help us learn more about healthcare managers' perspectives on palliative care service delivery planning and decision-making.

Sincerely,

Dr. Ann Casebeer
Associate Director
Centre for Health and Policy Studies
Associate Professor Department of Community Health Sciences

c.c. Dr. Gail MacKean
Encl.

**Palliative Care Service Delivery Decision-Making
Towards an Understanding of Healthcare Managers' Perspectives**

Appendix 2 - Consent Form



FACULTY OF | UNIVERSITY OF
MEDICINE | CALGARY

Centre for Health and Policy Studies

August 2005

Health Sciences Centre
3330 Hospital Drive NW
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E: alcasebe@ucalgary.ca

Title: Palliative Care Service Delivery Decision-making: Towards an Understanding of Healthcare Managers' Perspectives

Sponsor: Pallium II Project [funded by Health Canada's, Primary Health Care Transition Fund]

Investigators: Dr. Ann Casebeer, Dr. Gail MacKean, Dr. Jose Pereira, Dr. Rob Wedel
University of Calgary

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

Study Background

These interviews are being conducted, as part of a project being undertaken by CHAPS (Centre for Health and Policy Studies at the U of C) for the Pallium Project. The primary aim of this phase of the Pallium Project is to increase the capacity of health care professionals, lay community health care workers and communities across rural and remote Western and Northwestern Canada in the provision of primary, hospice palliative care. The Pallium Project is funded through Health Canada's Primary Health Care Transition Fund. The Alberta Cancer Board is the partner responsible as project sponsor and administrative host for Pallium's 40 stakeholder member organizations. The aim of this sub-project or study is to increase knowledge about decision-makers views on palliative care as part of the health care service delivery system, and on how resource allocation and policy decisions impacting the delivery and development of palliative care services get made. This increased understanding will assist the Pallium Project in the development of effective system readiness strategies for palliative care service delivery development.

Study Purpose

The aim of this project is to increase knowledge about decision-makers views on palliative care as part of the health care service delivery system, and on how resource allocation and policy decisions impacting the delivery and development of palliative care services get made. This increased understanding will assist the Pallium Project in the development of effective system readiness strategies for palliative care service delivery development.

Your Participation

We are requesting your participation in a semi-structured, individual interview that will either be conducted face-to-face or over the telephone. If it is being conducted face-to-face, the interview will take place at a location of your choice. It is estimated that this interview will require approximately one hour of your time. Your participation in this interview is voluntary. We are requesting your consent to audio tape the interview. The taping is important, as we want to ensure that we have access to a complete record of everything that you say for analysis purposes. We may also ask your permission to phone or email you about follow-up questions that may arise when we are analyzing the interview data. There are no risks that we are aware of to participating in this interview.

If you agree to participate in this study there may or may not be any direct benefit to you. The information we get from this study, however, will assist the Pallium Project in the development of effective system readiness strategies for palliative care service delivery development. The study results will also be shared with all participating health regions.

Your participation in this study is entirely voluntary, and you may withdraw at any time. Once the interview is underway, you are free to refuse to answer a particular question and/or to stop the interview at any time. You are also free to refuse permission for the study investigators to contact you with any follow-up questions.

You will not be paid for participating in this study. If you incur parking expenses for the interview, then you are able to request compensation from the study investigators.

Privacy & confidentiality

Only the principal investigators and research assistants will have access to the un-analyzed interview data. Unauthorized external or internal access will be prevented by having electronic data stored on computers that are password protected, and that have current virus protection.

Hard copies of transcribed interviews will be kept in locked filing cabinets. All raw data will be disposed of five years after the completion of the project.

The information that you provide through the interview is confidential, in that neither your name, nor the name of your health region, will appear in any of the reports pertaining to this project. Anonymous quotes may be used in the final report to illustrate important points. Only those quotes that do not threaten individuals' or health regions' anonymity will be used.

**Palliative Care Service Delivery Decision-Making
Towards an Understanding of Healthcare Managers' Perspectives**

Compensation

In the event that you suffer injury as a result of participating in this study, no compensation will be provided to you by the Pallium project, the University of Calgary, or the study investigators. You still have all your legal rights. Nothing said in this consent form alters your right to seek damages.

Signatures

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the study and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time. If you have further questions concerning matters related to this project, please contact Dr. Ann Casebeer at (403) 210-9324 or 210-8565.

If you have any questions concerning your rights as a possible participant in this study, please contact Pat Evans, Associate Director, Internal Awards, Research Services, University of Calgary, at 220-3782.

 Participant's Name

 Signature and Date

 Investigator/Delegate's Name

 Signature and Date

 Witness' Name

 Signature and Date

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.

Please return signed consent form to
403-210-3818 (fax)
Attn. - Dr. Ann Casebeer

Appendix 3 – Semi-structured Interview Guide

INTRODUCTION

These interviews are being conducted, as part of a project being undertaken by CHAPS (Centre for Health and Policy Studies at the U of C) for the Pallium Project⁴. The aim of this project is to increase our understanding about decision-makers' views on palliative care as part of the health care service delivery system, and on how resource allocation and policy decisions impacting the delivery and development of palliative care services get made. This increased understanding will assist the Pallium Project (and others) in the development of effective system readiness strategies for palliative care service delivery development.

- Ask if they had any questions about this project, or the consent form
- Confirm that the interview participant understands that our conversation is being taped
- Your name or the name of your health region will not appear in any of the reports describing the findings of this study (other than a general description of the kinds of Regions who participated)
- This is a conversational style interview (common in qualitative research)
- No right and wrong answers to these questions; these questions are just to guide our discussion
- If I ask a question that is unclear, please let me know (don't struggle to try and answer it)
- We are trying to learn from your experience. You are the expert here.
- Check how much time they have for the interview

⁴ The primary aim of this phase of the Pallium Project is to increase the capacity of health care professionals, lay community health care workers and communities across rural and remote Western and Northwestern Canada in the provision of primary, hospice palliative care. The Pallium Project is funded through Health Canada's Primary Health Care Transition Fund. The Alberta Cancer Board is the partner responsible as project sponsor and administrative host for Pallium's 40 stakeholder member organizations.

QUESTIONS⁵

1. How long have you been working in the area of palliative care OR had some responsibility for palliative care services?
Sub-question:
What is your current position in the Region?

2. Are you familiar with the term hospice palliative care? Describe what you understand hospice palliative care⁶ to be? OR Define it for me.
Possible sub-question:
When (in a disease trajectory) do you believe patients benefit from hospice palliative care?

3. How does your region/HA currently provide hospice palliative care services?
Possible probes:
 - Palliative care program
 - Palliative care coordinator?
 - Trained nurses and physicians (do you have a program to educate health care professionals in the provision of hospice palliative care)?
 - Palliative care rooms?
 - How are primary care/family physicians involved?

4. How do you think your region/HA doing with respect to providing hospice palliative care to the population you serve?
Possible sub-questions:
 - What do you think you are doing well?
 - What do you think you are doing less well?
 - Is there consistency (as opposed to variability) across your region?

5. How would you describe the quality of your hospice palliative care services?
Possible sub-questions:
Have you done any benchmarking?
Have you been comparing what you are doing to 'best practices' or any 'gold standard'?

6. What resources or supports have you/your Region used to develop your palliative care services?
Possible probes:
Individuals?
Organizations?
Websites?
Literature?

⁵ If a dual interview approach is proceeded with (i.e., interviewing a senior decision-maker/administrator and a palliative care coordinator/manager in each selected health region), these same questions (with slightly different emphasis in some cases) would be asked of both interviewees.

⁶ The operational definition of hospice palliative care for the purpose of this study is "*care for patients with progressive, incurable illnesses.*" In Canada, a hospice generally refers to a freestanding unit outside of an acute care facility that provides care to patients in their last days and weeks of life.

7. How visible do you think hospice palliative care is in your organization? Explain.
Possible sub-questions:
Is it clearly defined in your organizational chart?
Is there anything about hospice palliative care in your overall organization strategic plan?
Is there a managerial or clinical champion?
8. Does your region/HA have a policy or plan specific to the development and delivery of hospice palliative care services?
Possible sub-question:
How do you feel about this policy/plan?
Are there aspects of your palliative care policy and plan that you think could be better and if so, which are they?
9. Is there a person in this health region who has direct operational responsibility for palliative care?
Possible sub-questions:
How involved is that person in decision-making (re organizational operations, budgeting, etc.)?
10. How do you engage stakeholders (including community members) in discussions about needed support and services?
Possible sub-question:
Have you conducted a palliative care needs assessment?
11. How do you partner with others to provide hospice palliative care services to your population?
Possible sub-questions:
Other sectors?
Family physicians?
12. Do you sense that your region/HA is getting pressure to do more with respect to hospice palliative care in your region? OR is hospice palliative care “on the radar” in your region/HA? If yes, where is this pressure coming from?
Possible probes:
Political pressure?
Public pressure?
Pressure from primary care providers such as family physicians, and others?
Is hospice palliative care discussed when you meet with others at a provincial level?
13. How would you describe the challenges that your Region/HA face in implementing hospice palliative care services?
14. What would help you do more in the area of hospice palliative care? What kinds of supports do you need to move forward?

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Towards an Understanding of Healthcare Managers' Perspectives**

15. Approximately what percent of your Region/HA's budget is currently allocated to hospice palliative care?
Possible sub-questions:
In long term care settings?
In acute care settings?
In community-based settings?
In other settings?

16. How do you make decisions with respect to resource allocation to different programs?
How do you make the business case?
Possible probes:
Do you have a formal process that you use to determine funding priorities (e.g., PBMA; formal criteria)?
Do you/would you look at benchmarking data comparing yourself to other regions?
What about program evaluation data?
What about accreditation?
Where does pressure fit in?

17. Is there anyone else you would recommend we talk to, either in your health region or another one?

18. Is there anything else that you would like to say, that we didn't get a chance to discuss?