



## Select Bereavement Programming in Western Canada and a Discussion of Current Scholarship

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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 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prior to peer-review publication, or work otherwise destined to become difficult to access "grey literature" (i.e., unpublished commercially, see [www.greynet.org](http://www.greynet.org)).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.

## **ACKNOWLEDGEMENTS**

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## **NOTICE ABOUT THE REVISED EDITION**

This occasional paper is a revised edition of a March 31, 2006 monograph that was submitted as part of the local planning support for a bereavement centre in Regina. Efforts have been taken to extend the original investment in monograph completion, by completing a copy edit, incorporating a foreword and offering additional references/planning information of interest to a national audience in order to support use of this paper by others in Canada.

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## FOREWORD

This first of the *Knowledge For Action* occasional paper series is important along three dimensions, namely content, process and symbolism.

In 2002, the Canadian Hospice Palliative Care Association released, *A model to guide hospice palliative care: Based on national principles and norms of practice*<sup>1</sup> (i.e., *CHPCA Norms of Practice*). At the time I suspect few understood how forward thinking that document is, and will be, to design responses for an aging population presenting with a range of chronic progressive illness.

The *CHPCA Norms of Practice* enables issues associated with life-threatening and life-limiting illness to be engaged in ways which are life-, dignity-, and hope-affirming and Population Health-oriented. It reinforces the importance of much earlier involvement in an illness trajectory than has historically been practiced in first-generation (i.e., pre-*Norms of Practice*) palliative care service design. The *CHPCA Norms of Practice* also signals the importance of well-designed, after-death care for survivors by explicitly including bereavement as part of the scope of Hospice Palliative Care in Canada.

To those whose principal service focus is the relief of pain and suffering as part of end-stage, primary-care clinical services, bereavement support may not seem as immediately important. When viewed through the twin lenses of Population Health and sustainability of public-funded health care in Canada, the role of Hospice Palliative Care<sup>2</sup>, including earlier issue engagement and after-death bereavement support is both crucial to the well-being of survivors and strategic in sustaining public-funded health care and private disability insurance/EFAP programs.

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<sup>1</sup> Ferris, F., Balfour, H.M., Bowen, K, Farley, J., Hardwick, M., Lamontagne, C., et al. (2002). *A model to guide Hospice Palliative Care: Based on national principles and norms of practice*. Ottawa: Canadian Hospice Palliative Care Association.

<sup>2</sup> See Ferris, et al. (2002), *Figure 8 – The role of Hospice Palliative Care during illness*, page 18.

In 2006, mental health-related issues became the leading claim cause and cost to disability insurers in Canada (excludes WCB). Field reports which helped to inform the business case planning process for a Regina Bereavement Centre note generic Employee and Family Assistance Program (EFAP) providers are encountering more cases of complicated grief or death-loss associated issues that they are poorly equipped to manage within full-service, generalist EFAP counselling practices.

We are in the earliest days of digesting the importance of well-designed, properly-resourced and functionally-integrated bereavement support as part of robust Population Health<sup>3</sup> strategies. To this end, this work informs longer-term capacity-building in Primary Health Care. Our collective work in this regard does not end with the sun-setting of the PHCTF, rather it signals a beginning.

We have a current generation of adult children, many whom are making it to middle-age without attending a funeral or otherwise having to engage life-loss as part of the human condition. We have a generation of children and young adults, many whose rich relationships with aging grandparents have been nurtured by relatively healthy elders serving substantial child care giving roles, who are poorly prepared for processing loss of said grandparents or others as a learned life-skill. We also have unprecedented, multi-generational cultural diversity within families that blurs established loss-processing practices, co-mingles traditional and modern concepts and results in considerable ambiguity. There is growing indication of confounding factors and societal/familial deficits in the capacity to process death-loss in ways which support health and wellness.

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<sup>3</sup> **Population Health** in Canada is generally defined as seeking to maintain and improve the health status of the entire population and reduce inequalities in the health status between groups/sub-groups. Within the Project the idea of population health is used to better understand the overall health status impact that a life-threatening and life-limiting illness has not only on the individual, but on the circle of family/informal caregivers, friends and communities.

We are also in the early days within the mainstream of understanding the impacts that colonization and institutionalization has had on many Aboriginal people, fueling complex and compounded, unresolved personal, family and community grief. Achieving broader public policy goals, such as interrupting the cycles of extreme poverty and marginalization in many Aboriginal communities, will require creative responses which have to largely be championed by Aboriginal people, but enabled and supported by those with Primary Health Care accountabilities, including the Hospice Palliative Care community.

To this end, this first *Knowledge For Action* occasional paper makes a significant early *content* contribution to bridge theory and practice as it pertains to post-death aspects of the CHPCA *Norms of Practice* in a Canada-specific context.

In September 2000, Canada's First Ministers agreed that improvements to primary health care are crucial. In response the Government of Canada established the Primary Health Care Transition Fund (PHCTF), which is the catalyst of financial support that has enabled the development and publication of this work and the Pallium Project (Phase II), more generally.

The PHCTF has had a focused and strategic emphasis on renewal through new approaches to primary health care delivery. The Fund has supported said work throughout Canada through a series of provincial/territorial and purpose-specific, public investments. The Pallium Project (Phase II) has been funded by a one-time investment from the National Envelope of the PHCTF under a *National Initiatives* category. *National Initiatives* are national in scope, but occur primarily in local or regional settings, focusing on developing skills/capacity of primary health care providers and facilitating greater collaboration<sup>4</sup>.

In this instance, we are witness to collaboration between colleagues at the University of Regina and other community-based collaborators, principally through Regina Palliative Care Inc. (a broad-based, community-based charity) and Regina Qu'Appelle Health Region, Palliative Care Services (the delegated authority for health service delivery). Consistent with the PHCTF *National Initiatives'* intent, others in Canada benefit through this paper from access to a resource with origins in a practical local/regional application.

Collaboration comes in many forms and is desired for many reasons. This KFA occasional paper and others you will find in the series illustrates the kind of collaboration made possible when scholars from academic and academic health sectors make conscious choices to become productively involved to help address and inform the priority needs of their local communities and/or regions.

The authors very kindly make reference at the outset of this paper to scholarly contributions that my colleagues Drs. Wayne Lambie, Bert Einsiedel and I have made about *University-Community Engagement*. This concept is deceptively simple and rooted in old-fashioned "prairie pragmatism." It's Canadian origins date back to early last century and it was "hard wired" into several research-intensive, western and Maritime-region universities as extension or cooperative education. For instance, Henry Marshall Tory, first President of the University of Alberta, noted in commissioning the University's original Extension Department, that: *Many of them [people of Alberta] will never see the place, much less have an opportunity of attending or having their children attend its classes. Yet we want the citizens of the Province to feel that the University belongs to them, that it exists to serve them. The time may come when the existence of a university will depend of the public's assurance that its thinking and research are of vital importance to the community.*<sup>5</sup>

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<sup>4</sup> The reader is directed to Health Canada's web site for additional PHCTF background information ([www.hc-sc.gc.ca](http://www.hc-sc.gc.ca)).

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<sup>5</sup> Page 24. See Corbett, E.A. (1957). *We have with us tonight*. Toronto: Ryerson Press, for a detailed account of the UofA's early contributions to economic development and quality-of-life.

University-community engagement, although not called that at that time of Dr. Tory, is an animating idea that public-funded universities ought to be accountable and productively engaged in addressing priority societal needs of citizens and jurisdictions who are “paying the bills,” through various tax expenditures and public contributions to academic infrastructure and programs.

*Benefits to Canada* criterion and *Knowledge Translation and Exchange* (KTE) initiatives are used to legitimize this policy ideal in public research funding [e.g., see Canada Foundation for Innovation or Canadian Institutes of Health Research (CIHR)<sup>6</sup>]. It has also been discussed as the *Social Accountability of Canadian Medical School's*<sup>7</sup> and has been debated extensively in the United States through the letter-report process of the *Kellogg Commission on the Future of State and Land-Grant Universities*<sup>8</sup>.

On April 16, 2000, the seeds of the Pallium Project were planted when Dr. José Pereira first sat down with Dr. Bert Einsiedel and I over coffee to explore what might be done to address priority continuing professional development (CPD) needs of rural primary-care professionals. Since that day more than a century of university extension tradition has informed the Pallium Project, although this has taken the form of “embedded design” which is largely invisible to stakeholders. That tradition continues through the University of Regina work on bereavement scholarship herein and more generally, through this occasional paper series.

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<sup>6</sup> The CIHR has defined Knowledge Translation as *the exchange, synthesis and ethically-sound application of knowledge - within a complex system of interactions among researchers and users - to accelerate the capture of the benefits of research for Canadians through improved health, more effective services and products, and a strengthened health care system.*

<sup>7</sup> See Health Canada (2001). *Social accountability: A vision for Canadian Medical Schools* (Catalogue No. H39-602/2002). Ottawa: Health Canada.

<sup>8</sup> See, for instance, *Returning to our roots: The engaged institution*. Available at <http://www.nasulgc.org/Kellogg/kellogg.htm>

University-community engagement has been enabled in Phase II through: 1) meaningful HPC *service learning*<sup>9</sup> opportunities for undergraduate and graduate students and recent graduates at formative times; 2) facilitating incentives to align curiosity-driven scholarship with the priority needs of communities; 3) supporting academics by documenting in writing the significance of proposed research for HPC capacity-building in formal letters of support to third-party funding agencies; 4) actively facilitating university-community collaboration; and 5) finding functional, credible vehicles to make the products of scholarly activities more accessible to those who are being charged with implementing “evidence-based” service, program and policy development responses in the field.

The *process* importance underlying this KFA paper and the series it represents, therefore, illustrate several transferable processes that those in academic, service delivery and government roles may choose to model and further adapt. These processes have been explicitly supported as part of Primary Health Care renewal efforts in Canada.

Finally, the *symbolic* importance of this paper should also be noted. For some two decades there has been a “quiet revolution” at North American campuses. The symbolic seeds of this revolution can be traced back to *Scholarship Reconsidered: Priorities of the Professoriate*.<sup>10</sup> In this Carnegie Foundation for the Advancement of Teaching report, Dr. Ernest Boyer called for moving beyond rewarding academics principally upon the Scholarship of Discovery (i.e., what most understand as curiosity-driven, basic research), to a broader vision which acknowledges and rewards contributions to scholarship of Discovery, Integration, Application and Teaching.<sup>11</sup>

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<sup>9</sup> See, for instance, <http://www.servicelearning.org/>.

<sup>10</sup> See, Boyer, E.L. (1990). *Scholarship reconsidered: Priorities of the professoriate*. Princeton, NJ: Carnegie Foundation for the Advancement of Teaching.

<sup>11</sup> See, Braxton, J.M., Luckey, W., & Helland, P. (2002). Institutionalizing a broader view of scholarship through Boyer’s

Those who do palliative care clinical research and teaching intuitively (but not necessarily explicitly) understand this imperative as it applies to access and quality improvement. Many have voiced frustration with institutional disincentives in remuneration and faculty tenure and promotion reward structures within many health science faculties. Many who work in palliative care service delivery also intuitively understand the scholarship of Integration and Application, because of the inherent multi- and trans-disciplinary nature of the work. In HPC this is particularly so because of the primacy of multi-disciplinary teams and of practice improvements derived from application-oriented, evidence generated by clinical and other research studies.

This KFA paper brings into focus much of the current scholarly activity at those points where social science scholarship intersects with life science clinical practice. There has been much early programming leadership in western Canada as well as scholarship in the area of bereavement, including some early exploration of the intersection of bereavement and culture.

What one also sees emerge from a careful read of this paper is a disquieting picture of a growing body of published scholarship which is apparently disconnected from translation into demonstrable service and program development practice improvements. That is, what is being studied and learned is not necessarily making it into practice.

A much better job is required to translate these findings into practice, including demonstrating the Population Health pay-back (or Return on Investment [ROI]) achievable with well-designed "preventative" bereavement programming. This does not necessarily mean delegated authorities (i.e., Regional Health Authority, Health Region, Local Health Integration Networks, District Health Region, etc.), have to directly provide services, but

they are certainly challenged to be active partners in broadly-based, community solutions.

Emerging from this paper we see some good early examples of community-based programming, including many voluntary-sector responses which demonstrate important practical, accountable and operationally efficient ways that community-based voluntary sector organizations complement public-funded, delegated authorities in Canada.

Symbolically then, we see within this first KFA occasional paper a substantial academic *service learning* effort led by an early career person, to support HPC service and program improvement in Canada. This is achieved through a synopsis of bereavement programming in western Canada, including a baseline survey of the landscape, a sense of who early leaders are, what they have been doing and why. This paper also reflects a commitment to help focus and integrate in one place a sense of the current published literature and associated products of the scholarship of Teaching and Application.

This helps otherwise uninitiated practitioners, volunteers and service/community leaders make sense of the early and current scholarly knowledge base in bereavement- and healing-related topics. The paper demonstrates one way to help make current programming activity and literature more accessible to practitioners/volunteers, service/program leaders, and to community-leaders with an interest in improving local bereavement support.

This KFA occasional paper is best considered in conjunction with a companion paper entitled, *Building community capacity: A retrospective of bereavement services in Regina, Canada*,<sup>12</sup> which is also part of the Pallium Project, *Knowledge For Action* occasional paper series.

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four domains. *ASHE-ERIC Higher Education Report*, 29(2). San Francisco: Jossey-Bass, for implementation ideas for the four domains.

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<sup>12</sup> This companion paper is web-accessible in PDF format at [www.pallium.ca/infoware/KFA\\_2006-02\\_BereavementRetro.pdf](http://www.pallium.ca/infoware/KFA_2006-02_BereavementRetro.pdf)

In closing I would like to bring us back to where we proverbially began. In a 1954 biography of Henry Marshall Tory there is a chapter entitled *The University of Alberta*, which describes the 1908 commissioning of the University of Alberta and the catalytic impact of a specific professional group.

The passage goes, *Dr. Tory at once began to prepare a building plan upon which could be based such parts of a permanent structure as were within the reach of the prospective budget. The President and other members of the staff were in constant demand for speaking engagements throughout the Province. Every club and social organization had to be visited. According to Dr. Tory the climax was reached when the undertaker's association asked him to address their annual meeting, the subject suggested being "What the undertakers can do to promote the prosperity of Alberta."*<sup>13</sup>

As we see then, through this paper and the companion retrospective of bereavement services in Regina, scholars can and are returning to their roots with community partners to become purposefully engaged in priority community issues. In turn, we are in the early days of rediscovering those "win-win" opportunities where scholars are finding ways to work with the "community as laboratory" for mutual and mutually-respectful benefit.

It is my hope that readers find cause to celebrate the good early work happening in bereavement programming and scholarship. It is also my hope that in time, this paper may serve as a foundation

and focal point for periodic updates so as to develop a more complete picture of Canadian bereavement program and scholarly activity in support of improved access and quality.

I thank Jill Nutini, a senior undergraduate Arts honours student at the time this work was commissioned, for an admirable early first effort at documenting and discussing bereavement programming and scholarship. I also thank Drs. Mary Hampton and Michael MacLean for their mentorship of Ms. Nutini and the leadership they have generally demonstrated in this and related components of the academic support which has helped inform business planning for the Regina Bereavement Centre. I also thank the people at the various bereavement services and programs in western Canada who agreed to participate in the Activity Profile portion of the work.

Finally, I remind readers that this paper is an illustrative and not exhaustive accounting of bereavement programs and scholarship in one part of Canada. I therefore strongly encourage you to contact the team via the designated contact if you have information for possible inclusion in future revisions/editions.

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November 2006

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<sup>13</sup> Page 103. The reader is directed to Corbett, E.A. (1954). *Henry Marshall Tory: Beloved Canadian*. Toronto: Ryerson Press, for an additional historical account of the foundations of research intensive universities in contributing to economic prosperity and community development/quality-of-life in western Canada.

I personally find this a poignant and relevant historical reference given that it has been funeral home-affiliated community leaders who have played a significant role over the last quarter century in founding and sustaining Regina Palliative Care Inc., a community non-profit organization which has marshalled funds for many of the service delivery innovations which RQHR Palliative Care Services has pioneered, including community-based bereavement programming, spiritual care and music therapy.

## Executive Summary

This working paper presents many existing resources and a literature review about grief and bereavement. It is offered to assist local planners about the current state of knowledge and practice, with a specific western Canadian focus.

The methods used were:

1. a literature search of databases including PsycInfo, Medline and PubMed;
2. a thematically-organized, Canadian-focused literature review of published and review articles about grief and bereavement; and
3. a high-level, activity profile using key informant interviews with senior staff of purposively-selected, existing bereavement services in western Canada. The latter method was used to create a baseline profile of existing services, education/training, funding, resources and sustainability options.

The methods generated baseline information about existing, mission-specific bereavement services in western Canada; sample Canadian resources; an opportunity to discuss recent research on bereavement in a national and international context; recent insights about cross-cultural issues in end-of-life care in a Canada context; and an illustrative sample of Canadian researchers doing related study.

Issues and recommendations about future research and clinical practice are presented as guided to a goal of enhancing quality bereavement services to people in Canada, regardless of ethnicity, culture or creed. The utility of having more evidence to confirm arguments for support of improved access and quality practice, research, education and policy in bereavement is suggested in domains that include:

1. unique needs of culturally diverse populations in Canada;
2. future bereavement services for people in rural and First Nations reserve lands;
3. research and clinical differences of bereavement for those suffering complex losses and those experiencing loss as a part of the life cycle;
4. policy and procedures for quality bereavement practice and protocols at the provincial/territorial and national levels;
5. improved support of collaboration among researchers and practitioners to articulate the links between well-supported bereavement and quality end-of-life care;
6. the role of gender in service participation in bereavement and end-of-life care;
7. the opportunities and challenges associated with community diversity, including the role of diversity in achieving quality bereavement as part of quality end-of-life care; and
8. the challenge to ensure that bereavement services are adequately supported and resourced within health care and social service systems, in order to significantly influence population health.

Addressing these opportunities and continuing challenges will predictably enhance the future impact of bereavement care. Canada has pockets of promising early leadership in practice, research, education and policy development in bereavement and end-of-life care. This occasional paper summarizes some of the strengths and outlines challenges as we take the next step in leadership on these issues.

**Introduction:  
A Review of Bereavement**

This occasional paper presents a review of existing resources and literature on grief and bereavement and offers a baseline profile of the current state of practice developments, models and knowledge. The scope was limited to a Canadian context and particularly western Canada. A principal catalyst for this work was to inform a project development plan for a proposed community-based, bereavement centre in Regina, Saskatchewan. Drawing on insights from our study, recommendations for future bereavement research, clinical practice and continuing challenges are offered.

Bereavement is generally defined in the literature as the state of having lost a significant other to death (Steen, 1998). Grief has been defined as an emotional response to having lost a significant other (Stuart & Sundeen as cited in Youll, 1996). The focus of this review is on both the current research on bereavement and on research that explores the experience of grief that occurs during this state. Support for individuals and family members who are grieving and bereaved has been shown to be helpful (Penson, Green, Chabner & Thomas, 2002; Stroebe, Schut & Stroebe, 2005).

Although bereaved individuals suffering from grief can often be cradled by one's natural support systems (i.e. friends and family), our culture's aversion to dying, death and grief can complicate and worsen the feelings of grief (Stroebe, Hansson, Stroebe & Schut, 2001). An "attitude of denial" often coincides with the refusal to acknowledge and accept death and this can make healing from a loss drawn-out and complicated (Kleepsies, 2004). Often, natural support systems are not enough and an individual may seek professional support services to assist in

healing (Youll, 1996). Many who don't receive initial bereavement support subsequently present with psychiatric problems and others will require medical intervention (Youll, 1996).

It has been estimated that at least approximately ten percent (10%) of bereaved people may benefit from specialized grief and bereavement intervention. This would be based on grief that is assessed as complicated or pathological grief, or grief that is longstanding, debilitating and interferes with ability to carry out activities of daily living (Ellifritt, Nelson & Walsh, 2003). Moreover, research suggests that the effectiveness of bereavement intervention appears to increase the more complicated the grief process is (Bartell & Kissane, 2005, Department of Human Services, 2004; Youll, 1996).

It is important to assess risk and match service, if warranted, to level of need. Failure to complete a well-founded needs assessment may result in professional interventions doing more harm than good, including use of scarce professional resources which may be of little benefit. The importance of assessing risk and matching service to level of need is stressed in the literature (Department of Human Services, 2004; Stroebe et al., 2005; Walsh-Burke, 2000).

In general, the most effective services for bereaved individuals are flexible, timely and responsive to individual needs, since no two people grieve alike (Department of Human Services, 2004). Bereavement centres offer these specialized support services. The Canadian Hospice Palliative Care Association has expanded its conceptual model of *Hospice Palliative Care* to include the continuum of end-of-life care, with bereavement and after-care cited as essential services (Ferris, et al., 2002).

A Bereavement centre in Regina will begin operation in 2006. This Centre will consolidate a range of dispersed services which have evolved since 1988. It will provide a locus and focal point to better coordinate and support independent, community-based resources. As background preparation for this community initiative, members of the University of Regina have conducted this review of existing resources and research in western Canada to contribute to the overall knowledge base of bereavement. This will form the basis for subsequent functioning of the centre in terms of quality services, beneficial programs, operating programs, prospective research directions and sustainability.

### Methodology

For the purposes of this study a targeted literature review was conducted to provide insight into bereavement issues. Special attention was given to Canadian research and literature involving scholars or research with a western Canadian dimension. In many cases this has involved identifying pan-Canadian research activities. The initial search was done using keyword searches on constructs of "palliative care", "terminal care", "death and dying", "hospice" and "end-of-life." The search terms were then combined with the term "bereavement" to further delimit and focus the search. Electronic databases used were PsycInfo, Medline and PubMed. Literature search findings were sorted according to themes. Only published studies and review articles that were relevant to the area of grief and bereavement within a Canadian context were included.

In addition, key informant interviews with senior staff representatives from existing bereavement services operating in western Canada was undertaken using a purposive selection strategy. Simply put, if the research team knew about a bereavement centre or a

significant bereavement programming operation, or was otherwise referred by another party aware of our study, we attempted to contact a senior representative and organize a key informant interview. Information regarding education and training for counsellors, funding, resources and sustainability and the types of services provided at each Centre was collected, reviewed and is presented herein.

### Limitations

Methodological limitations of the literature search and activity profile work include the potential for significant, promising Canadian programming innovations that have not been analyzed because they remain unpublished in academic and professional journals or are part of hard to access "grey literature." Grey literature in the scope of this study includes internal planning documents, operations reviews and other evaluation documents that would be otherwise useful to presenting a more complete, descriptive summary of the Canadian context, but have not been published in indexed, commercial peer-reviewed academic or professional journals.

The activity profile of existing bereavement services in western Canada is also a function of public profile and awareness of existing services and operations. It is possible that promising innovations or existing bereavement programming may have been missed. We offer this limitation based on the reasonable assumption that we as a research team are not be dealing with "perfect information" in awareness of all existing services within our geographic study catchment. This study is intended, however, as a baseline and singular "snapshot" at the time the field work was conducted in late 2005 and early 2006. It is, therefore, presented as an illustrative and not necessarily exhaustive discussion of bereavement programming.

**Conceptual Theoretical Framework**

The concept of university engagement practice described by Aherne, Lamble & Einsiedel (2004) guides our work. We are academic researchers from the University of Regina collaborating with service providers in the community and with the Pallium Project to share our expertise in order to more effectively serve society. Specifically, we have conducted this review of resources with a goal of contributing a picture of the "landscape" of existing bereavement research and resources that inform palliative and end-of-life care delivery in western Canada at this point in time. As a bereavement centre in Regina begins its commissioning year, we draw on the principles of university engagement to support a two-way exchange. Practitioners operating the Regina Bereavement Centre as well as other readers who are stakeholders of the Pallium Project may benefit from this overview. In turn, we as scholars are afforded an opportunity to ground our scholarship for benefit of the community in which we reside.

**Activity Profile Results - Existing Bereavement Centres in Western Canada**

Bereavement centres started to emerge in western Canadian in the early 1980's. Statistics cited by various researchers suggest that mental health effects of bereavement can be debilitating and affect individuals, families, and workplaces. Snyder, Ellison & Neidig (2002), note death is not widely accepted in the average North American's mindset, and "Bereavement may be one of the most difficult and traumatic transitions. Business is not 'as usual' for the bereaved. Those who suffer loss can experience adverse physical, emotional, spiritual, and social sequelae. Most are unprepared for these changes. Many lack knowledge of the grieving process and do not know where to find help or support" (p. 6).

These assumptions coupled with empirical evidence of the effectiveness of bereavement support, have led to establishment of bereavement programs (Snyder, et al., 2002). A recent report released in Australia stated it is estimated that at least eight people for whom a deceased person is significant are impacted by the death. As well, research suggests that the majority of individuals do not require clinical interventions from specialist grief practitioners, but benefit from lower-level community supports such as groups. It is suggested that as many as twenty percent (20%) of persons, however, require and could benefit from specialist care in the form of individual counselling, group programs/ counselling and family counselling associated with complex grief (Department of Human Services, 2004).

The following are western Canadian Bereavement Centres we identified, contacted and with which we conducted key informant interviews. Information describing each centre was gathered through semi-structured telephone interviews. Several of these centres have been operating for many years and make significant contributions to supporting people in the bereavement process. Demand for their services continues to grow and the representatives we contacted have a keen interest in furthering their understanding of bereavement issues, in order to help advance best practice.

### Edmonton Bereavement Centre (EBC)

Operated by Jewish Family Services and Pilgrims Hospice Society, Edmonton, Alberta.

Contact: Carol Kottish-Butt  
Education Co-coordinator  
10339-124 Street, Suite 202  
Edmonton, Alberta T5N 3W1  
Phone 780 454-1231 or [ebc@jfse.org](mailto:ebc@jfse.org)

This small yet renowned centre is funded by Family Community Social Services (FCSS), Edmonton Adult Learners (EAL), the United Way and Jewish Family Services. Carol Kottish-Butt founded the EBC in the mid-1980's. EBC operates under a "donation only" mandate, and does not refuse service if clients are unable to pay.

Clients are assessed by their needs and screened in order to provide either, group or individual counselling. Clients who have additional needs are referred to outside programs/clinicians. Minimum qualifications for counsellors include a degree in Social Work and successful completion of a mandatory, formal training program offered at the Centre. This training includes crisis intervention training, grief education and training in active listening.

Outreach Education includes: Grief and Loss Support for Businesses/Organizations which includes debriefing, overview of loss/grief, review of coping skills and referral to resources; Living with Loss, a community lecture on coping with loss.

The most popular program, *Walking with Grief*, is an 18-hour certificate in bereavement support for professionals and volunteers. EBC also has a Bereavement Lending Library operated by volunteers. Future endeavors include outreach programs to local Aboriginal reserve communities, establishment of more thorough training for volunteers, and development of a full-service web page.

### The Support Network (TSN), Edmonton

Contact: Teresa King  
Program Co-coordinator  
11456 Jasper Avenue, Suite 301  
Edmonton, Alberta T5K 0M1  
Phone (780) 482-0198  
[www.thesupportnetwork.com](http://www.thesupportnetwork.com)

This Edmonton-based centre originated in the 1980's and offers bereavement support for losses associated with suicide. The non-profit, "donation only" centre operates under a "no-refusal", "solution-focused," client-centered model to provide group, one-on-one and walk-in counselling services. Screening and needs assessment is done for every person in need, from walk-in to third party referral.

TSN has a distress line and a community referral line. There are three, 2-tiered, programs offered through both in-centre and outreach: 1) suicide prevention and education intervention; 2) post-loss, suicide bereavement which is conducted in groups and focuses on debriefing and supports; and 3) caregiver support programs which offer networking, resources and support to those caring for a loved-one with suicide ideation. Funding is lacking for this program.

TSN has a publications and lending library. TSN actively incorporates client ideas into programming. Clients have initiated annual marches, fundraisers and Christmas suppers. Volunteers undergo a thorough and formal training process and work primarily on the Distress Line. Future endeavors include establishment of systematic and supported outreach to local and reserve Aboriginal communities.

**Prince George Hospice House and  
Bereavement Centre, British Columbia**

Contact: Jesse Bowen,  
Volunteer Resources & Grief Support  
Prince George Hospice Society  
1506 Ferry Avenue  
Prince George, BC V2L 5N4  
Phone (250) 563-2551  
[www.hospiceprincegeorge.ca](http://www.hospiceprincegeorge.ca)

The Prince George Hospice House and Bereavement Centre now operates as the *Prince George Hospice Society*. The Society has grown considerably and has two locations including Rotary Hospice House. The name of the bereavement centre is Forest Expo House – the Caring Place.

This volunteer-based bereavement centre operates from funding that comes from private, community or corporation donations and fund-raising. Volunteers are trained regardless of formal education and fit is dependent on personality. Informal screening and needs assessment are done prior to admission to any of the programs. Services include “Broken Circle” for adults, for which a fee is required and “Rainbows” which is for children ages 5-14 years (offered at no cost).

Counselling is by donation on a sliding scale. The centre offers an 8-wk group program that focuses on dying/grief education, coping skills and supports. The Forest Expo House – the Caring Place offers brochures, pamphlets and a lending library which are all free of charge. Rural and Aboriginal outreach programs to surrounding reserves are not currently, nor anticipated to be, near future endeavours of the Centre.

**Calgary Health Region (CHR) Grief  
Support Program**

Contact: Rev. Bob Glasgow,  
Head of Spiritual Care  
c/o Rockyview General Hospital  
7007 14<sup>th</sup> Street, S.W.  
Calgary, AB T2V 1P9  
Phone (403) 943-3533  
[www.calgaryhealthregion.ca/scs/](http://www.calgaryhealthregion.ca/scs/)

The Grief Support Program (GSP) is located at the Rockyview General Hospital but functions as a separate bereavement centre. Reverend Bob Glasgow started the GSP in 1985 in response to an apparent need for bereavement services in acute care settings. The Centre’s principle source of funding is from community-based sources of Government of Alberta lottery/gaming revenue. Funding remains a constant challenge, even though today it is reported that the centre is more financially secure. Centre leaders stress the importance of fund-raising to sustain the centre when there no external resources have been available.

Currently, the GSP has four part-time counsellors, qualified at the graduate degree-level, either in Social Work or Psychology. Volunteers are placed with staff and assist in group therapy. Many volunteers are former clients of the GSP or are palliative care nurses. These volunteers bring compassion and an experiential knowledge base to the work of the centre.

The GSP currently helps approximately 1,000 clients with complicated grief through closed-group therapy and one-on-one counselling. Approximately 12-15 people attend closed-group programs once a week for 6 weeks. These groups are organized into categories of loss: Loss of Children, Loss of Siblings, Loss of Parents and Loss of Young Spouses.

The majority of clientele include those that have experienced a sudden death, those referred from the palliative care unit and third-party referrals from psychologists in private practice. The centre also has a lending library for clients and provides an educational piece called "How to Care, What to Say" for healthcare providers.

Practicum students have been accepted at the centre for 15 years and this program has successfully encouraged many social work and psychology students to continue providing end-of-life care services. Future endeavours of the centre include hiring a full-time educator to develop and deliver educational programs and material and also developing a second centre in Calgary.

### **Hospice Calgary Society, Outreach Centre**

Contact: Sarah Walker, Executive Director  
833- 4th Avenue SW  
Calgary, Alberta T2P-3T5  
Phone (403) 263-4525  
[www.hospicecalgary.com](http://www.hospicecalgary.com)

Hospice Calgary has been in operation for over 20 years. Rosedale Hospice provides 24 hour palliative care services for cancer patients with advanced illness and the Society operates a free-standing bereavement centre called the Outreach Centre. The society provides service to over 1,800 people per year. Fund-raising and special events enabled the Centre to operate. Family Community Social Services (FCSS) and major donations from corporations also provide funding. Donations for services from clients are made on a sliding-scale.

The Outreach Centre provides bereavement services in both anticipatory and sudden death grief to both in-patient and outreach clients. People in need of services are generally referred by other agencies, but the

Centre maintains an "open-door policy," meaning service is rarely declined. Self-referrals, third-party referrals, family members of past families that received services, schools, health regions, etc., are accepted.

The Outreach program specializes in services for bereaved children and youth through groups programs, trauma work and summer camps. There is short and long term counselling for adults and parents. All counselling groups are led by masters' degree level prepared facilitators with special training in bereavement. Facilitators are assisted by volunteers with extensive training in specific areas of bereavement.

The Centre offers education and training workshops for teachers, guidance counsellors, community professionals. It runs a week-long trauma course for professionals interested in working with children and youth. The Centre offers a telephone bereavement support program, a Day Hospice Program and a lending library. Some 120-200 trained volunteers provide services annually. The Centre has intakes of practicum students from universities and participates in research studies as a community collaborator/partner.

### **Victoria Hospice Society, Bereavement Services (British Columbia)**

Contact: Wendy Wainwright, Manager,  
Counselling and Spiritual Care Services  
1952 Bay Street  
Victoria, BC V8R 1J8  
Phone (250) 370-8715  
[www.victoriahospice.org](http://www.victoriahospice.org)

Victoria Hospice Society was founded in 1980. It provides palliative care clinical services and bereavement services as a community partner agency of the Vancouver Island Health Authority (VIHA). It also operates a respected regional education and training centre.

The Bereavement Services Program provides care to families and persons of significance to the deceased up to one year post-death. The bereavement program has 90-100 volunteers trained in grief awareness and communication. Volunteers do random telephone check-ins, provide clerical support, assist in groups and entirely oversee "Walking Groups." Counsellors are master's degree level trained in Social Work, Psychology, Child & Youth and are supported in their own educational pursuits while employed at the Centre.

The bereavement program has been mainly funded by donations and other active fundraising. Programs and services are either free, on a sliding-scale or cost-recovery fee-based. The Program is referral-based, but rarely denies "walk in" self-referrals. The Bereavement Program carries 200-300 new clients (clients who have lost loved ones that were not on Victoria Hospice's palliative care patient roster).

There is generally a needs assessment prior to a death event. The Centre uses the BRAT (Bereavement Risk Assessment Tool). Prospective clients can drop-in, phone their crisis line or be referred for service.

Bereavement programs include "Men's Bereavement Group", "Parent and Children's Groups", "Young Widows Group", "Walking Groups", "Bereavement Support Group", "Journal Group", "Saturday Night Social Group" and "Wednesday Drop In Group". The Centre provides grief support pamphlets/handouts and professional one on one counselling. The Program provides instructional presentations on grief and bereavement. The bereavement counsellors have a list of recommended bereavement educational resources and books on the website.

The bereavement office produces a quarterly bereavement newsletter called *The Four Seasons*. The Bereavement Services Program also has a research component.

As part of its educational mission, VHS has supported its staff in the publication of professional materials, including a major Canadian professional book with a bereavement focus entitled *Transitions in dying and bereavement: A psychosocial guide for hospice and palliative care* (Victoria Hospice Society, Cairns, Thompson & Wainwright, 2003) and *Medical care of the dying* (4th ed.) (Downing & Wainwright, 2006).

### **Regina Bereavement Centre**

Contact: Marlene Jackson  
Bereavement Coordinator  
4400 4<sup>th</sup> Avenue.  
Regina, SK S4T 0H8  
Phone (306) 766-2884

Bereavement services have been a community-health care delivery partnership in Regina since community champions facilitated introduction of basic bereavement support in 1988. The Regina experience with bereavement programming is discussed in greater detail in a companion monograph entitled *A retrospective of bereavement services in Regina, Saskatchewan: Recommendations for future directions in bereavement care* (Melvin, Hampton & MacLean, 2006a) and in the Pallium Project Knowledge for Action (2006-01) occasional paper *Building community capacity: A retrospective of bereavement services in Regina, Canada* (Melvin, Hampton & MacLean, 2006b).

The vision and mission statement for the recently commissioned Regina Bereavement Centre are guided by the United States, National Hospice and Palliative Care Organization *Guidelines for bereavement care in hospice* (Bouton, et al., 2002).

Vision - A holistic, caring environment to support individuals, families, groups and communities understand the grief experience; to cope with grief and loss; and to learn appropriate methods of expressing grief that facilitates healthy adaptation to a death loss.

Mission - The Centre contributes to the health and well-being of communities by improving access to and expanding existing bereavement services; heightening the awareness of the impact of loss and grief; developing culturally sensitive care; providing training, education, consultation and research promoting evidence-based knowledge and practice.

Key purposes:

1. Offers a safe, warm and nurturing environment to begin the healing process.
2. Bridges existing gaps and capacity issues with the expansion and development of comprehensive services and programs, building on the solid foundation of existing bereavement services.
3. Provides bereavement services to the Regina Qu'Appelle Health Region and out-reach services to rural Saskatchewan as a result of a death loss.
4. Ensures competent, qualified and compassionate professionals provide quality bereavement services.
5. Sustains collaborative, respectful working relationships with other community professionals who are an appropriate referral resource for individuals and families beyond the scope of the palliative care bereavement program.
6. Provides consultation, training and education for professionals and organizations.

7. Respects ethnicity and cultural background of individuals, with a strong Aboriginal component to the Centre.
8. Accessible services regardless of age, race, sex, socio-economic status, educational level and lifestyle.
9. Conducts or participates in research to enhance service provision.
10. Conducts evaluation of services for program and service delivery improvement as well new program development.
11. Provides quality internships for graduate students from a variety of disciplines, to enrich educational experiences by translating knowledge and values into practice competency.
12. Provides current, evidence-informed grief resources for individuals, families, communities and organisations.

Currently (winter, 2006), bereavement support is offered at the Bereavement Centre by Regina Qu'Appelle Health Region (RQHR)'s Palliative Care Services, Bereavement Services unit. These services include:

- Individual Bereavement Counselling
- Adult Bereavement Support Group
- Childhood/Teen Grief Support Group
- Young Adult Group
- Daytime Support Group for Loss of Spouse
- Caring Hearts Camp: A Weekend Retreat to Help Grieving Children and Teens

### **Common Themes Expressed by Bereavement Centre Key Informants**

Key issues and themes of concern emerged from the key informant interviews:

1. One of the foremost and most challenging concerns is maintaining sufficient funding for optimal operation. Two of the existing centres operate with inconsistent funding from their provincial governments. All centres rely on fund-raising from corporate or non-profit organizations and extensive use of volunteers to remain operational.
2. Resources and funding, specifically from government agencies, are available before an individual dies (i.e. for Palliative Care), but few resources are available for bereavement services. Participants question priorities about those making decisions about critical public services. There was a general consensus that government support for their services is severely lacking.
3. Centres provide services under an "open-door," "donation-only" policy. That is, monies will only be accepted after the services have been provided and only by donation from their clients. Participants felt that this policy is the most appropriate given the sensitive nature of their services. The offering of a donation is considered a symbolic investment of "quality assurance and beneficial services" provided to those in need.
4. Public awareness and screening for clients emerged as important themes. Each informant expressed the view that they are constantly challenged to maintain public awareness of their services. Television, radio and newspaper ads, as well as flyers and pamphlets, are all forms of public awareness used by the centres. All participants felt that screening and needs assessment were paramount in determining appropriateness for service (i.e., suitability and predictable benefit). All Centres prefer that bereaved

individuals seeking services have been three months removed from the death of a loved one or are, at least, not in a crisis situation.

5. Cultural diversity and unique needs of rural communities are key concerns. In terms of future directions and interests of the centres, all participants stated bereavement services and programs for Aboriginal and rural communities in their surrounding areas are needed. Centres that do not have web-based services are striving for this resource. Funding for these resources is a problem. All centres feel it is imperative to provide educational material on dying, death, grief, bereavement and bereavement counselling to clients and service providers in the community. Some centres had research sections and lending libraries for clients.

Notwithstanding these challenges, the bereavement centres discussed in this study are providing a significant resource to people in their communities. These centres are early and important leaders in conceiving, developing and offering bereavement programming which is, and which is seen to be, of value in their communities. The potential for valuable partnerships exists between these centres and university researchers. Innovative research can be developed in bereavement to further our Canadian knowledge base and translate that into more informed, accountable and effective practice. One example of this partnership is Calgary's Grief Support Program, connected to the University of Calgary through co-op training programs offered to graduate students who wish to train in bereavement services. None of the other existing centres disclosed a connection to a local academic program, but all expressed the importance or desire for this liaison. Research on best practices would lead to innovative education and policy advances on bereavement issues.

### Canadian Resources

Consistent with University Engagement principles (Aherne, et al., 2004), many academic researchers are disseminating bereavement information using virtual and audio-visual methods. Use of video for imparting social sciences-related information has been shown to be an effective teaching tool (Dowrick, 1991; Marx & Frost, 1998).

### Illustrative Sample of Educational and Training Resources from Western Canada

1. The Canadian Virtual Hospice ([www.virtualhospice.ca](http://www.virtualhospice.ca)) is a source of self-support and education and mutual support for patients, families, friends, volunteers and professionals and is enabled by online information and interactive features. The CVH is a Winnipeg-based project, initially funded by Health Canada and Western Economic Diversification (WED), which operates with ongoing in-kind and financial support of the Government of Manitoba and contributions from other Manitoba resources.

2. The Pallium Project is a Hospice Palliative Care capacity-building project. It has been funded in two separate phases by Health Canada and extensive in-kind contributions from practitioners, academics, policy and voluntary sector leaders from various locales in Canada. A listing of Phase I and Phase II resources accessible to stakeholders can be found under the PHASE I and PHASE II links, respectively, at [www.pallium.ca](http://www.pallium.ca) and at the Canadian Hospice Palliative Care Association's, CHPCA Marketplace service at [www.chpca.net](http://www.chpca.net).

3. A guide to end-of-life care for seniors. "Un guide des soins en fin de vie aux aînés" (Fisher, Ross & MacLean, 2000). A Canadian edition jointly published by the University of Toronto and University of Ottawa, with broad national reviewer participation, that addresses

multiple issues and challenges. It provides guidance to those whose everyday practice involves end-of-life care. The authors offer a consensus-based approach to "best practice" in Canada, with respect to the overall function of the socio-economics in health care, regarding end-of-life. Chapter titles include *Toward Optimal Care, Living and Dying Well in Later Life, Ethical Issues, Care for the Caregivers, Spirituality and Aboriginal Issues*. The French-language edition is a significant resource for Francophone communities in western Canada.

4. *Counselling the bereaved: Caregiver handbook* (revised edition) published by the Calgary Centre for Suicide Prevention (Hamilton & Mesecar, 2003), is a handbook dedicated to education and awareness of suicide bereavement. The handbook answers the question: Why pay attention to suicide bereavement? Chapter titles include, "Normal Death", "Loss, Death and Grief in Children and Adolescents", "Complicated Grief" and "Suicide Bereavement." There is also a section on the application of responding to suicide bereavement and the Grief Facilitation Model.

### Illustrative Sample of Audio-Visual/New Media Resources from Western Canada

1. Canadian Virtual Hospice (CVH) – [www.virtualhospice.ca](http://www.virtualhospice.ca). As mentioned the CVH is an online network and community where people can seek support and mutual support, by asking questions, finding answers and share their experiences as patients, family members, volunteers and professionals, including matters involving grief and loss. The site provides support for physical, emotional and spiritual concerns related to death and dying.

2. *In our own voices: Aboriginal perspectives on hospice palliative care* (Pallium Project, Hanson & Brook, 2005). This resource is a set of

instructional video segments, in DVD and other digital media formats (e.g., Windows Media format, RealVideo format), with the titles of Connecting with Self and Others, Communication and Relationship Building, A Journey to Our Roots and Responding to Aboriginal Diversity. Three segments are devoted to planning care involving patients' decisions, requests to die at home and working with local authority figures.

*Completing the circle: End-of-life care with Aboriginal families.* (Hampton & Associates, 2005). Documentary-style, key informant interviews with southern Saskatchewan Aboriginal Elders concerning cultural, spiritual issues regarding quality end-of-life care services. It is designed to share insights from Elders to health care providers about care for Aboriginal people. A streaming media version of the video can be viewed at <http://uregina.ca/hamptoma/eol/healthcare.html>

*Completing the circle: Healing words about end-of-life spoken to Aboriginal families.* (Hampton & Associates, 2006). Documentary-style, key informant oral tradition/ narrative-based interviews with Saskatchewan Aboriginal Elders, speaking to Aboriginal families about protocols and offerings of words of comfort to bereaved families.

*Living with hope.* (Duggleby & Associates, 2004). Living with hope is an internationally award winning video designed to support research dissemination. It provides insight into the understanding of, and the expressions of hope experienced by terminally ill cancer patients and their family caregivers. A streaming media version of the video as well as ordering information can be found at <http://www.usask.ca/nursing/research/livingwithhope/video.htm>

*Supporting the bereaved through the holiday season.* (Wainwright, 2005). This is a 47 minute audio recording and written transcript from the Pallium Project (Phase II), Monthly Continuing Professional Development (CPD) Audioconference Program. It is available on the *Conversations on Caring – Volume One* learning resource set (CHPCA Item #0620 - Audio CD set or Item #0621 - MP3/PDF CDR).

Although not focused on end-of-life issues, *Honouring our gift of life* is a video that follows three Alberta-based, Aboriginal families as they demonstrate healthy choices which balance and align with emotional, physical, mental, and spiritual realms of their lives (Alberta Cancer Board & Nolin, 2005). The focus is on cancer and other chronic disease prevention, such as heart disease and diabetes.

### **Bereavement Research**

The priority recommendation put forward by the Canadian Hospice Palliative Care Association's, *Agenda for Research in Palliative Care* (Canadian Palliative Care Association, 1999) is research capacity building. Capacity building is defined as the need: to train a new generation of independent researchers in the field of end-of-life care; and to fund all types of research programs.

For purposes of our review of research, we have focused on Canadian research. More specifically, within the scope of this study at this time, we have reviewed published research conducted by western Canadians. We concentrated on bereavement research rather than palliative care research, however, these distinctions were often difficult to maintain. Generally, research in palliative care services for advanced end-stage illness dominates the Canadian research landscape, suggesting that additional scholarship and knowledge transfer in bereavement is an area that needs to be supported and nurtured.

Selected research articles and research teams are presented herein. A recent Government of Canada study conducted from the University of Alberta, Faculty of Nursing reviewed existing literature to identify best practice delivery models for integrated end-of-life care in Canada (Wilson, 2005). The researchers focused, as we did, on studies conducted in Canada and identified a small number of published papers.

Themes of current Canadian research that emerged from their 2003 review of literature include: quality of life; the family as a component of end-of-life (EOL) programs; health services utilization by individuals at the EOL; the assessment and evaluation of professional roles and activities; and dying at home. Published research by western

Canadians has increased since the 2003 review. Themes emerging from our review of current programs of research overlap these findings, but also include several other themes of importance: individual issues; issues of access, rural research, family bereavement, home care, empirical bereavement research, Aboriginal theoretical research, and bereavement and the workplace. We also briefly review international bereavement programs of research.

### **Individual Issues (Health Service Utilization by Individuals at the EOL)**

The majority of research focuses on individual issues facing dying patients. Local research conducted in Regina has highlighted the potential for personal, psychological growth as an outcome of bereavement. Marlene Jackson, currently the Bereavement Coordinator for Regina Qu'Appelle Health Region's, Palliative Care Services found that bereaved family members in her study maintain a psychological and spiritual connection to deceased family members (Jackson, 2003). She suggests this model reflects psychological health rather than dysfunction. Inger Frombach examined the experiences of young adult women whose mothers died of cancer and concluded that theories of post-traumatic growth can reflect the experience of loss and deepening expressed by these women (Frombach, 2004).

Darren Heyland and colleagues have conducted large cross-Canada, multi-site studies investigating dying patients' participation in decision-making at the end-of-life, including perceptions of seriously ill patients and their family members (Heyland, et al., 2006). Heyland and his colleagues have also investigated the dying experience within the hospital setting (Heyland, Tranmer & Feldman-Stewart, 2000; Heyland, et al., 2000).

Winnipeg-based academic psychiatrist, Dr. Harvey Max Chochinov, currently Canada's sole Canada Research Chair (CRC) in Palliative Care and Director of the Manitoba Palliative Care Research Unit, suggests that while a great deal is known about individual grief, less is known about the phenomenology of global sorrow following catastrophes (Chochinov, 2005). Following the global media impact communicated about the Asian Tsunami and the New York "9/11" World Trade Center bombing, the collective psychological landscape is disrupted when these "distant" events upset the illusion of stability and permanence as human trauma graphically plays out in real time on television within the intimate confines of our homes. Grief, manifested vicariously, can affect us on a global level as people react to others' local tragedy. Chochinov concludes that global sorrow bears further examination, that the field of palliative care claims expertise in issues related to death and bereavement, yet its role in assuaging global sorrow has yet to be defined.

### **Issues of Access**

The Canadian Virtual Hospice [CVH] ([www.virtualhospice.ca](http://www.virtualhospice.ca)) went on-line on February 6, 2004 with "aspirations to help transform the landscape of Canadian end-of-life care" (Chochinov & Stern, 2004). The CVH was born from a guiding idea of offering information, support and mutual support in a way to eliminate the barriers of time and place. The CVH is a web-application that provides access to many resources, virtual community access and a portal where patients and families can ask questions of professionals. This resource has been called "a very Canadian response to the universal challenge of confronting illness and loss" (Chochinov & Stern, 2004). The theme of "access" reflects the rural geographic reality of Canada (Aherne & Pereira, 2005); end-of-life

support needs of rural communities appear to be more important research areas than for other regions of Canada.

Richard Doll, Maria Cristina Barroetavene and colleagues of the B.C. Cancer Agency's, Sociobehavioural Research Centre report issues of access and navigation for patients with cancer have been a problem (Doll, et al., 2003). Access issues in this work focus on internal system problems rather than geographical issues. Research conducted by academic social workers Mary Lou Kelley and Holly Prince, from Lakehead University's, Centre for Education and Research in Aging and Health (CERAH), in collaboration with northwestern Ontario First Nation chiefs found access to culturally appropriate palliative care services is the foremost need for northwestern Ontario First Nations (Prince & Kelley, 2006). They describe a process of collaboration between regional palliative care experts and local caregivers offering palliative care on reserves to increase access to services.

### **Rural Research**

While end-of-life, palliative and bereavement care in rural Canada has clearly been practiced for many years, there has not been much published research on these topics to date. Mary Lou Kelley and other Canadians colleagues, including Michael MacLean have investigated various issues on the provision of end-of-life and palliative care in rural Canada (MacLean & Kelley, 2001a, 2001b; Allard et al., 2003; Kelley, Sellick & Linkewich, 2003). Some of this research touches on bereavement care but there is much more to do (Hughes, et al., 2004). There will need to be future research on bereavement care in rural areas but, to date, the emphasis has been on developing conceptual models for palliative and end-of-life care. Carol Sakundiak has completed a descriptive study of palliative care services in most of the health regions in Saskatchewan

(Sakundiak, 2005), so there is reference to issues in rural areas but, again, the focus is not so much on bereavement as it is on end-stage palliative care services. Future research on rural areas and bereavement care would have considerable benefit to Canada to inform improved population health strategies. Research teams in Saskatchewan have responded to need for research in this area and are currently conducting studies-in-process entitled *Timely Access and Seamless Transitions in Rural Palliative/End-of-Life Care* (Allison Williams, McMaster University/Wendy Duggleby, University of Saskatchewan are research team lead contacts); A University of Saskatchewan-based team is also using Saskatchewan Health Databases to examine which patients access palliative care in Saskatchewan (also see Duggleby for first point of contact).

#### **Family Bereavement/Family as a Component of End-of-Life Programs**

Dr. Donna Wilson of the University of Alberta, Faculty of Nursing (Wilson, 2005) notes that literature to date has focused almost entirely on patient issues rather than broader family issues. For example, little research attention has been paid to needs of bereaved parents or to pediatric end-of-life care in a family context. Dr. Nancy Reeves, a psychologist practicing in Victoria, B.C., specializes in the area of trauma, grief and loss with adults and children (Reeves, 2002). She has developed specialty resources in the form of books, workshops and retreats for bereaved parents (Reeves, 2001). Dr. Susan Cadell, formerly of the University of British Columbia (now at the Centre for Healthy Living, Wilfred Laurier University), has teamed with other researchers in Canada to research bereaved parents' experience (Janzen, Cadell & Westhues, 2004). They offer advice given by 20 bereaved parents for ways in which professionals can respond in helpful

ways to parents healing from the sudden death of a child as they negotiate the immediate period from death notification through to the funeral. Five themes associated with the grieving process of parents include: the reconstruction of the death scene; issues of control and the shattering of the assumptive world; saying goodbye; making sense of the death; and carrying the deceased child forward in the parents' lives.

Wilson (2002) has compared the degree of end-of-life dependency of home care clients and hospital inpatients. Researchers from Mississauga, Ontario (Baxter & Stuart, 1999) first established a bereavement support group in a secondary school following a grade nine student's sudden death in 1979. Based on their successful work over the years working with bereaved adolescents they developed a resource handbook for bereavement support groups in schools.

#### **Home-Based Family Caregivers Experiences**

Home-based caregiving is a high-priority research area since a current policy trend is to promote home-based palliative care services rather than hospital in-patient services. This, in part, reflects a growing commitment to accommodate patients' expressed desire to be cared for at home as long as possible (Leis, Kristjanson, Koop & Laizner, 1997). Kelli Stajduhar and Betty Davies from the University of British Columbia have reviewed the history of the migration towards use of home care in Canada and articulate challenges (Stajduhar & Davies, 1998).

Stajduhar and Davies have conducted ethnographic research examining the social context of home-based palliative care caregiving (Stajduhar & Davies, 2005; Stajduhar, 2003). The purpose of her research program is to describe the variations in and

factors influencing family members' decisions to provide home-based palliative care; she concludes that families' "decisions" are constrained and influenced by social context. They suggest that interventions are needed to better prepare caregivers for their role, enhance caregivers' choice in the decision-making process, improve care for the dying in hospital and consider the development of alternate options for care. Findings further suggest that shifts toward providing care closer to home not only changed caregivers but also changed the home setting where palliative care was provided.

Debra Wiszniak (2002) conducted a qualitative study exploring quality of life of informal caregivers caring for someone with a terminal illness which illustrates the stresses as well as the positives of such an experience. Prince and Kelley (2006) found, in their survey of First Nations communities in Ontario, that over half of their respondents had cared for a dying family member at home. They estimate that 86.5 hours per week were required to care for a dying family member at home and they found family members were unequipped to devote this amount of time to the process. However, most respondents believed that, if services were available and adequate, community members would choose to die at home.

Priscilla Koop and Vicki Strang, from the University of Alberta have established a strong research focus in the area (Koop & Strang, 1997). The researchers have studied caregivers and concluded there is wide variation in the characteristics of caregivers (Strang, Koop & Peden, 2002). Although the vast majority of caregivers for terminally-ill family members are female, they have found, contrary to other researchers, that there are no significant relationships between gender and bereavement outcomes (Beck-Friis & Strang, 1993).

One of their qualitative studies with home-based family caregivers asked the question "How do family caregivers of patients with advanced cancer perceive the effects of home-based caregiving on their bereavement?" (Koop & Strang, 2003). Caregivers reported both positive (e.g., feelings of accomplishment, improved family relationships) and negative (e.g., haunting images, feelings of failure) outcomes that they attributed to having cared for their family members. Overall, positive outcomes predominated. These results offer bereavement counsellors insight into potential focus areas. They also found "coping" emerged as a salient category needing further analysis (Strang & Koop, 2003).

Factors facilitating coping include characteristics of the caregivers themselves; contributions made by the dying person and supportive networks (both formal and informal), available to the caregivers. The dynamic relationship between the caregiver and the dying person emerged as a unique factor that has not received adequate attention in the literature. These researchers also critique methodological recommendations for prospective research rather than retrospective bereavement research since their participants (who were completely immersed in the caregiver process) would have found participation in a prospective study impossible.

### **Palliative Care Workers'/Caregivers' Bereavement Issues**

Little research exists on bereavement issues facing the palliative care provider. Patricia Boston and Anna Towers from McGill University (note, Dr. Boston has been Director, Division of Palliative Care, University of British Columbia since 2003) discuss a case example from a larger narrative case-based study that illustrates the premise

that dying is ultimately a complex experience and one that the caregiver may never truly understand (Boston, Towers & Barnard, 2001). They suggest that both patient and caregivers remain learners. They propose that while the process of achieving empathic communication necessarily demands "good listening," the palliative care provider (both professional and familial) may be invited to go beyond the domain of listening, to emotional realms that are neither easy nor comfortable.

These results have implications for bereavement centres that could offer training and support for caregivers. Margaret Mantz and Jacqueline Crandall examine the larger context in relation to the move toward greater home-based care (Mantz & Crandall, 2000). They suggest that, with the rising age of the population, hospital cutbacks, and increased attention to home-based care for the dying, the community can expect to experience more intense care situations and a greater potential for palliative care crises developing in the home setting. They surveyed professional palliative care workers to understand the definition of a "crisis" from their perspective. Results highlight the need for support in the workplace for palliative care workers and the need for integrated crisis palliative care initiatives similar to that recently developed by the Victoria Hospice Palliative Response Team.

### **Empirical Bereavement Research**

Empirical end-of-life research is a growing area in Canada; however, empirical bereavement research is lacking. Existing empirical research uses both qualitative and quantitative methodologies. Researchers from the University of British Columbia co-authored a prospective study examining resilience to loss and chronic grief from pre-loss to 18-months post-loss (Bonanno, et al., 2002). This article provides an excellent

review of empirical and theoretical bereavement literature. The authors state that the vast majority of bereavement research is conducted after a loss has occurred. Knowledge of the divergent trajectories of grieving or their antecedent predictors is lacking. They surveyed 205 individuals who anticipated the death of a spouse several years prior to the death and at 6- and 18-months post loss.

Five core bereavement patterns were identified: common grief, chronic grief, chronic depression, improvement during bereavement, and resilience. Common grief was relatively infrequent and the resilient pattern most frequent. The authors tested key hypotheses in the literature pertaining to chronic grief and resilience by identifying the preloss predictors of each pattern. They conclude that chronic grief was associated with preloss dependency and resilience was associated with preloss acceptance of death and belief in a just world.

One salient recommendation suggests that studies include predictive data. Treatment implications suggest that chronically grieving individuals are most in need of intervention and that screening bereaved clients may detect this pattern of grief (approximately 16% of their participants). Implications for bereavement centres reinforce the importance of screening and suggest that focusing on clients suffering from chronic grief would be beneficial.

Studies focused on dying and the bereaved include *Quality of Life* as a construct, which comprises a large body of research and includes the well-being of family, friends, immediate caregivers, healthcare providers and the dying patient. Issues about decision making and choices of the dying are aimed at increasing the quality of life and well-being.

The manifestation of hope in palliative patients is linked with their quality of life, and the lives of their informal and formal caregivers.

Dr. Wendy Duggleby and colleagues from the University of Saskatchewan have been early Canadian leaders in investigating *Hope* in relation to quality of life for palliative patients and their caregivers. Researchers suggest that increasing hope is a way to contribute to patients' quality of life as a desired goal of end-of-life care (Duggleby & Wright, 2005; Herth, 2000), as part of quality end-of-life care in Canada (Chochinov, 2001; Senate of Canada, 2002). Research conducted in quality-of-life often overlaps with themes of hope (i.e. having hope increases quality of life).

Duggleby & Wright (2005) explore the manifestations and transformation of hope in elderly palliative patients. Hope, as described by the home-care palliative patients in this study, was defined as expectations of "not suffering anymore" and "having a peaceful death," while transforming hope involved the patients searching for meaning and positive reappraisal of the dying experience. Findings from this study provide an empirical basis for informing health-care providers, caregivers and patients, as to how palliative patients can live with hope. Furthermore, nurses can also be informed of ways to enhance hope, meaning-making, spirituality, and quality of life for palliative patients.

Duggleby and Wright (2004) published a paper describing what patients hope for as their life comes to an end. Themes which emerged include hope-fostering strategies such as "leaving a legacy", symbols of hope, supportive family and friends and positive thoughts. Fostering and maintaining a sense of hope positively influenced the ability of patients to make decisions, set goals and in

general, improved quality of life for both patients and their families. Both studies conclude that the hope program provides effective strategies for nurses who can facilitate patients' self-reflection, meaning-making, hopefulness for the future, and ability to live life to the fullest and die with dignity, peace and comfort.

Research conducted by Lorraine Holtslander, Wendy Duggleby, & Karen Wright at the University of Saskatchewan and Allison Williams at McMaster University, specifically explore the experiences of hope among informal caregivers of palliative patients (Holtslander, Duggleby, Williams & Wright, 2005). Previous research identifies hope as a strategy that allows informal caregivers to continue day to day care of their dying family member.

Holtslander et al. (2005) report that caregivers define hope as inner strength which gives the courage to pull through difficult situations. These researchers conclude that it was important to also consider factors that contribute to "eroding hope." Caregivers felt their hope was eroded when they had difficulty communicating with healthcare professionals, felt depersonalized, or received too many negative messages. Supports of family, friends and healthcare professionals and "spirituality that connects with something bigger," were helpful in maintaining hope and support for informal caregivers. They conclude that the well-being of the caregiver is essential to successfully providing palliative care at home and therefore supporting caregivers' hope is paramount to the quality of life and well-being of all parties involved.

Anne Leis (University of Saskatchewan) has contributed to development of the QOLLTI-P (Quality-of-Life in Life Threatening Illness),

which is a revision of the widely-used MQOL (McGill Quality of Life Questionnaire). In a qualitative, multi-site study conducted with palliative cancer patients, the content validity of MQOL was supported; yet themes emerged from this study that suggested a need for revising this instrument (Cohen & Leis, 2002).

Harvey Max Chochinov has developed a program of research that he calls the Dignity Model. Qualitative research with fifty (n=50) terminally-ill cancer patients revealed three broad categories that comprise patients' conception of dying with dignity including illness-related concerns, dignity conserving repertoire and a social dignity inventory (Chochinov, Hack, McClement, Kristjanson & Harlos, 2002). This qualitative research was followed by a psychotherapeutic intervention they have coined Dignity Therapy (Chochinov, Hack, Hassaard, McClement, Kristjanson & Harlos, 2004). These authors state that very little empirical research on psychotherapeutic interventions for dying patients has been done. Their team has completed some of the first empirical studies on the issue of dignity among the dying. Preliminary, pilot evaluation data suggests that Dignity Therapy has potential to favorably influence the patient as well as their loved ones at end-of-life.

Terry Kaasa from the Cross Cancer Institute in Edmonton, along with Jean Wessel from McMaster University, have examined the validity of the revised version of the Edmonton Functional Assessment Tool (EFAT-2), an instrument designed to measure physical impairment and functional performance of patients in palliative care (Kassa & Wessel, 2001). However, similar to other tools and research, the focus is on end-stage palliative care experiences.

### Aboriginal Research -- Theoretical Publications

In addition to the resources and literature further described in the *Cross-cultural end-of-life resources* section of this paper, several empirical and theoretical publications have emerged from Canadian prairie researchers. Angelina Baydala and Mary Hampton from the University of Regina have described end-of-life philosophies as spoken by Lakota pipe carriers (Baydala, Hampton, Kinunwa, Kinunwa & Kinunwa, 2006). This work is relevant to Canadian Plains First Nations, many of whom follow the teachings of the Sacred Pipe.

Louise Halfe, a Cree woman from Meadow Lake, Saskatchewan notes there is a dearth of literature on death and dying from a Native perspective (Halfe, 1989). She states a similar philosophy to that described by Baydala et al. (2006). That is, the circle of death is linked to giving birth/new life as part of God's way and is a central tenant of many native peoples' belief systems. Traditional Native spirituality strongly reinforces the principle of a circle of life and death; the cycle of dying and grieving for the dying and the bereaved comes full circle to growth and insight.

Halfe also describes traditional bereavement ceremonies and practices that are still practiced today. She reminds readers that, "...with the lower life expectancy and high rate of alcohol abuse, accidental deaths and suicide, the native community is well practiced in burying its dead. The surviving members and the community as a whole have an approach to life that is different from mainstream societies, but does it make the transition to death easier for the dying patient? Death is not welcomed with open arms, but is rather viewed as a reality of life" (p. 39).

Joseph Kaufert at the University of Manitoba (U of M) and his colleagues have contributed to our theoretical understanding of issues facing Aboriginal individuals at end-of-life (Kaufert, Putsch & Lavallee, 1999). Kaufert and John O'Neil are medical anthropologists in the U of M Faculty of Medicine, working out of the Centre for Aboriginal Health Research. They articulated cultural differences between mainstream biomedical explanations of death, dying and grieving and the very real problem of mediation between these assumptions and a Native worldview of these experiences (Kaufert & O'Neil, 1991).

One solution has been to bring Aboriginal cultural-medical interpreters/brokers into hospital settings. These interpreters, however, often experience role conflicts and difficulties when they attempt to broker the medical culture of one society to the members of another. This becomes a particularly critical task when there is a conflict between Aboriginal people and hospital personnel over the nature of death, the appropriate expression of grief, and the proper treatment of dying and dead persons (Shah & Dubeski, 1993; Sherley-Spiers, 1989).

Kaufert, Putsch and Lavallee (1999) extend the narratives and theoretical work presented by Kaufert and O'Neil (1991), by analyzing twelve cases involving cross-cultural communication between Aboriginal patients and non-Aboriginal health care providers in end-of-life decision-making. In these cases, Aboriginal interpreters' roles in facilitating communication between participants who hold disparate values and frameworks for guiding end-of-life decision making were examined. They conclude that cultural perspectives and personal values held by patients, families, and caregivers influence day-to-day clinical communication. However, the cultural perspectives have their most

profound impact on end-of-life decisions making. Without the intervention of cultural mediators, these ethnocentric assumptions may be invisible and pass without commentary (Reynolds Turton, 1997).

Paul Hackett from the University of Manitoba retrospectively studied historical mourning practices of Cree and Ojibway First Nations people of the Central Subarctic (Hackett, 2005). He found there were two main and consistently adhered to mourning practices (Hackett, 2005). He also noted that as early as 1846, there was unprecedented abandonment of these practices. The current reality is a dual reality of some who continue to mourn based on traditional practices, while others have either abandoned or modified these practices.

### **Bereavement and the Workplace**

There is a lack of research in Canada in the area of bereavement and the workplace. However, this remains an important area for future research and devoted care (Maxim & Mackavery, 2005; Tyler, 2003). The Grief Recovery Institute, a private firm operating in the United States and Canada ([www.grief-recovery.com](http://www.grief-recovery.com)) refers to staff impacted by death as: "The Working Wounded....grief in the workplace is an inescapable part of life. Research indicates costs to organizations in terms of tardiness, absenteeism, decreased productivity, increased accidents, increased turnover, increased drug and alcohol use, lower morale and disruptive communication/relationships." Research in this area would directly benefit policy making and implementation of "bereavement leave" in the workplace.

### **Sample International Bereavement Research**

Examples of international bereavement research are presented in this section. Research questions about quality of life for caregivers and the dying, palliative care and

health care services, caregivers' grief and bereavement counselling seem to be the focus for research in most countries. However, based on the review, it became apparent that other countries are studying different issues as well. These differences include more focus on caregivers' well-being pre- and post-death. There is also a research focus on "continuity of care" both between the dying experience and caregivers' experience pre- and post-death.

The literature review revealed an interest in immigrants' experiences of end-of-life care. Furthermore, there is an interest in discrimination and racism experienced in end-of-life and bereavement care. These all reveal a breadth of interest and knowledge in the area of death, dying and bereavement, yet with the unique special interests of certain cultures and what researchable questions are valued.

### Australia

Australia is an early established leader, having had a national grief and bereavement capacity since 1996, through an independent, non-profit Australian Centre for Grief and Bereavement ([www.grief.org.au](http://www.grief.org.au)).

There are many researchers and practitioners devoted to end-of-life care and bereavement services/research. The Metropolitan Health and Aged Care Services Division (MHACSD) of the Department of Human Services (DHS – Victoria) sponsored a research report entitled Review of Specific Grief and Bereavement Services (Department of Human Services, 2004). The purpose of this review was to determine how the four grief and bereavement services funded by the DHS could be optimized to help communities in deal with grief and bereavement. Main conclusions from the review are:

- 1) the need for greater community awareness of grief and bereavement which coincides with the need for more specialist services at the community level and a better community education strategy;
- 2) a need to develop a future directions framework for grief and bereavement to ensure future initiatives have a set of service standards concurrent with a tertiary education sector;
- 3) grief and bereavement training for generalist healthcare professionals, including more flexible models of training to support those practicing in rural areas; and
- 4) all future directions should be consolidated by stable funding and agency structures.

The authors conclude that more research is needed into the efficacy of bereavement services. The study calls for more research specific to the Australian context as an emergent need.

Other Australian researchers concerned with systems of practice are O'Conner, Peters, Lee and Webster (2005). Their study illustrates the type of work and length of time taken to deliver care to families and the deceased from a nurses' perspective. Post-death care is an essential but unacknowledged part of palliative care nursing, and there is a dearth of literature describing the nurses' role post-death. They conclude that nursing after a death is made more complex by a lack of multidisciplinary and ancillary supports, which in turn lengthens the time taken to discharge the deceased and care for their families. This delays the admission of new palliative patients.

The book *Nonfinite loss and grief: A psychoeducational approach* (Bruce & Schultz, 2001), speaks to the experience of losing a loved one. This book reveals the manifestations of un/complicated grief in the

individual, the family and the community. Educational and community support networks are discussed. Also, *Meaning reconstruction and the experience of loss*, edited by Robert Neimeyer (2001), is a book that focuses on the experiences of loss. It states these personal experiences all share the commonality that the process of struggling to find a sense of meaning after the loss is what enables the final adjustment to major loss. This book also addresses the dynamic, indefinite and emotional nature of loss as experienced by different people from different cultures and cohorts.

Australian researchers, like Canadians, note the importance of culturally appropriate end-of-life care for Aboriginal communities. The National Indigenous Palliative Care Needs Study (Government of Australia, 2003) responded to an identified need for information about the definition and availability of palliative care services by designing information/fact sheets for Aboriginal families presented in culturally relevant format. Similarly, Dr. Margaret Charles, et al. at the University of Sydney (personal communications, August 2005) are investigating best practices and outcomes for Aboriginal palliation in Queensland and New South Wales (Reymond, et al., 2005).

**Europe : Netherlands, Norway, Spain, Sweden, United Kingdom (UK).**

The United Kingdom produces extensive end-of-life research. Others from the Netherlands, Norway, Sweden and Spain are included in the review as well. The resources from the United Kingdom are focused on health care services (primarily nurses) and therapeutic counselling, caregiver well-being during the bereavement period, and bereavement awareness. A handbook called *Lost for words: Loss and bereavement awareness training*, is an excellent resource for bereavement educators

of children, adolescents and adults (Holland, Dance, MacManus & Stitt, 2005). The handbook includes sections on research, experiences of loss, models of loss, children's understanding of death, death as taboo, anticipated and sudden death, loss response policies and helping agencies/resources. This handbook is easily reproduced, is reader-friendly to the layperson and provides many up to date and important statistics on death, grief and bereavement.

James Youll (1996) wrote an article that explores therapeutic counselling for the people suffering from complex bereavement. Research has shown that nurses provide much of the existing bereavement care and that there have been factors that predispose bereaved people to experience abnormal or complicated grief in bereavement. He concludes that it is important for nurses to become educated on the grieving process and to know what actions or interventions are appropriate. He also concludes that bereavement services are most beneficial to those who believe their friends and family to be unsupportive or are, for other reasons, deemed "at-risk".

Moreover, some people who do not receive bereavement services may present with psychiatric or medical problems. One researcher from the UK, John Costello (1999), produces a very thorough paper on anticipatory grief, with his findings supported by his interviews with bereaved, older spouses. The article reports that anticipatory grief allowed for adaptation to the loss prior to the death. Costello also recommends that nurses providing palliative care to the dying ought to be trained to recognize anticipatory grief so that they can provide quality care and support to families and patients at end-of-life.

Grande and colleagues conducted a retrospective study on the impact of hospice home care on informal caregiver outcomes (Grande, Farquhar, Barclay & Todd, 2004). It was concluded that hospice home care had no effects on bereavement outcome; however, the informal caregivers' perceptions of care received in hospice had an effect on bereavement outcome. Interestingly, death at home was associated with more positive bereavement trajectory and health after 6 months. This study indicates that more research is needed in the area of home death.

A study conducted by Christine McPherson and Julia Addington-Hall of King's College School of Medicine in London concluded that the passage of time was an important factor in the discrepancies between caregivers' bereavement experiences (McPherson & Addington-Hall, 2004). This retrospective study collected data on pain, anxiety and depression among bereaved caregivers, at 3-5 months and again at 7-9 months post-death. The study found that there was consistency for anxiety over time, while pain and depression varied and became less severe with the passage of time.

A number of important early bereavement studies have come from a team in Norway. A longitudinal study of caregiver grief and bereavement up to one year post-loss was conducted by Gerd Ringdal and colleagues (Ringdal, Jordhoy, Ringdal & Kaasa, 2001). The study compared two groups of family caregivers whose deceased family member received either: (1) comprehensive palliative care; or (2) conventional care. There were no significant differences in the grief reactions of the caregivers who received either treatment. They concluded that caregivers' grief significantly declined from 1 to 13 months after the loss of their loved one from cancer,

confirming their hypothesis that severity of grief reactions decreased as a function of time.

Ringdal, Jordhoy & Kaasa (2001) also investigated factors that affect grief reactions in close family members of individuals who have died of cancer. Age and gender of the bereaved persons were found to influence the bereavement trajectory. These researchers found grief reactions to be more intense for female and older bereaved family members.

The following two articles from the UK and Sweden, are focused around quality of life and the experiences of terminally ill patients, months before death. Geoff Scobie and Clare Caddell from the University of Glasgow have published findings on quality of life, examining how spirituality plays a role in coping strategies at end-of-life (Scobie & Caddell, 2005). They used an adapted version of the McGill Quality of Life Questionnaire – MQOL- (co-developed by Canadian researcher Robin Cohen in 1995) to evaluate quality of life in study participants. Spirituality did have an effect on coping strategies and better quality of life as ascertained by the MQOL.

Research in Sweden by Sahlberg-Blom, Ternstedt and Johansson (1998) reported on fifty-six (n=56) adult patients' last month of life at a hospice care ward. Continuity of care, care site and place of death were all compared between patients. The time spent at home was also compared to time spent in the hospital. A pattern was found between the type of cancer the patients had and where they spent their final month. There were great variations between the participants, with 10 dying at home and 46 dying in the hospital. This study shows the need for bereavement training to healthcare providers.

Researchers in Spain have looked at health-related quality of life of caregivers during the bereavement period after they lost an elderly loved one (Rebollo, Alonso, Ramon, Vilagut, Santed & Pujol, 2005). Emotional health was determined to be affected the most during the bereavement period. Relationship to the deceased, younger age of the deceased, as well as a lower level of education were related to greater emotional pathology, (i.e., at risk for depression). Results suggest the need for research into secondary prevention strategies for depression in primary caregivers.

Margraret Stroebe, Wolfgang Stroebe and Henk Schut are a team of researchers from the Netherlands that have done extensive and insightful work on theoretical bereavement, bereavement experiences and outcomes of counselling. Their work is often published in the U.S. (in English). They published an article *Grief work, disclosure and counselling: do they help the bereaved?*, that seeks to explain why some individuals fair better in counselling while others do not (Stroebe, et al., 2005).

### United States

Research in the United States has produced several comprehensive resources for bereavement researchers. The American Psychological Association has shown a commitment to end-of-life research by publishing a comprehensive document describing ethical considerations at end-of-life (Kleepsies, 2004). The Handbook of bereavement research (Stroebe, et al., 2001) was published by the American Psychological Association in 2001 and provides access to a wide range of bereavement research. These have developed a research program investigating various aspects of the bereavement experience, including the social context of grieving and family issues (Strobe, et al., 2005; Stroebe, et al., 2001).

Another comprehensive resource, *Living with dying: A handbook for end-of-life healthcare practitioners* by Berzoff and Silverman (2004), is a comprehensive resource for bereavement researchers. A discussion paper on complicated grief and a national survey of potential risk factors, such as a history of mental health issues or the sudden loss of a child, are presented by Ellifrit et al. (2003). Gwen Wyatt (1999) provides a profile of bereaved caregivers following the death of a terminally-ill loved one. She addresses the importance of terminal care and bereavement support being incorporated into all professional health care services. George Bonanno and colleagues address resilience to loss and issues surrounding the bereavement experiences of spouses, parents and gay men (Bonanno, Moskowitz, Papa & Folkman, 2005). This team argues that normative tendencies in bereavement cannot be pinpointed without considering individuals' resilience trajectory, which is a varied and very dynamic attribute.

Much of the US literature speaks to the experience of healthcare service providers and seeks to provide guidelines for bereavement services. Research by Karen Steen (1998) informs the reader of risk factors for health deterioration during bereavement. She stresses the need for effective screening and assessment tools. Possible guidelines and considerations for multi-cultural loss and multi-cultural bereavement are provided.

Draft guidelines for palliative care services in the U.S. Indian Health system have been developed by various researchers in the U.S. who are conducting research and working on guidelines for issues pertaining to palliative care for the U.S. Indian Health System (Kitzes & Berger, 2004; Kitzes & Domer, 2003; Chino & Debruyne, 2006). Themes included in the draft include: physical, psychological, spiritual aspects of care, care of the

imminently dying patient and ethical and legal considerations in caring for the dying person. There is little mention of bereavement. Sally Ellis Fletcher (2002), reports a case study of an African American woman who loses her premature twins one hour after birth in Cultural implications in the management of grief and loss. Fletcher suggests that to provide the best possible care, caregivers need to be aware of their own orientation (e.g., beliefs, values, underlying assumptions) and appreciate uniqueness within cultures.

U.S. researchers are concerned with translating research into practice. Snyder et al. (2002) provide a thorough review of the development of a bereavement program in a medical centre. The authors conclude that in the wake of recent terrorist attacks and natural disasters, many patients are dying tragically and suddenly in hospital. There should be a bereavement care facility in tertiary medical centers. That is, the care should not stop after death has occurred. A team of researchers and practitioners in hospice and palliative care from the U.S., have put together *Guidelines for bereavement care in hospice* (Bouton, et al., 2002) as a framework and standard of practice.

These guidelines include assessment, community bereavement services, community collaboration, discharge, evaluations, fees for services, reimbursements for bereavement care, research, resources, students and interns and volunteers. Barbara Bouton is the lead researcher on this project. Bouton (2004) also published *Community bereavement centers: Nuts and bolts, trials and tribulations*, which addresses various issues and models of practice within four U.S. bereavement centers.

Freeman and Ward (1998), Sutcliffe, Tufnell and Cornish (1998) and Walsh-Burke (2000), provide issue analysis and insights into bereavement counselling, variations in the

grieving process and factors that shape these. Each study provides a framework or model of counselling practice useful for matching services to level and type of need. Walsh-

Walsh-Burke (2000) especially emphasizes the need for screening and assessment prior to any bereavement counselling and because no two people grieve alike, grief and bereavement counselling is presented with a unique challenge to recognize behaviour, experience and match level of need with appropriate services in order to provide best practices and effective services.

Widowhood is another special focus of U.S.-based researchers, Victoria Raveis (1999) and Carolyn Walter (2005). Both examine the psychosocial well-being and the process transformation of "meaning-making" in women who have lost their partners. Both stress the importance of assessing risk for complicated bereavement. Implications for best forms of therapy (e.g., group vs. one-on-one) are discussed based on varying degrees of bereavement morbidity.

Joan Teno and colleagues suggest issues stemming from mismatching level of need with service arise due to a lack of measurement tools for end-of-life care (Teno, Casey, Welsh and Edgman-Levitan, 2001). Her retrospective research uses the Toolkit of Instruments to Measure End-of-life Care (TIME) to address this gap. The book *Grief counselling and grief therapy: A handbook for the mental health practitioner* (Worden, 2001) is widely cited and used in the aforementioned studies. Rickerson and colleagues evaluate care efficacy of informal and formal caregivers of palliative patients (Rickerson, et al., 2005). The study concluded that healthcare staff were interested in additional sources of bereavement support as a support for themselves and support to patients' families.

American researchers have also studied bereavement in the workplace. Maxim and Mackavery (2005) conclude that: (1) employers should be flexible with work demands and provide time off following a loss; (2) there should be an unspoken permission to put family first; (3) employers should have a role in providing information about community resources, such as counsellors, therapies, training, virtual resources, etc.; and (4) employers should realize employees receiving understanding, compassion and special treatment during times of loss tend to be more loyal and hard-working as an expression of appreciation for employer support at times of loss.

These conclusions are reinforced by Zaslow (2002), who concludes that employees' job performance following loss might be challenged after initial return to work. With patience and understanding, however, productiveness, communication and well-being at work improves. Open communication between employer and employee and flexibility are important to successful management of bereavement in the workplace. It is also imperative that policies and procedures for handling matter such as life insurance, bereavement leave, emergency loans and condolence gifts be available to bereaved employees immediately after loss (Tyler, 2003).

### **Conclusion**

Death is a universal experience, an emotional experience of grief tends to be universal, yet the ways in which bereavement as a process manifests tends to be individually and culturally bound. This is reflected in research questions. Canada presents with a wealth of information on palliative care and there is a current dearth of research on bereavement. The United States has made significant early contributions to bereavement knowledge,

including suggested standards of practice and guidelines for services. Canadians are for the most part in the early days of developing responses relevant to our Canadian context. This is especially true for policy development and bereavement programming.

### **Cross-cultural end-of-life research/resources in Canada**

The term "cross-cultural" is used by several Canadian researchers. For example, a B.C. Cancer Agency research team sponsored the first national workshop on cross-cultural cancer research and care in February, 2004. Building Collaborative Communities brought together over 60 national stakeholders, including policy makers, researchers, health professionals and community members to outline priority research areas such as communication, complementary and alternative health care and palliative/end-of-life care (B.C. Cancer Agency, 2004).

Cross-cultural end-of-life health care is described in the literature as a dynamic, new direction for palliative care (Field, Maher & Webb, 2002; Health Canada, 2002b; Nyatanga, 2002; O'Neill, 1994). Drawing on the conceptual cross-cultural theoretical framework described by Berry, et al. (1992) the model of cross-cultural palliative care described in the literature suggests that palliative care principles and practice are influenced by cultural values and must be uniquely adapted if ethnic minorities are to have confidence in the care provided (Nyatanga, 2002).

### **Aboriginal Peoples' End-of-life Health Care**

Healthcare of the aging and dying is an emerging health issue affecting Aboriginal peoples. Changing demographics in Canada reflect changing realities for Aboriginal populations. Off-reserve rates have quadrupled in western Canada since 1966 (Frideres, 1998). The Aboriginal population in Saskatchewan was estimated at 14% of the total population in 2001 and is projected to increase to 21% by 2017 (Health Canada, 2002a). The higher mortality and growing chronic illness rates among Aboriginal

peoples suggest a need for culturally appropriate end-of-life health care delivery (Waldram, Whiting, Habbick & Kordner, 2000; Young, 1994). Although older people in First Nations make up only 3-5% of Canada's population as compared to 11% in the non-Aboriginal populations, mortality rates among all ages of Aboriginal Canadians are 4-5 times the rates of the non-Aboriginal population (Fisher, Ross & MacLean, 2000; Kent, 2001).

Diseases of the circulatory system were the leading cause of death in both males and females in 2000, followed by an increasing rate of neoplasms [i.e., cancers] (Regina Health District, 2000b). The 1999 standardized death rate for the Saskatchewan Registered Indian population indicates that death rates are higher for males than females; however, rate of female deaths increased from 1999 to 2000 suggesting that gender is an important determinant of health in this population. Despite the continued higher morbidity and mortality rates among Aboriginal individuals in Canada, the life expectancy of Aboriginal peoples rose steadily and dramatically between 1996-2001 and continues to increase suggesting that end-of-life health care needs among elders and those suffering from chronic illness is growing (INAC, 2000; Statistics Canada, 2002).

A discussion paper on end-of-life/palliative care for Aboriginal peoples was drafted in 2002 by the National Aboriginal Health Organization (NAHO, 2002). This document was developed as an input into a National Action Planning Workshop for End-of-life Care (NAPELC) conducted by Health Canada in Winnipeg, March 2002 (Health Canada, 2002b). Culturally appropriate end-of-life care is seen as a priority health area for many First Nations. Recognition of the distinct needs of Metis peoples was also highlighted in this document.

### **Aboriginal Peoples and Palliative Care**

Research on utilization of services suggests that most Aboriginal individuals receive end-of-life health care in acute care settings (Castellano, 2002). A recent survey of Canadians found that only 53% have heard of palliative care (Gardner, 2001). Research documenting use of these services by Aboriginal families in Canada does not yet exist; however, anecdotal and preliminary survey data collected by our Regina-based research team suggest that a smaller percentage of Aboriginal families have heard of palliative care services or have access to these services.

Aboriginal people in Canada are in particular need of attention from end-of-life health care researchers due to high mortality rates and a fast-growing population. Aboriginal cultures are diverse and include First Nations, Metis, and Inuit cultures. "Cross-cultural" rather than terms such as "intercultural" or "multicultural" is an appropriate conceptual framework for our work since we are attempting to encourage understanding across/ between cultural groups (non-Aboriginal and Aboriginal).

Barriers to end-of-life care specifically for Aboriginal Peoples. A major barrier specific to Aboriginal peoples is the occurrence of under-referral (Fried, 2000; Kaufert & O'Neil, 1991; McGrath, 2000; O'Neill, 1994). In addition, a "culture clash" between dominant western biomedical-based health care values and beliefs and traditional Aboriginal cultural values, beliefs and protocols often manifest as cultural and systemic barriers. Symptoms include communication difficulties, discrimination, institutional structures which interfere with traditional kinship responsibilities, etc. (Fisher et al., 2000; Halfe, 1989; Hallenbeck, et al., 1996; Hepburn & Reed, 1995; Kaufert, Putsch & Lavalley, 1999;

McGrath, 2000). The result is profound access and quality care problems. McGrath (2000) writes, "A degree of cultural brokerage, in which messages, belief systems and instructions are exchanged between cultural groups, is required" (p. 48). Lack of resources for dialogue between cultures, delayed diagnosis due to social isolation or lack of health education has also been cited as barriers (Fisher, et al., 2000; Fried, 2000; Halfe, 1989; McGrath, 2000).

### **Ethical Research with Aboriginal Communities**

Principles of Ownership, control, access and possession [OCAP principles] (Schnarch, 2004) and the "ethical space" paradigm suggested by Ermine, Sinclair and Jeffery (2004) should guide all research conducted with Aboriginal communities. The Canadian Institutes for Health Research (CIHR) has also developed draft guidelines for conducting ethical research with Aboriginal communities (CIHR, 2005) as has the IDRC (Grenier, 1998).

### **Examples of Published Aboriginal-focused Research: Western Canada**

*Death, dying, grieving, and end-of-life care: Understanding personal meanings of Aboriginal friends* was recently published in *The Humanistic Psychologist*. This article by Baydala, et al. (2006), discusses dialogue between Lakota pipe carriers and non-Aboriginal researchers where messages about end-of-life beliefs and protocol are conveyed from Lakota individuals to non-Aboriginal family members.

*The circle: Death and dying from a Native perspective* published by Halfe (1989) in the *Journal of Palliative Care*, investigates and provides first-hand insight into the differences between First Nations experiences with death and dying and those of the western researcher. The author realizes that

there is a lack in the literature on death and dying from a Native perspective and she speaks to that through tradition and example.

*Cultural mediation of dying and grieving among Native Canadian patients in urban hospitals* (Kaufert & O'Neil, 1991), published in, D. A. Counts and D. R. Counts (Eds.), *Coping with the Final Tragedy: Cultural Variation in Dying and Grieving* discusses the issues that Native Canadians face when they receive healthcare within Canada.

*Palliative care in First Nations communities: The perspectives and experiences of Aboriginal elders and the educational needs of their community caregivers* is Prince & Kelley's (2006) monograph-based report on a participatory, community action project in collaboration with northern Ontario Chiefs, which facilitated issues discussion about access to and delivery of palliative care services on First Nations. Overall, respondents stated that they need culturally appropriate, easily accessible palliative care programs in their communities.

### **Aboriginal-oriented Resources**

Several research teams have responded to recent calls for a "cultural shift" in the field of knowledge translation (CIHR, 2005) by using an Indigenous Knowledge System dissemination strategy (Smylie, et al., 2004; Smylie, McShane & Tungasuvvingat Inuit Family Resource Centre, 2005). Nyatanga (2002) writes, "The successful provision of culturally sensitive palliative care in the future will depend on minority ethnic groups taking an active part in seeking more information about the nature of services available in their region" (p. 244).

Use of video is recommended as an additional tool for cross-cultural palliative care (O'Neill, 1994). Previous research suggests that video

material can be effectively combined with academic knowledge to convey cross-cultural information (Jennings & Jennings, 1990; Hampton, Hampton, Kinunwa & Kinunwa, 1995). Use of video has been adopted by various disciplines (i.e., visual anthropology) as an effective analytic tool for accurately conveying "native" storytelling (Jackson, 2003) and for health care research (Mackenzie & Xiao, 2003; Riddle, et al., 2002).

Mary Hampton and colleagues have produced two videos describing culturally appropriate end-of-life protocols with Aboriginal Families. A 23 minute video entitled *Completing the circle: End-of-life care with Aboriginal families* (Hampton & Associates, 2005) is intended to help non-Aboriginal health care providers increase their awareness of issues of importance to Aboriginal families. This video is to be delivered by members of the research team along with a PowerPoint presentation and handout. A second video entitled *Completing the circle: Healing words about end-of-life spoken to Aboriginal families* (Hampton & Associates, 2006) is a 55-minute video containing messages from elders to Aboriginal families, in which they purposefully share ways of knowing and being about culturally appropriate end-of-life protocols, as informed by traditional knowledge.

*Responsive hospice palliative care with Aboriginal clients in rural and remote settings* (course planning manual & courseware) (Hanson & Aherne, 2004). This is a curriculum resource which includes sections on cross-cultural relationship building, building and keeping care relationships with Aboriginal people, establishing a climate of diversity and community orientation. Dyadic-based teams of Aboriginal and non-Aboriginal facilitators have been oriented to the courseware resource in September 2005 in partnership with the Aboriginal Nurses Association of Canada and

a separate facilitator orientation was conducted with Aboriginal social work students in March 2006, in partnership with Lakehead University and the Government of Ontario. This courseware has also been used for customized training in Manitoba, Saskatchewan and British Columbia as part of outreach education and professional development during Pallium Project, Phase II (Pallium Project, Aherne & Frère, 2006).

Several research teams in Ontario have recognized the importance of palliative care for First Nations. Their focus is specifically palliative care rather than bereavement or the larger spectrum of end-of-life care. At Lakehead University, Dr. Mary Lou Kelley and Holly Prince are working collaboratively with First Nations in their area to document palliative care needs (Prince & Kelley, 2006). A caregivers manual entitled, *First nations – Caring for the terminally-ill*, produced by a collaboration of Thunder Bay area care providers and Aboriginal people describes and defines a range of palliative health care issues presented in culturally relevant format (Thunder Bay Community Care Access Centre, 2003).

### **Canadian Chinese Community**

Two other cultures that have been the specific focus of cross-cultural end-of-life research in western Canada are the Chinese-Canadian and Indo-Canadian communities. This research has principally occurred in British Columbia.

#### ***Published Studies***

The experience of Chinese bereaved persons: A preliminary study of meaning making and continuing bonds. *Death Studies*, 29, 923-947. This study by Chan, et al. (2005), explores the bereavement process of Chinese persons living in Hong Kong, with focuses on meaning making and maintaining bonds with

the deceased. These aspects were found to be similar to those found in other cultures, but the ways in which they arose were unique to Chinese culture and spirituality. Results provide implications for interventions with the bereaved.

Chinese community views: Promoting cultural competence in palliative care. *Journal of Palliative Care*, 21(2), 111-116. This study, by Payne, Chapman, Holloway, Seymour and Chau (2005), addresses issues that many Chinese persons living in the United Kingdom face in terms of indirect or direct discrimination from health care providers and especially, when in palliative care. The aim of this study is to provide insight into “culturally competent” palliative care practices.

End-of life care in China: A review from Beijing. In R.H. Blank & H.C. Merrick (Eds.), *End-of-life decision making* (pp. 33-59). Cambridge, MA: The MIT Press. This chapter by Yiting, Doring, Fang, Li, and Baoqi, (2005), addresses spiritual, social, economic issues unique to contemporary China and how the private nature of death makes research in this area very difficult to conduct. The goal of the chapter is to make the reader aware of the challenges between traditional, humanistic Chinese philosophy and contemporary Chinese philosophy regarding death and dying, whilst, the importance of universal respect and compassion is stressed in the culture. The sole aim is to improve scholarship of research on end-of-life care issues in China.

#### ***Research Projects***

*Understanding the Psychosocial Needs of Chinese Cancer Patients and their Caregivers.* Investigators: Dr. Maria Cristina Barroetavena, Dr. Lyren Chiu, Richard Doll & Dr. Chong Teh. BC Cancer Agency. This

project focused on better understanding of the psychosocial, social, and cultural needs of Chinese cancer patients and their caregivers. The researchers are working in close collaboration with a community advisory committee to understand support issues emerging from the unique Chinese experience of cancer.

*Interpreters in Cancer Care: Communication Issues and Experiences.* Investigators: Dr. Maria Cristina Barroetavena, Beth Stanger, Suzanne Barclay, Kiran Malli, Dr. Susan Cadell, Violet Poruchko, Gina MacKenzie, Merissa Myles. B.C. Cancer Agency. This study is a partnership between the B.C. Cancer Agency, the Provincial Health Services Authority, Fraser Health Authority and Vancouver Health Authority. This study examines the communication issues and experiences of Chinese and Punjabi speaking interpreters working in the context of cancer care.

*P-SCAN Translation into Chinese & Punjabi.* Investigators: Dr. Maria Cristina Barroetavena and Dr. Wolfgang Linden. This study is a partnership between the B.C. Cancer Agency, the Provincial Health Services Authority, Fraser Health Authority and Vancouver Health Authority. This study examines the communication issues and experiences of Chinese and Punjabi speaking interpreters working in the context of cancer care.

*Towards Culturally Responsive Care in the Community: Early Intervention in Dementia-related Decline.* The Pallium Project (Phase II) has supported early exploratory, participatory action research based work in collaboration with the Department of Family Medicine, University of Alberta. Chinese (Mandarin/Cantonese) communities were part of four distinct cultural communities who were studied to determine how ethnicity and culture operate as variables in recognizing,

caring for, and treating dementia and developing more effective responses for community care.

## Indo-Canadian Communities

### Research Projects

*Cancer Incidence and Mortality in BC Indo-Canadians.* Investigators: Dr. Greg Hislop, Dr. Maria Cristina Barroetavena and Sita Ram Saroa. B.C. Cancer Agency.

*A Qualitative Investigation of Beliefs, Ways of Coping, Family Functioning and Distress in a Canadian Sample of Punjabi-Speaking Women with Breast Cancer.* Investigators: Dr. Joanne Stephen, Richard Doll, Gina McKenzie, Balbir Gurm, Dr. Maria Cristina Barroetavena and Dr. Susan Cadell. B.C. Cancer Agency. Research on women with breast cancer documents that psychosocial distress is widespread, although mediated by many factors including family support and methods of coping. Although there has been considerable research documenting the experience of English speaking Caucasian women from middle and upper classes, much less is known about the experience of women from ethnically diverse populations who are under-represented in research studies. In the absence of explicit cultural knowledge, health professionals may practice passively based on assumptions derived from the "mainstream norm" and stereotypes regarding factors such as beliefs and spirituality, decision-making, the role of family and ways of coping. The objective of this study is to investigate the experiences and belief of Punjabi-speaking women with breast cancer in order to understand factors relevant to this population's psychosocial functioning.

### **Canadian Researchers and Research Teams**

The Canadian Institutes of Health Research (CIHR) is the major public funding body for basic and applied health research in Canada. The Institute of Cancer Research (ICR) has identified seven strategic priority areas, of which palliative and end-of-life care is one. The ICR Palliative and End-of-Life Care initiative commenced in 2003 and led from a recognition that palliative and end-of-life care is an under developed component of cancer control (CIHR, 2004).

CIHR ICR advisory committee members stated that, "historically, palliative and end-of-life care research has been under-funded in Canada and small groups of highly committed and dedicated researchers have struggled to obtain recognition for the field as an independent health discipline" (CIHR, 2004, p. 9).

End-of-life care research is a growing international priority. Many countries are devoting increased resources to building strong research communities in this area. Canada has responded to this growing need to encourage research in this area. In its initial year, ICR identified palliative and end-of-life care as its number one priority and partnered with CIHR's Institute of Aging to fund five-year New Emerging Team (NET) grants, primarily focusing on issues of aging. This institute is partnered with the National Cancer Institutes of Canada (NCIC) to support Strategic Training Programs over a 6-year period. This was followed by the launch of the Palliative and End-of-Life Care initiative in 2003.

In 2004/2005 the final phase of funding for this initiative was completed with the support of an additional nine NET grants and designated Palliative and End-of-Life Peer Review

Committee. Research support continues in the form of a programmatic operating grant funding for palliative and end-of-life care research that extends beyond cancer. An illustrative list of ongoing research programs funded under these CIHR initiatives (CIHR, 2006 access) include, New Emerging Teams (NETs) Engaged in Palliative and End-of-Life Research and the principal named contacts are:

- *Optimizing End-of-life Care for Seniors.* ALLARD, Peter, Elizabeth Bruyere Research Institute, Ottawa, Ontario.
- *New emerging teams in palliative care: Cancer-associated cachexia-anorexia syndrome.* BARACOS, Vickie, University of Alberta, Edmonton.
- *End-of-life care and vulnerable populations.* CHOCHINOV, Harvey & STIENSTRA, Deborah., University of Manitoba, Winnipeg.
- *Palliative care in cross-cultural context: A NET for equitable and quality cancer care for ethnically diverse populations.* DOLL, Richard; KAZANJIAN, Arminee; BARROETAVENA Maria Cristina; FYLES, Gillian; JOHNSTON, Gracei, LEIS, Anne BCCA, University of British Columbia, University of Saskatchewan and Dalhousie University.
- *Developing, evaluating and implementing new interventions in palliative care.* GAGNON, Pierre, Laval University, Quebec City, QC.
- *A multidisciplinary cancer pain research network to improve the classification, assessment, and management of difficult cancer pain problems.* HAGEN, Neil; FAINSINGER, Robin & BRASHER, Penelope, University of Calgary & University of Alberta, Edmonton.

- *Understanding and improving communication and decision-making at the end-of-life.* HEYLAND, Daren, Queen's University, Kingston, Ontario.
- *Overcoming barriers to communication through end-of-life and palliative transitions.* KIRK, Peter & LAU, Francis, Royal Jubilee Hospital & University of Victoria, Victoria, British Columbia.
- *Transitions in pediatric palliative and end-of-life care.* SIDEN, Harold, University of British Columbia, Vancouver.
- *Family care-giving in palliative and end-of-life care: A new emerging team.* STAJDUHAR, Kelli. & COHEN, Robin, University of Victoria, B.C. & McGill University, Montreal.
- *Prevalence of palliative patients and their health services utilization in Saskatchewan: A feasibility study.* Leis, Anne (PI). Dr. Leis is a Canadian Cancer Society Research Scientist.
- *Access to care at the end-of-life: Encounters between home care nurses and family caregivers.* Stajduhar, Kelli, Cloutier-Fischer, D.S., McLeod, B.E., Purkis, M.E., Roberts, D.K. & Stevenson, R.L. (2006-2008), University of Victoria, British Columbia.

Ongoing CIHR Funded Operating Grants (Palliative and End-of-Life Care):

- *An international multicentre validation study of a pain classification system for advanced cancer patients.* Fainsinger, Robin & Nekolaichuk, Cheryl (2005-2007), Alberta Cancer Board, Cross Cancer Institute, Edmonton.
- *Developing and piloting cross-cultural curriculum for delivery and utilization of end-of-life health care services.* Hampton, Mary; Baydala, Angelina; Bourassa, Carrie; & Hadjistavrapoulos, Thomas (2004-2005). University of Regina, Saskatchewan.
- *Completing the circle: End-of-life care with Aboriginal families.* Hampton, Mary; Baydala, Angelina; Bourassa, Carrie; Clark, Velda; MacLean, Michael; & Saul, Gerald (2006-2009), University of Regina.
- *Innovative Bayesian methods for biostatistics and epidemiology.* Gustafson, Paul; Le, Nhur; Levy, Adrian; & Macnab, Ying (2006-2111), University of British Columbia, Vancouver.

**National Cancer Institutes of Canada (NCIC)**

Another important funding body for end-of-life care research is the National Cancer Institutes of Canada. Several end-of-life projects have been funded. Illustrative projects are:

- *Quality of life of palliative care patients & their family caregivers.* Cohen, R. & Leis, A. (2001-2005).
- *The value of quality of life information to cancer patients.* Brundage, M. & Leis, A.: (2003-2005).

**Canadian Prairies Funded Research**

The Saskatchewan Health Research Foundation has funded several projects focused on end-of-life. They have also encouraged University of Saskatchewan and University of Regina researchers by providing funding to develop a research team focused on end-of-life research.

- *Quality End-of-life Care Research Group.* Duggleby, W., Kaiser, A., Baydala, A., Bourassa, C., Gjevre, J., Goodridge, D., Hampton, M., Leis, A., MacLean, M., Quinlan, L., Thomas-MacLean, R., & Saul, G.: Funding provided by the Saskatchewan Health Research Foundation, 2006-2008.

- *Quality of End-of-Life Care: The perspectives of bereaved family members of lung cancer and COPD patients, health care providers and policy makers in rural and urban areas.*  
Goodridge, D., Duggleby, W., Rennie, D. & Marciniuk, D., (2005-2007)

The Alberta Cancer Board, Palliative Care Research Initiative (PCRI) was a one-time, multi-year coordinated effort to support the study of palliative care with a focus on comprehensive, multi-disciplinary approaches to the study of end-of-life issues for cancer patients. Information on legacy reporting documents from the PCRI should be directed to Dr. Vickie Baracos at [vickie.baracos@ualberta.ca](mailto:vickie.baracos@ualberta.ca)

The Pallium Project, Health Canada

The Pallium Project started as an applied Health Human Resources (HHR), Continuing Professional Development (CPD) collaborative project of the Institute for Professional Development, University of Alberta and the Division of Palliative Care Medicine, University of Alberta. The original Health Canada Contribution Agreement funding from Health Canada's, Rural and Remote Health Innovations Initiative (RRHII), which enabled commissioning of the Pallium Project in 2001, coincided with Pallium Project co-founder Dr. José Pereira's, appointment to the Division of Palliative Care Medicine, Department of Oncology at the University of Calgary.

From 2001 – 2002, the Pallium Project (i.e., Phase I) was administratively hosted by the Research Administration Division of the Alberta Cancer Board. In late 2003, the Pallium Project's Phase II funding was announced as a one-time, \$4.3 million Contribution Agreement contract between Health Canada and a collaborative of more than 200 individuals from some 40 Canadian

organizations. The Medical Affairs & Community Oncology (MACO) Division has been the administrative hosting authority and Project Sponsor for Pallium Project (Phase II).

Pallium Project (Phase II) is mandated from December 2003 – September 30, 2006 and is focused on a variety of primary-care capacity-building initiatives aimed at improving access, enhancing quality and building longer-term system capacity to care those with chronic progressive illness, the actively dying and their families. Archival sites of Phase I and Phase II resources can be found at [www.pallium.ca](http://www.pallium.ca). A Phase III Feasibility Study was announced by the Pallium Project (Phase II) Project Steering Committee in September 2006.

Researchers Listed on Canadian Virtual Hospice:

*Western Canada*

- Harvey Max Chochinov, Canada Research Chair in Palliative Care, Cancer Care, Manitoba
- Gillian Fyles, M.D., Cancer Centre, Kelowna, B.C.
- Kelli Stajduhar, Ph.D., University of Victoria, B.C.
- Simone Stenekes, Canadian Virtual Hospice, Winnipeg, MN.

*Canada*

- Robin Cohen, Montreal, QB
- Daren Heyland, M.C., Kingston General Hospital, Queen's University
- Dianne Iverson, MN, St. Lawrence College, Kingston, ON
- Grace Johnson, Ph.D., Dalhousie Univ., Halifax, NS
- Christine McPherson, Ph.D., University of Ottawa, ON
- Anita Stern, MScN, Burlington, ON
- Viola Raymond, M.D., Queen's University, Kingston, ON
- Keith Wilson, Ph.D., Ottawa, ON

### Future Pathways: Research Considerations

Recommendations for future research and improved clinical practice in bereavement as part of quality end-of-life care should continue and transcend ethnicity and culture. This includes developing knowledge of the nuances of diverse populations in Canada, so bereavement services evolve to support all who need them. It is also imperative for future Canadian bereavement service provision to study and develop pathways to effectively “reach” and “service” these populations in many areas. Developing end-of-life care services and bereavement counselling for people in marginalized contexts is a significant need, whose importance is increasingly being better documented for historically underserved and poorly serviced populations.

All grief is not created equally! A better understanding of loss as part of the human condition as well as complex loss and factors which complicate loss, the grieving process and healthy bereavement is important for risk assessment and service design. While a great majority of people may benefit somewhat from general bereavement services, a greater benefit may be provided for those people who experience complex losses and are in a state of chronic bereavement. Future research on the differences of bereavement services for those suffering complex losses and for those suffering losses of a natural event of the life cycle would be helpful to bereavement centres.

The bereavement research community is in the early days of demonstrating the efficacy of well-designed bereavement responses for improved population health (e.g., mental health and wellness). To date these “preventative medicine” arguments are poorly understood by public funders of health

services and their delivery agents. Further systematic inquiry, evidence, guidelines and policies for quality bereavement responses are required at many-levels. This, in turn, will build a foundation for which bereavement programming demonstrates its cost-benefit as part of preventative health services. In time, we will come to see that well-designed and properly resourced bereavement programming, particularly for “at risk” populations, is not only a “nice to do,” but an essential investment in our communities.

Canada is a leader in many areas of palliative and end-of-life research (e.g., end-stage clinical efficacy to ameliorate symptom distress) and a follower in others (e.g., bereavement, psychosocial, existential, spiritual aspects, etc.) (Chochinov, 2006). Recent public research investment, much of it enabled through CIHR processes and initiatives referenced herein, provide an important opportunity for those interested in improved bereavement policy and programming performance. There are many potential and exciting opportunities to link into innovative research in end-of-life care, training of new clinicians and investigators. The principles of university engagement practice are an important approach to enable more productive collaboration among researchers and community-based service providers. It is essential for academics and potential community collaborators to consider and explore the potential to work more constructively together, to assure relevance and effective translation of findings into clinical practice and service design.

### **Continuing Challenges For Bereavement Programming**

The focus of this work has been a review of existing research and resources on grief and bereavement to discuss the current state. We have highlighted some of the literature and outlined some areas for bereavement research. We have shown there is considerable practice, research, education and policy development in bereavement. We have shown colleagues in Canada are in a formative period in developing bereavement knowledge that is useful for improving quality care. Many Canadian scholars and practitioners are at the forefront of bereavement research questions, especially those involving cultural diversity. This should not come as a surprise. Canada has evolved into one of the most globalized nation-states. The challenges we face in the populations we serve clearly reflects the people who we have collectively become.

There are a great many challenges that will confront bereavement service providers over the next few years. Those challenges include:

1. Recognition that family members are part of the “unit of care” in a Population Health informed approach to palliative and end-of-life care. There is a focus on care for the dying family member and the family prior to the death event, yet it seems worthy to note that once the loved one has died, the care relationship often abruptly terminates. That is, the family is left to grieve the loss of their loved one, separated from the aid and support of health care and social service providers. This challenge of “continuity of care” seems to be ongoing and worthy of much discussion and investigation.

2. The role of gender in bereavement support. Most health care providers, including palliative care providers and people providing bereavement programs, are female.

This raises a potential challenge that may benefit from a gender-based analysis of the topic of bereavement.

3. Effectively engaging and responding to Aboriginal cultural diversity and context. There is an ongoing challenge to attain and sustain connections between Aboriginal populations and non-Aboriginal people, particularly because of a historical context which drives continued mistrust and a proliferation of profound and unresolved grief. Issues of communication, intention and understanding all arise in identifying and mapping best practices of benefit to Aboriginal and non-Aboriginal peoples. There is a great potential to combine aspects of traditional Aboriginal knowledge and western biomedical approaches to bereavement care. The challenge in this work will be to develop respectful, mutually equitable and sustainable partnerships in the knowledge development journey.

4. Developing other cultural competence. There is a great opportunity in Canada to develop bereavement care sensible to cultural and ethnic traditions and nuance. Increasingly primary-care professionals will be expected to conduct their regulated professional practice in a way that incorporates the construct of cultural competence. There is an opportunity and a challenge to learn about bereavement care within different ethnic traditions, in order to develop bereavement programming responses that are sensitive to and sensible about different cultural and ethnic practices. Our providers need to ask skillful questions, understand the influences of major traditions in the communities they serve and find pathways to provide culturally competent care in a context of growing inter-cultural and inter-generational complexity.

5. Sustainable knowledge translation, program development and program funding. Research funding for palliative and end-of-life care is increasingly available. Funding for knowledge translation, however, to effectively transfer the insights from research into useful resources for improved bereavement and grief support is lacking. It will be a challenge to ensure that bereavement services and programs continue to evolve as a significant component of the health care and social service system.

6. Adequate resources and community engagement. There is a great opportunity and need for more research on bereavement care. While there is promising bereavement care practice in Canada, there has not been much clinical/applied research because those providing the care do not have the time and in many cases, the infrastructure and research skills, to conduct systemic inquiry into their practices. Much of this reflects a reality that bereavement programming has been the domain of community service agencies which do not have comparable research capacity to teaching hospitals and research universities. The challenge here is for bereavement service providers to establish meaningful partnerships with university researchers and other clinical researchers in order to undertake priority research on key bereavement care research questions. Such community-university partnerships have the potential to significantly increase the research on bereavement care in the immediate future.

### **Conclusion**

The challenges are clear but manageable. By addressing these challenges, the practice, research, education and policy development on bereavement care and services will be significantly improved in the near future.

### **Contact**

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### **Getting Started – Translating Knowledge in this Paper into Local Action**

The paper has been released, in part, to support the translation of knowledge from a specific instance of inquiry for the benefit of others locally as applicable throughout Canada. To this end, we recommend that this paper be used in conjunction with *Applying a model to guide Hospice Palliative Care* (i.e., CHPCA Norms Toolkit) as well as *A model to guide Hospice Palliative Care: Based on national principles and norms of practice*. These documents are both available for download at no direct cost to end-users in PDF format from the Canadian Hospice Palliative Care Association's web at [www.chpca.net](http://www.chpca.net) under the Marketplace link. This paper should also be used with *Building community capacity: A retrospective of bereavement programming in Regina, Canada*, which is accessible at [www.pallium.ca/infoware/KFA\\_2006-02\\_BereavementRetro.pdf](http://www.pallium.ca/infoware/KFA_2006-02_BereavementRetro.pdf)

#### **Taking Stock**

- Do your local primary-care stakeholders, including health delivery system management, think about and design services by recognizing the family unit (broadly defined) as the “unit of care,” including the personal/family health risks associated with longer progressive illnesses and post-death event care availability for survivors?
- Do your local primary-care professionals understand the differences between anticipatory grief, post-death grief as part of normal loss processing, and complicated grief?
- Do your local primary-care professionals and social welfare/human services professionals understand the impact of complex, chronic and compounded unresolved grief as a disabling force for specific “at risk” populations/communities?
- Do your local primary-care professionals think about “cultural competence” as an important emerging component of care for regulated health care providers and a “rights”-aligned organizational/community capacity?
- Does your local health delivery system/community health system have processes for identifying “evidence gaps” about important community health questions, including processes for engaging and discussing those with the nearest local academic health sciences institution?

If you answered *No* or *Somewhat* to any or all of these questions, you may wish to consider ways to facilitate a community capacity building response to improve local bereavement support?

#### **Getting Started**

- Summarize what you have discovered, the concerns you have and share them locally.
- Share this paper and your concerns with other local champions in your community.
- Initiate an informal “study group” or working group to further discuss information in this paper with the intent of identifying some possible local “go forward” priorities.
- Present the findings of your local considerations to health delivery system management and other community-leaders as appropriate to the content, possibly within the context of a local change management or quality improvement project.