



Building Community Capacity: A Retrospective of Bereavement Services in Regina, Canada

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ABOUT THE PALLIUM PROJECT

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

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

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

ABOUT THE *KNOWLEDGE FOR ACTION* OCASSIONAL PAPER SERIES

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prior to peer-review publication, or work otherwise destined to become difficult to access "grey literature" (i.e., unpublished commercially, see www.greynet.org).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

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NOTICE ABOUT 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.

TABLE OF CONTENTS

Foreword	4
Introduction.....	7
Relevant Local Research.....	7
Purpose	8
Procedure/Methods	8
Key Informants.....	8
Demographic Information	9
Summary of Findings	
Bereavement Services Currently Available in Regina	9
Bereavement Services unit Development	11
Community Bereavement Supports Historical Summaries	13
Bereavement Centre Development	15
Bereavement Centre Development Intent	16
Bereavement Centre Vision & Key Components	17
Future Directions for Bereavement Services	18
Recommended Future Directions of Bereavement Services in Regina.....	20
Limitations.....	23
Conclusion.....	24
Contact.....	24
References.....	25
Appendix A – Key Informant Interview Guide	26
Appendix B – Regina Bereavement Programming Timelines.....	28
Getting Started – Translating Knowledge in this Paper into Local Action.....	30

FOREWORD

In 1994, CBC Radio One broadcast a multi-part series entitled *Community and its counterfeits*¹ as part of the radio network's daily *Ideas* program. *Ideas* program host David Cayley explored the pervasiveness of social services in modern community life with Northwestern University community development scholar/activist/thinker, Professor John McKnight. McKnight focused on the prolific growth of human service "technologies" in the form of professionalized human services. He vehemently argued that professionalizing care inevitably degrades and destroys the inherent capacity of citizens to care for themselves within local communal structures.

Inspired by his CBC *Ideas* engagement, McKnight went on in 1995 to publish one of his last books entitled, *The careless society: Community and its counterfeits*². McKnight's views are informed by formative experiences grounded in the urban turbulence of the 1960's U.S. Civil Rights era and some 40 years of systematic inquiry. He argues that the reality of modern life as defined by social welfare systems creates a monopoly on legitimate forms of action and legitimate actors, often neutralizing citizen-driven, collective capacity.

He extends the earlier critique that uncritical and unchecked professionalization of direct service delivery and institutional models of care systematically undermines the inherent capacity of citizens to care for themselves in communion. The result he suggests has effectively created "crime-making corrections systems, sickness-making health systems and stupid-making schools based on a social model that conceives of society as a place bounded by institutions and individuals."³

McKnight opens *The careless society* with a chapter entitled *John Deere and the Bereavement Counselor*. In this chapter McKnight uses a historical account of blacksmith John Deere's, 1837 invention of the steel forged plow (i.e., the "sod buster") as an instrument of innovation used to tame the matted

prairie grasses of the Sauk Prairie area of Wisconsin, thus enabling homesteading. He goes on to share how European settlers used Deere's technology to break the land, ignoring long established traditional ways that Sauk Indians used to carefully steward the land to grow wheat. The reader shortly learns it took one generation to deplete Wisconsin homesteaders' land, forcing successors to move further west.

An analogy is drawn to a modern technology called "bereavement counselling," in which a professional social worker enters a rural prairie community to "meet the needs" of those experiencing death by offering direct, professional service. The story ends with the departure of the bereavement counsellor (without replacement) and citizens no longer feeling that long established (but now displaced) processes of community mourning and support are legitimate, without being validated through professional bereavement services. McKnight reminds the reader that "grief is common property, an anguish from which the community draws strength and which gives it the courage to move ahead."⁴

I also find McKnight's, Wisconsin story of more than passing co-incidental value, because so much of the challenge in constructing community capacity for healthy bereavement within Aboriginal communities in Canada specifically, predictably involves returning ownership for said processes to Aboriginal people as informed in large measure by traditional ways of knowing.

I share these ideas at the outset of this *Knowledge for Action* occasional paper for they provide some important lessons for the Canadian Hospice Palliative Care community. First, we are cautioned that no human service "technology" including new "evidence-based" processes, however well-intended, come without a downside risk. Our colleagues in medicine have instilled this concept as part of their professional socialization only early last century through vigilance for *iatrogenic disease* (i.e., physician-induced harm). If we are to

be true to the fundamental tenants of Primary Health Care (PHC), then we best ask ourselves to what extent does introducing new services risk displacing inherent citizen-based community capacity for supporting what we understand to be the basic and secondary determinants of health and well-being?

Second, and key to navigating a practical pathway in building community capacity which enables citizen initiatives to co-exist with professional services, we are challenged to consider how leaders in Regina have modelled cooperation. This has resulted in benefits of safe, ethical and accountable bereavement support practices while creating community ownership and enabling citizen-based, community capacity to co-exist with professionalized services. This is indeed a rarity and something worthy of separate examination.

Finally, I share what I have distilled from McKnight's writings as a gentle reminder to Regina stakeholders to proceed with caution in their pioneering work with a structured community-based bereavement centre, lest it result in an inadvertent co-opting of citizen processes in the name of community capacity.

Many in Canada often incorrectly assume that Primary Health Care (PHC) is only about the "front gate" to health care services through professional service providers. This is more accurately described in Canada as *primary care* and refers to the myriad ways that citizens engage human service delivery through structures such as family medical practices, primary health networks, public health, community home care, etc. A more interesting and often less talked about story in Primary Health Care (PHC) is about the co-existence of community-based, citizen-led initiatives (often but not necessarily) in partnership with delegated health authorities (i.e., Health Region, Regional Health Authority, Regional Health District, Local Health Integration Network, etc.), leading to successful community capacity.

One of the proverbial "elephants in the room" for Canadian Hospice Palliative Care involves the inherent tension that exists in many jurisdictions between citizen-led, community-based hospice palliative care responses and the professionalized responses of public-funded, delegated authorities. This is somewhat analogous to what some have witnessed in the U.S. in a bifurcation of hospice and palliative care medicine clinical capacity.

Many Canadian delegated authorities have quickly evolved into highly-integrated, academic health science enterprises operating with multi-million (and in some cases billion) dollar annual budgets. Too often within our Canadian HPC community we have seen deeply-committed people personalize what are fundamentally system and structural conflicts, rather than seek alternative pathways of "peaceful co-existence" or active cooperation between community organizations and those with public authority for service provision as delegated by federal or provincial/ territorial governments.

There are several subtexts of note about the retrospective you will read in this occasional paper. One is a model of broad-based, community leaders coming together through a community charity entitled Regina Palliative Care Inc. (RPCI), to provide leadership, support innovation and commit citizen input within a context of working with public-funded, core health service and academic colleagues.

Another is a story of citizen-led responses at the "grass roots" community- and local funeral home/ memorial staff-levels navigating constructive ways to cooperate with large health systems. The longer term story, left to emerge over time, is about if and whether the actors in this Regina-based story do indeed succeed in sharing broadly-defined "community space" in support of persons processing loss as a universal part of our human condition.

The authors allude to a point that we would not be reading this paper if it were not for RPCI. I

Building Community Capacity A Retrospective of Bereavement Services in Regina, Canada

believe they are right. The Canadian model of Hospice Palliative Care has broad scope in terms of the role of Hospice Palliative Care during illness and bereavement⁵. Not all services and supports which are within the scope of Hospice Palliative Care will necessarily have to be, nor will they be, funded through governments, nor provided directly by delegated health authorities. That will be a decision which stakeholders within communities across our country will ultimately negotiate together as guided by norms/standards.

There are population health-based arguments emerging that strongly suggest thoughtful, preventative “upstream” investments in well-designed bereavement support can off-set many “downstream” mental health and chronic illness costs. In time more will be done on the cost-benefit argument to make the “show me stuff” transparent for service funding decision makers.

What we see emerge in this paper, however, are tangible, demonstrated expressions of what is possible when community leaders collectively taken action to make local priorities happen and when citizens find solutions for mutual support⁶.

On behalf of the people working together within The Pallium Project to improve the quality of living and dying in Canada, I extend sincere thanks to those in the Regina area who graciously engaged the Project to explore the possibility of taking bereavement programming in their community to another level. In doing so they have opened their experiences and processes to the nation for careful scrutiny of: Where did this come from? How did it evolve? What has been the experience to-date? What might others learn? How might others “leap frog” the experience to accelerate bereavement programming innovation in their communities?

I wish to thank Drs. Michael Maclean and Mary Hampton from the University of Regina for bringing increasingly scarce academic resources to help inform community capacity building. They worked with a range of current and former students to pull together work product and two

earlier local monographs, one upon which this occasional paper is materially based. It is my hope that other Canadian communities might use the University of Regina process presented in this occasional paper as one tool/model to inform ways they might work with local academic resources, including replicating/building on the methodology to identify and make progress on their own community bereavement capacity.

Finally, I wish to thank Marilyn Komick of Prairie Sage Productions who patiently and diligently navigated among stakeholders within Regina over several months on the practical planning work which is referenced in this paper. I also thank Dr. Bert Einsiedel, Professor Emeritus of Extension at the University of Alberta, for his skillful facilitation work with stakeholders and mentoring/coaching. If I have learned one thing over the last few years, it is the importance of involving a range of skills and experience in HPC capacity building. Ms. Komick and Dr. Einsiedel efforts in the subproject clearly exemplify this.

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¹ CBC (1994). *Written transcript - Community and its counterfeits*. Toronto: CBC RadioWorks.

² McKnight, J. (1995). *The careless society: Community and its counterfeits*. New York: Basic Books.

³ McKnight, J.L. (1987). Regenerating community. *Social Policy* (Winter 1987), 54-58.

⁴ *ibid*, 1995, p. 5.

⁵ The reader is directed to Figure 8 on page 18 of *A model to guide Hospice Palliative Care: Based on national principles and norms of practice* as listed in the Reference section.

⁶ On a note which offers balance to the extreme critiques of earlier writings and “go forward” hope for inter-sectoral actors who need to work together, John McKnight suggested possibilities that present as responses like those in Regina, specifically through RPCI. The reader is directed to McKnight, J.L. (2003, May). *Regenerating community: The recovery of a space for citizens*. Paper presented at The IPR Distinguished Public Policy Lecture Series, Northwestern University, Chicago. Retrieved, November 30, 2006, from http://nationalservicerresources.org/filemanager/download/community_development/mcklecture.pdf

Introduction

Examining bereavement services that are available in the Regina area became a priority in early 2005 when Regina Palliative Care Incorporated (RPCI), a Regina-based community charity, and Regina Qu'Appelle Health Region (RQHR), Palliative Care Services (PCS) took the lead on exploring a free-standing bereavement centre in Regina. At RQHR PCS's invitation, the Pallium Project became engaged and offered support with initial funding for stakeholder meetings, business planning and research support in collaboration with the University of Regina.

Relevant Local Research

A local research project that is relevant specifically to bereavement centre development in the Regina area is *A community assets/needs assessment of bereavement services: Gathering support for a bereavement resource centre in Regina, Saskatchewan* (Melvin, 2002). Melvin administered a questionnaire to community members and human service providers, asking them about current bereavement services. She also asked respondents if they felt a bereavement centre would be a supplementary and/or complementary resource for bereavement services in the Regina community.

Identified themes emerging from the work included: 1) a need for additional bereavement services that are more accessible and specialized (including referral and resources) and continued education/training for professionals and the public; 2) stronger connections and communication among service providers about resources, referrals, professional support and decreased competition between agencies as well as decreased duplication of services; 3) concerns about funding for such a centre; and 4) specifically a need to address service

provision to rural areas and school settings. Based on analysis of this survey data, Melvin concluded that community barriers existed for creation of a bereavement centre at that time. Such a centre, however, would be a useful resource in the Regina area and builds upon existing Palliative Care Service programs and expands possibilities for service provision and research. The survey used for the current study builds on Melvin's (2002) work. It provides additional contextual and background information, describing bereavement centre development possibilities in the Regina area.

Another significant community-based research project was conducted by Carol Sakundiak (2005), entitled *A study of palliative care in Saskatchewan Health Regions*. Sakundiak studied palliative care service delivery models within various Saskatchewan Health Regions. Her literature review describes several relevant pieces of research supporting the need for bereavement care with families of dying persons during and following end-of-life care. For example, the *Guide to End-of-Life Care for Seniors* (Fisher, Ross & MacLean, 2000) recommends "continuity of care from admission through the families' bereavement period" (Sakundiak, p. 9, 2005).

Sakundiak discusses challenges when providing service to rural communities and the role of social work in providing support and education within the field of palliative care. The need for expanded, specialized bereavement services was supported by Sakundiak's findings, identifying that "psychosocial support is an integral aspect of palliative care, but other than in the tertiary centres, psychosocial, grief and bereavement counselling needs were mainly referred to mental health, community health, the hospital social worker, or were picked up by churches or funeral homes in the case of bereavement

care" (p. 39). One theme Sakundiak identified is Child and Family Needs, which includes bereavement care for families following palliative care client deaths. Sakundiak's findings support bereavement care services to be expanded within palliative care programs and health regions. She further reinforces the need to expand overall palliative care services, including bereavement services to rural communities.

Purpose

This study is a 20 year community-oriented retrospective analysis of developmental milestones associated with Regina area community capacity in bereavement, including community-based resources, clinical care and research. Data was collected from key informants, thematically analyzed and organized into a retrospective of local developments, challenges, successes and insights for future development. We use this information to provide comments and suggested future directions on how grief and bereavement services could be arranged to respond to the needs of Regina and adjacent communities. This retrospective along with the recommendations are a source of information for those considering creation of a bereavement centre, as informed by the Regina experience to-date.

Procedure/Methods

Potential key informants were contacted via telephone to determine if they were willing to participate. Open-ended questions comprised the interviews and a copy of the interview schedule used is presented in Appendix A. Interviews were conducted over a three week time period, either in person or over the telephone, and averaged 20 minutes in duration with a range of 10-30 minutes each. Two respondents replied in writing. Upon receiving a brief explanation regarding the purpose of the research and what would be

done with the results, key informants were asked the questions. Notes were taken on a record form for each of the questions and interviews were not tape recorded. Using qualitative research methods, responses were coded into relevant response categories and organized into themes. Results from the interview data were then analyzed to generate a retrospective timeline of bereavement services. Recommendations for future directions were informed by these results.

Key Informants

Twenty individuals who work as service providers, policy makers or community leaders with Regina area palliative care services or in community bereavement service organizations comprised our sample of key informants. Fourteen respondents were interviewed and four others were unreachable, equaling a 77.8 % response rate. Individuals were purposely selected and approached as potential key informant candidates based on roles with the Regina Qu'Appelle Health Region's (RQHR), Palliative Care Services, Bereavement Services unit, Regina Palliative Care Inc. (RPCI), and other known/visible community support groups and services.

The research team collaborated with local health services leaders to gain access to the field. Following initial contact with RQHR's Director of Palliative Care Services, the Bereavement Coordinator, the Bereavement Centre Project Coordinator, current and former RPCI Board members, and community groups, prospective interviewees both in Palliative Care Services and in the community at large were identified. Basic demographic information was requested in the interview.

Demographic Information

The breakdown of key informants by gender is: 14.3% male (n=2) and 85.7% female (n=12). Some 71.4% of informants are of Caucasian ancestry (n=10) and 7.1% with some Aboriginal ancestry (n=1). The ethnicity was not obtained for three respondents. All of the respondents were based in an urban setting, in particular the city of Regina.

The various occupations and roles of key informants included roles within RQHR Palliative Care Services, such as: Bereavement Coordinator, Director of Palliative Care Services, Bereavement Centre Project Manager and an RPCI board member. Key informants also served in roles within the Regina community, including various community grief groups, a funeral director, funeral home aftercare counsellors, an Aboriginal health consultant, a perinatal program coordinator, a youth clinical caseworker and a private practice psychologist.

Summary of Findings

This section summarizes the findings from the key informant interviews according to services currently available, a historical frame for evolution of the RQHR Palliative Care Services, Bereavement Services unit and historical information for other community-based bereavement resources in the Regina area.

Bereavement Services Currently Available in Regina

Current bereavement services vary in range of service provision for various age groups, types of death, religious perspectives, non-profit status, and relation to the health care system. A Bereavement Services unit and a Bereavement Coordinator, jointly supported by RQHR PCS and RPCI, provide the majority of formal bereavement services in the Regina area. The services of this unit are available to

any grieving persons. Access is *not* limited to families of those on a RQHR PCS palliative care roster, or with cancer. This is a common misperception.

The Bereavement Coordinator provides individual bereavement counselling, organizes various grief groups and other bereavement-related activities. The Coordinator also organizes volunteers who facilitate groups and camps/other duties. These services currently include Adult Bereavement Groups, Childhood and Teen Grief Groups, Walking Groups, Young Adult Bereavement Groups, Daytime Grief Groups, *Caring Hearts Camp*, and the *Hope for the Holidays* service.

The Adult Bereavement Groups run three times a year, once a week for five weeks during evenings. This group is accessed by adults experiencing grief from a death loss of a loved one from any cause.

The Childhood and Teen Grief Groups (ages 5 -18) operate twice a year, once a week over six weeks and in concert with a concurrently-conducted group for parents/caregivers. The death losses in these groups are varied in terms of bereaved persons' relationship to the deceased and the causes of death.

Participants in the *Miles and Memories* walking group meet for physical activity and receive mutual support by sharing their grief experiences with others processing a death loss.

The Young Adult Bereavement Groups are offered twice yearly, once a week over six weeks with the focus age group being 18 – 30 (approx.) years. This group does not run if there are not enough participants registered (usually a minimum of six).

The Daytime Grief Groups run in the afternoons weekly for five weeks at a time and are similar in focus to the Adult Bereavement Groups.

The *Caring Hearts Camp* is a grief camp for children and teens (ages 5-18) which is held annually at the Dallas Valley Ranch Camp. The camp combines memorial activities and sharing of grief experiences along with fun activities.

The *Hope for the Holidays* service is a yearly non-denominational service held in early December. It provides support for grieving persons to better cope with the especially challenging nature of loss during the holiday season.

Community-based bereavement services include aftercare grief services based in funeral homes and non-profit support groups such as *The Compassionate Friends (TCF)*, *Survivors of Suicide (SOS)*, *Bearing Loss* and *GriefShare*. These non-profit groups each offer support services to groups of people suffering particular losses.

The Compassionate Friends offer monthly support meetings, telephone friends, an occasional newsletter and a lending library of 300 resources. It also offers connections to national and international TCF bodies that host conferences and workshops for families, parents and siblings experiencing loss of a child at any age and from any cause. The Regina TCF group is organized out of a volunteer chapter leader's home.

The Regina TCF chapter will often refer people to the Bereavement Services unit groups and SOS, especially when they receive inquiries from bereaved individuals whose needs are beyond the scope of TCF's mandate (e.g., a widow/widower). TCF chapter leaders

consistently direct bereaved persons to more suitable services when needs do not fit the mandate. In the past, the Regina chapter had one of the few formalized TCF sibling support groups. This category of client group, however, has not met formally in the past eight years.

Survivors of Suicide (SOS) provides support, through a process of monthly meetings and use of resources, to individuals grieving the death of a significant person, where cause of death is suicide. It is organized out of a volunteer coordinator's home.

GriefShare is open to anyone grieving the death of someone significant. It offers support based in a Christian faith perspective through 12 volunteer staff. The group formed at Faith Baptist Church and has since expanded. *GriefShare* is now provided by various Christian congregations, such as Apostolic, John Paul II Centre and Lutheran.

A *GriefShare* session is conducted over a 13-week period, with 13 sessions of sharing groups facilitated with videos on specific bereavement topics. Groups are approximately 30 adults, mostly women, experiencing the loss of a spouse. *GriefShare's* organizers also lend out their videos to rural areas. If facilitators feel someone needs further care, or if there are children involved, they will often refer to the Bereavement Services unit or other counselling agencies (e.g., *The Caring Place*).

Bearing Loss is a group which began recently out of an identified need for a more specific focus on perinatal (pre- and post-natal) loss. This group offers monthly support to parents who have experienced a perinatal death loss and is run via the YMCA's perinatal programs. The group is intentionally designed to be welcoming, flexible and open for

sharing. Emphasis is placed on the uniqueness of the grief journey, honouring the deceased and “going on with living.” The group is attended by parents and some grandparents. Supportive friends are welcome but rarely attend. Siblings and children are referred to Bereavement Services unit’s, children groups.

Another element is perinatal loss support offered through an annual *Infant Loss Memorial Gathering*. A yearly gathering provides a safe environment to acknowledge loss for parents and families whose babies have died from miscarriage, stillbirth and post-natal death. The gathering provides a service, a memorial book and memorial pins for parents and families.

Funeral home-based aftercare services exist through the Regina Funeral Home (RFH) *Arborcare*® support program. A RFH resource person provides individual and in-home counselling along with monthly group sessions on specific topics that are informative and also focus on caring and sharing as a supportive practice.

Lee Funeral Home and Victoria Avenue Funeral Home provide aftercare counselling through *Family Service Coordinators*. The Family Service Coordinators in Regina also provide a referral brochure of various bereavement services of which they are aware, other resources, a one-on-one “listening ear” when needed and referrals to other agencies (i.e., Palliative Care Services, TCF, SOS and GriefShare).

Speers Funeral & Cremation Services has a library of resources for the bereaved and any aftercare follow-up is usually by referral to the RQHR PCS Bereavement Services unit.

Another relevant bereavement support service in Regina and area is the local Victim Services

programs. The police-affiliated victim service programs are: Regina Victim Services of the Regina Police Service and Regina Region Victim Services of the RCMP Regina Detachment (this program offers support to nine detachments in rural Saskatchewan communities). These services offer immediate support following traumatic deaths involving the police services (i.e., road trauma, suicide, homicide or sudden, unexplained deaths). Victim Services current capacity includes immediate support in the crisis stage and follow-up support, resources and referrals to other agencies. They often make referrals to Survivors of Suicide and RQHR Palliative Care Services, Bereavement Services unit.

Bereavement Services unit Development

In order to better understand the state of current bereavement services and the utility of a bereavement centre, we provide a brief history of bereavement services managed by the RQHR Palliative Care Services, Bereavement Services unit. By analyzing data obtained from key informants, a narrative describing the potential role and utility of a bereavement centre emerges, as informed by historical developments, key milestones and framing of the current context.

Regina Palliative Care Inc. (RPCI) is a community-based, non-profit charitable organization established in 1983, with the first annual meeting occurring in spring 1984. The RPCI board structure has always been broad-based. This has enabled the engagement of local leaders from business, government and agencies who have a sphere of influence in the community, and an interest in advancing palliative care. With extensive community networks, RPCI board members facilitate fundraising and volunteer recruitment. RPCI board members serve for up to a six year term.

As needs have arisen, members of RQHR's, Palliative Care Services team have attempted to provide services to help address emerging needs, beginning with the Bereavement Follow-up Groups (now the Adult Bereavement Group) in 1989. The RPCI set up a Bereavement Committee, with board member Joe Gauthier serving as Chair. This committee saw a need in the community for such a group. A partnership of board members and counsellors secured space at the former Family Service Bureau (present name - Family Service Regina) and began the Bereavement Follow-Up Group.

An initial challenge was clarity of the group's purpose among the public. That is, the group was originally advertised to the community as being for anyone suffering the "loss" of a loved one. This led to interest in participation from those who had experienced other significant life losses (e.g., divorce and pet deaths). It became necessary to specify that the groups were for those experiencing grief from a death of a person of significance to the bereaved. Other challenges included locating suitable space and working through functional formats for group facilitation (e.g., establishing a set of rules and guidelines for group size, frequency of the groups, etc.).

The groups initially met every week, later moving to every two weeks to mitigate overwhelming emotional experiences. A client-base evolved quickly and they were swamped with registrations. Creating a safe space was important for people to tell their stories and they were able to do so as often as needed to help process their grief. The groups were initially held three times per year.

Since the initial adult grief groups of 1989, the RPCI board has been a strong supporter of bereavement programming, with funding, training for volunteer facilitators, provision of

supplies and space for grief groups and promised financial support for a free standing bereavement centre. Following the success of the adult groups, the program expanded in 1994 to offer a Childhood and Teen Grief Group, which usually runs twice a year.

Following the success of the childhood and teen groups, *Caring Hearts Camp* was championed in 1997 by Marlene Jackson (then Music Therapist for Palliative Care Services). This camp provides a weekend retreat for grieving children and adolescents. It offers a combination of memorial activities, grief support and fun camp activities. *Caring Hearts Camp* has been a pioneering initiative in Canada. The Camp is one of the earliest examples of children's grief camp programming in Canada, remains one of the few to-date in the country, and has many unique elements in design and structure.

Through local advocacy and development efforts led by RPCI, a Bereavement Coordinator position for Regina Health District, Palliative Care Services was secured in 1998 (Regina Health District being the predecessor organization to the RQHR integrated health authority). The first coordinator was Sylvia Keall and the current coordinator (since 2000) is Marlene Jackson. This role provides individual counselling, organization and facilitation of bereavement groups, grant application preparation, organization and facilitation of the children's grief camps, liaison with the RQHR Palliative Care Services team (e.g., director, music therapist, physicians, spiritual care, medical social workers, the RPCI board, etc.). The current coordinator is in demand throughout Canada as a resource person for professional education, conference workshops and presentations.

Miles and Memories, a sharing and walking group, was started in 1999 and has had some success. Existing groups continue to operate. No future groups are currently planned, partially due to winter season barriers associated with outdoor walks.

The Young Adult Bereavement Group (YABG) was commissioned to address needs seen by the Bereavement Coordinator and a University of Regina, Counselling Services Counselling Assistant. After preliminary research into comparable groups, the first group was held in 2001. It was a joint effort of University of Regina, Counselling Services and the RQHR PCS Bereavement Services unit, conducted at the University of Regina. Since the initial group, YABG has been offered solely through RQHR PCS Bereavement Services unit and other bereavement programs at St. Mark's Lutheran Church.

Challenges have included a struggle with finding effective ways to reach/promote to the target age group (18-30ish years). Another recent addition to bereavement programming (February 2004) has been a Daytime Support Group, which has been thus far successful. This group serves as a resource for adults available during daytime hours (e.g., seniors, retirees, etc.).

Following successful development of the Regina Wascana Grace Hospice, the concept of a Bereavement Centre for Excellence was adopted by the RPCI board as a new community-led project. The bereavement centre design intent is to support "a mutually respectful, collaborative culture among human service systems and providers in order to establish a coordinated, comprehensive, and responsive continuum of human services" (Wizniak, 2006). The Centre's sanctioned service delivery model is informed by the U.S. National Hospice and Palliative Care

Organization's, *Guidelines for bereavement care in hospice* (Bouton, et al., 2002; Wizniak, 2006).

Dedicated volunteers, many whom facilitate on a regular basis, have been a key program component. RPCI's financial and training support including education for the Bereavement Coordinator and volunteer facilitators as well as equipment, rent and supplies have been critical success factors to-date. A continuing commitment of professional volunteer facilitators is another indicator of program success. This ongoing commitment facilitates relationship development, rapport, professionalism, trust, respect and deep commitment. Recruitment of volunteer facilitators generally happens informally or by referral.

The RQHR Palliative Care Services (PCS) program has been involved in many pioneer activities, including spiritual care research, video conference education for professionals, hospice development, multidisciplinary team practice and strong clinical guidance.

As the Bereavement Services unit addresses various bereavement needs which present, the major bereavement programming partners, often led by RPCI and RQHR PCS, have been responsive to emergent needs. This approach has led to successful and client-driven program development. A core of very committed RPCI board members supporting these programs and many volunteers with professional training, usually in helping fields (e.g., social work, counselling, nursing, etc.), are also integral to ongoing success.

Community Bereavement Supports Historical Summaries

Although RQHR Palliative Care Services, through a Bereavement Services unit, provides significant and highly-visible bereavement care in the Regina area, as

Building Community Capacity A Retrospective of Bereavement Services in Regina, Canada

previously noted several community groups also provide bereavement support. In this section we briefly elaborate on the origins of key community bereavement groups identified in the aforementioned summary of services.

The Compassionate Friends (TCF), Regina chapter was established by two couples in 1983. The group has grown and is now connected to national (see www.tcfcanada.net) and international TCF bodies (see www.compassionatefriends.org) that provide mutual support through conferences, workshops and other materials.

The *Survivors of Suicide* (SOS) began in 1985 by a couple looking for support with others who had experienced a death by suicide. The local SOS chapter is one instance of hundreds of such support groups in North America. Many start with resources made available by the American Foundation for Suicide Prevention (see www.afsp.org under the *Surviving Suicide Loss* link). In Canada, the Calgary-based *Centre for Suicide Prevention* markets a book entitled *Counselling the bereaved: Caregiver handbook* (see <http://www.suicideinfo.ca/csp/go.aspx?tabid=61>). In addition to generic bereavement process information, the book also contains a specific section on suicide bereavement.

Since 2000, the *GriefShare* support group has operated from the Faith Baptist Church using volunteer facilitators and a Christian faith-based approach. It has recently expanded to other churches and centres in the Regina area. *GriefShare* (www.griefshare.org) is an international, programmatic effort based in the U.S., which supports thousands of local groups in the United States, Canada and ten other countries.

Arborcare[®], an aftercare program offered from the Regina Funeral Home, has a ten year local history. Mary Sutton has been, and currently remains, the contact person for these services. *Arborcare*[®] is a company-wide, programmatic bereavement support approach that is localized within the service mix of community based funeral service providers of Arbor Memorial Services Inc.'s, 93 funeral homes located throughout Canada (see <http://www.arbormemorial.com>).

Lee Funeral Services, including Victoria Avenue Funeral Home, has also provided Family Service Coordinators for the past seven years. These two service providers have been part of the Alderwoods Group, Inc. As of late 2006, Alderwoods Group, Inc., has merged with Service Corporation International (SCI), which maintains a large library of corporately developed loss, grief support and bereavement resources. SCI operates under several brands and readers are directed to determine which SCI-affiliated operations may be operating in their local community (see www.sci-corp.com under the *Our Business* link, *Find a Local Provider* link).

Speers Funeral Home, an independently owned and operated service provider, refers all bereavement concerns to the RQHR PCS Bereavement Services unit to mitigate unnecessary service duplication. This is linked, in part, to a historical relationship of Speers' representatives actively supporting community-based bereavement programming through RPCI.

The *Infant Memorial Gathering* (IMG) offered by Regina General Hospital's, Spiritual Care and Perinatal Care units first ran in 2000. Marlene Glettler, now a former social worker on the Neonatal Intensive Care Unit (NICU) and Rev. Mary Brubacher, Director of Spiritual Care for RQHR were founding

champions of the concept. The original Planning Committee included community members from health district services (Women's & Children's Services), funeral services (Paragon) and community support groups (The Compassionate Friends). The IMG is a loss acknowledgement-based observance (memorial) service for parents who have lost babies through miscarriage, stillbirth and post-natal death.

The reader is directed to Figure 1.1 in Appendix B for a graphical timeline of this retrospective of bereavement services in the Regina area.

Bereavement Centre Development

In the previous three decades bereavement and grief support centres have emerged across North America. Some have a specific focus and others have general mandates (Melvin, 2002; Komick, 2005). Internal health region and local community dialogue about the concept of a community bereavement centre in Regina dates back to at least 2002. For a timeline of the bereavement centre development timeline of Regina, the reader is directed to Figure 1.2 as presented in Appendix B.

A University of Regina, master's student research project entitled *A community assets needs assessment of bereavement services: Gathering support for a bereavement resource centre in Regina, Saskatchewan* was completed that same year (Melvin, 2002).

In early 2005, the Director of the RQHR Palliative Care Services and the RPCI Board of Directors began exploratory planning work for a bereavement centre. The Primary Health Care Transition Fund (PHCTF) resources that the Pallium Project made available served as a catalyst and enabled technical, business planning and research assistance to support

prototyping and modeling of bereavement centre development in Regina.

The Pallium Project (Phase II) participated as a partner by providing technical and planning assistance through a Regina-based consultant (i.e., Marilyn Komick), who possesses extensive business planning and operations experience from work with private businesses and industry associations. In March 2005, the RPCI, RQHR Palliative Care Services and The Pallium Project jointly-sponsored an initial stakeholder meeting. This enabled shared brainstorming, visioning and early assessment of stakeholder commitment.

Meeting participants included participants from health region, community organization, government and academic settings. Guiding design principles for a centre identified at this meeting included: (1) open accessibility, although not all may be served; (2) compassionate, competent service delivery; (3) wellness and family-focused holistic care; (4) breadth in loss scope - address a range of expected and unexpected death situations (i.e. tragic and traumatic deaths); and (5) responsiveness – the right resources in the right place at the right time in the right form (Komick, 2005).

Komick (2005) outlines a second “key message” emerging from the March 2005 stakeholder meeting as: (1) bereavement is important to primary health care; (2) bereavement equals wellness; (3) death is the one experience that unites us as human beings; (4) honouring the grieving process while having the patience and courage to live productively (referring to the stages of grief common to all survivors of loss); and (5) staying connected and remaining an interactive participant in life (p. 3).

The multi-partner planning and development process which included RPCI, RQHR Palliative Care Services, the University of Regina and The Pallium Project was important to drive progress and maintain momentum.

Marilyn Komick, the aforementioned Regina-based consultant, was engaged to assist with a business plan outline and supported local stakeholders to develop a centre *Project Development Plan* (Komick, 2005). This plan, developed over several months, consolidated historical planning information, guidelines for future progress and a preliminary funding/resource plan for a bereavement centre.

In Fall 2005, Dr. Michael MacLean led University of Regina, Social Work graduate students in developing a draft mission statement for a bereavement centre as well as a plan for refining this statement with stakeholders. A November 2005 draft report entitled, *Toward a bereavement centre for Regina*, outlined this initial vision and mission statement. This draft report also contained important contextual information from an environmental scan of bereavement programming in western Canada and a review of selected Canadian literature.

Another bereavement centre developmental milestone was a decision by the RPCI Board of Directors to commit to an initial three year start-up funding package. This enabled commissioning of a Bereavement Centre Project Manager and securing of space in the community. Debra Wiszniak, a graduate-level trained social worker was seconded from RQHR as the Bereavement Centre Project Manager in November 2005. The project manager role includes project development plan coordination, detailed budgeting, troubleshooting start-up, negotiating counselling contracts, liaising with the RPCI

Board of Directors and sponsors of fund/resource development, graduate student supervision and supporting bereavement counselling practice consistent with the Canadian Hospice Palliative Care Association's, Norms of Practice (CHPCA, 2002).

A second community stakeholders meeting was hosted by RPCI, RQHR Palliative Care Services and The Pallium Project in January 2006 at the new bereavement centre location. This meeting focused on reporting back to stakeholders on progress since March 2005, to "introduce" the Regina Bereavement Centre to community stakeholders and to further collaborative relationships with community organizations.

Bereavement centre space was leased as of October 1, 2005 at Western Christian College. The spring 2006 grief groups were held in the new space. The intent is to achieve sufficient funding by late 2006, so as to provide ongoing bereavement services and research with qualified personnel. This represents a major developmental milestone. RPCI remains an instrumental local partner. Without RPCI's financial backing bereavement programs (e.g., groups, camp, etc.) would not be sufficiently resourced and the Regina Bereavement Centre would not exist.

Bereavement Centre Development Intent

A bereavement centre was identified by the RPCI Board of Directors as a community development project which is progressive and evolutionary. It consolidates existing programming and supports managed growth associated with 18 years of local bereavement programming. It responds to increasing service demands, including those for underserved populations such as rural and Aboriginal communities.

Demand for increased service has outweighed the ability of the RQHR Bereavement Coordinator to solely meet these demands. Time demands and providing service to an expanding client load has become overwhelming. Increased service demand was reported back to the RPCI Board and RQHR's senior management team as an ongoing concern.

Commissioning of a Regina Bereavement Centre was endorsed as the most suitable response to a growing need. Bereavement centre commissioning addresses the need for service expansion in various ways. This includes expanding service provision to more people in the community, including under-served populations in rural Saskatchewan, schools and community groups. The Centre is also intended as a visible referral source of specialized quality services, staffed with qualified professional staff and volunteers. Collaborative research and education partnership is also core to the Centre's design as a locus and focal point for quality bereavement practice and scholarship.

There was a deliberate, needs informed intent to have accessible bereavement support space separate from acute care, health care facilities. A bereavement centre concept supports a holistic and caring environment for the larger community of southern Saskatchewan, the current RQHR Palliative Care Services program and other health care services. A free-standing, community-based bereavement centre, which is independent from hospital-based palliative care services, also mitigates a common misconception that bereavement services are only available to those families served by the RQHR's in-patient palliative care unit.

A secondary intent for a bereavement centre acknowledges bereavement as a broader

societal issue which influences personal and family wellness and health. As one key informant indicated, "a lack of bereavement services can lead to complicated physical and mental health so a provision of quality bereavement services could be preventative medicine for families, children, youth, anyone."

Acknowledging bereavement and the process on a societal level may involve facilitating open dialogue about death, grief and dying and making such discussions more acceptable, as well as educating the public and professionals. One key informant felt that a purpose of a bereavement centre would be "to acknowledge grief as a process, validating the different ways of grieving." Means of facilitating these discussions around acknowledgement of grief and the grieving process would be via service provision, public education and research projects.

Bereavement Centre Vision & Key Components

At the aforementioned January 31, 2006, community stakeholder meeting, Regina Bereavement Centre project manager, Deb Wiznsiak, detailed that the Centre's mission will be to "contribute to the health and well-being of individuals, families, groups and communities" (Wiznsiak, 2006). Wiznsiak also confirmed key components of the Centre as education, existing clinical bereavement services, Aboriginal capacity-building and research.

Additional components of the Centre envisioned by key informants include appropriate space for current and future bereavement programming needs and a centralized location to coordinate multi-agency/community-led bereavement services. Additional opportunities for bereavement programming, additional trained professional

staff, and outreach for under-serviced or marginalized populations were also reported as additional potential contributions. Components such as beautiful, reflective and meditative areas for working with the bereaved were suggested.

Another main component emerging from key informant interviews is a desire that the Centre serves as a focal point to undertake original research to inform improved bereavement clinical care. High quality standards of care and a quality reputation were also suggested as important. Suggestions were also made for the Centre's vision to include a potential role as a focal point for resource provision and dissemination of information, provincially, nationally and internationally. Connection with Saskatchewan's Aboriginal population and inclusion of traditional Aboriginal beliefs and approaches to healing and grief were also identified.

Future Directions for Bereavement Services

Key informants were asked for their opinions about future directions for service organization and delivery in the community. The responses from key informants were coded into thematic categories.

The most commonly suggested future direction is for services to address cross-cultural issues and diversity, specifically the unmet needs of Aboriginal peoples, rural communities and under-serviced populations.

Better balance between "western" models of grief and healing and traditional Aboriginal models were suggested. This includes implementing programs to provide a concrete connection to Aboriginal communities, both urban and rural. This could be achieved by including Elders, implementing traditional

practices and promoting better understanding of the status and role of traditional ceremonies. Culturally diverse services might be achieved through better connection with community cultural, religious and spiritual groups.

Regarding rural service provision, Sakundiak's (2005) research suggested, and several key informants reinforced, that many rural areas have limited, if any, access to specialized bereavement services. Many rural bereavement services are woven into the fabric of other community infrastructures such as mental health, church groups and funeral services. Outreach to under-serviced populations and service provision in various community locations, such as services to street people, those experiencing addiction, youth, and other grass roots community project locations was suggested as another future direction.

The second most commonly suggested direction was for bereavement services to be provided out of a central place which is accessible to families. This centralized location would make referrals to specialized bereavement services and offer support for community grief groups, by providing access to space and additional resources. One key informant commented that "the centre would be a positive starting point and could act as a root or hub to work from" to provide bereavement services.

One interviewee specifically requested moving the *Bearing Loss* perinatal grief group into a bereavement centre, so clients could access trained and qualified facilitators as well as resources and a neutral space. The informant noted that "The idea of having it all in one place makes it easier for families and makes it easier for others to refer, rather than services being fractured and scattered, plus

the resources would be all in one place.” It was further suggested bereavement services provided through a centre may have an enhanced reputation if co-located with established services that have a strong reputation within the community. It was suggested that such a centre could host major conferences, provincially, nationally and internationally.

The third most common suggestion was for services that are, and that are seen to be, genuinely community-based and supported. Key informants emphasized a real connection to be made with communities, “not just lip service, but how will this happen realistically”? Service providers, focusing on the aforementioned populations, must find ways to connect with communities, community human service non-profit groups and agencies, community group locations, churches and religious groups and health region-based services.

It was also suggested that it is important to acknowledge community support already being received by the RQHR Palliative Care Services, Bereavement Services unit, including RPCI, the Regina Progress Club, the Regina Greek community and the Regina Pats. There is also academic community support from the University of Regina, particularly the Psychology and Social Work departments.

The fourth theme focused on communication with the community and bereaved populations. Several community groups involved in bereavement care suggested a meeting with those involved in bereavement centre development. Effective communication to facilitate connecting with people and to help communities and “helping communities” and individuals help themselves was also cited as a critical success factor. A publication indicating all the bereavement services and

groups available both in Regina and for rural areas (e.g., a brochure or a section in the community services pages of the phone book) is one suggestion. Such singular publication would help bereaved individuals seeking support but, it was also suggested, would also facilitate communication between bereavement groups, allowing them to all be “in the know.” This would enable more clarity of existing groups and the populations they serve.

Three other themes suggested as future directions are focused on education, expansion of current services and research. Suggested educational components include training locally and inter-provincially, for community groups, schools, and professionals (i.e. social workers, psychologists, counsellors, nurses, other health care workers) and conference presentations.

In addition to external training, it is essential for a bereavement centre to have skilled professionals and volunteers who can listen, make referrals and support program development and delivery. One key informant felt that “staff should have training but also life skills and experience,” however, life skills or experience were not defined. It was also suggested that a recognized post-secondary certification and training for professionals, such as a university-level certificate from social work or psychology in grief counselling would be well received.

Presentations at conferences for other professionals is also important and one informant mentioned grief education in elementary and secondary schools as “it is an important life skill for kids to learn about,” so community education could serve the Centre’s one goal of facilitating dialogue and action about grief as a societal issue.

Suggested service expansion includes outreach to rural and other communities, the possibility of offering new kinds of groups and services and extending services over the summer months. One key informant suggested services would “need to expand the existing base of counselling, create a team of professionals that will provide clinical, ethical and debriefing supports” both as centre staff and volunteers. Expansion may also include incorporating existing programs into the Centre’s programming (i.e., moving the *Bearing Loss* perinatal grief group to the centre or providing sustaining support to groups such as the recently defunct *Survivors of Road Trauma*). Service expansion, such as more groups, outreach, counselling and activities will be needed. In one informant’s opinion this is partly because “the aging baby boomer age group is going to bring more deaths thus more people will be needing support.”

Initiating and conducting original research was also suggested as another key focus area for a bereavement centre. Research could help assess bereavement outcomes and interventions, reinforce a quality reputation, and support engagement with the community and expand the bereavement knowledge base in Canada. Having a Centre research committee, connected to the University of Regina, was also suggested as essential to further develop a research program.

Other suggestions mentioned with less frequency include addressing ethical issues and adhering to professional ethical standards within service provision, research, documentation and confidentiality. The issue of “fee versus free” access for service provision was mentioned, with an opinion expressed by the informant that services should be free. Defining population(s) that the bereavement centre might focus on may be necessary to assist in determining initial priorities, especially with limited funding.

Caution was also urged so as to avoid service duplication in any expansion. One key informant appeared quite concerned that bereavement centre services would unnecessarily result in “doubling up or duplicating” services that are already out there, that those developing the centre would want to be careful about not “stepping on toes” and expressed concern about how such a project was going to be funded. Funding, territorialism and duplication were also identified in Melvin (2002) as potential barriers to a successful bereavement centre development process. These are areas that those involved in project development will be challenged to consider further.

Recommended Future Directions of Bereavement Services in Regina

Recommendations for future directions for bereavement service in Regina, as informed by the analysis of the data, are made here. Main areas of recommendation include: (1) expansion of bereavement care service provision; (2) further developing professional connections, education and training; (3) better coordinated communication with the community; (4) addressing needs of diverse or under-serviced populations; (5) research; and (6) continued bereavement centre development.

Recommended Direction 1 – Centre-based, bereavement service expansion. A bereavement centre is one way to expand bereavement service provision in Regina. A centre could act as a model on a provincial and national level for bereavement program development, within and outside of palliative care programs. As Sakundiak (2005) identified, many health regions in Saskatchewan are lacking elements of palliative care service provision including bereavement support, so perhaps a Regina Bereavement Centre might support more centralized bereavement service provision.

There are already many positive programs and supports happening in Regina. Some bereavement care related services, however, are not currently available or may not be as fully developed as they could be. Some areas of bereavement care, for instance, not currently addressed or demanding possible expansion include (in no particular order):

- support for abortion loss;
- expanded perinatal loss programs possibly in conjunction with the *Bearing Loss* program;
- ongoing anticipatory grief groups;
- support for disenfranchised grievers, such as those in gay and lesbian relationships;
- grief support for AIDS deaths;
- grief dynamics of blended families;
- further support for widows/widowers;
- Support for readjustment and avenues of expression for grieving men (e.g., a widower's cooking group);
- retreats for parents, adults, and young adults for bereavement work;
- grief support in the workplace;
- public education regarding grief, death and dying;
- World wide web-based local information and resources;
- outreach services to rural communities;
- connection to local Saskatchewan aboriginal grieving traditions; and
- provision of high quality resources including formalized linkages with providers of quality third-party content (e.g., The Centering Corporation).

Recommended Direction # 2 - Developing better professional connections, including shared education and training. Building professional community and respect for shared and interdependent skills is one way of linking professionals and volunteers to

mitigate territorialism and duplication of services. Beginning this process could be initiated by a professional organization/association in southern Saskatchewan for those whose work includes grief, bereavement and death education. Such an association could provide professional consultation opportunities. Providing further training opportunities can support professionals or volunteers in the human services fields, including, health care, corrections, addictions, mental health, social work, psychology, counselling, education, business, policing services (e.g., Next of Kin [NOK] notifications), victim services, other emergency services, core community groups and the media.

A partnership with the University of Regina could evolve into offering formal university-level or advanced certificate training. A formal training certificate could be a drawing point for both the Centre and the University. Other models exist such as the Certificate Program in Grief and Bereavement offered through distance education from King's College Centre for Education about Grief and Bereavement (<http://www.uwo.ca/kings/academic/programs/centres/deathed/>).

Centre management could also explore association/affiliation with the U.S.-based Association for Death Education and Counselling as they too have certification and training programs available (www.adec.org).

A bereavement centre's capacity to offer programs may not only depend on paid personnel but also on volunteers. Maintaining a professional volunteer base with appropriate training in grief and bereavement and in group facilitation is essential to program provision. This training could also be made available to volunteer facilitators with

other area non-profit bereavement groups to assist them in furthering programming and support capacity.

Recommended Direction 3 - Maintaining and increasing communication and connection with the community. For a bereavement centre to be a focal point for bereavement services in the Regina area, it is essential for the centre management to maintain effective communication with the larger community, both professionals and the public. A publication (i.e., brochure or telephone book community service page), would be a key communication tool at this time. The intent is to inform professionals and the public on what bereavement services are available through a bereavement centre and in the community at large as well. This would address a need to clarify and make more transparent to professionals and the public a clarification of the exact nature of bereavement services in the greater Regina area.

Furthering a bereavement centre's connections with the community might involve working with various organizations, such as school divisions, possibly under Saskatchewan Learning's School^{Plus} model. This could expand support services in grief and bereavement education and offer support school counsellors, and support and training for tragic events response. Linkages could be developed with other Saskatchewan health regions to offer specialized services in support of overall health and wellness. This could help decrease waitlists for mental health services and support palliative care service program development.

Connections with the Department of Community Resources and Employment (DCRE), especially for those in foster care, etc., and with First Nations bands in

Saskatchewan could result in services respectful of Aboriginal traditions and support First Nations personnel in offering services. Connections with occupational Health & Safety programs, especially focused on deaths in the workplace are possible. Connections with Human Resource departments about workplace grief and its impact on efficiency and productivity are also possible. Finally, working with addictions agencies, in programs addressing substance abuse connected to "unresolved" or "complicated" grief responses would also be useful.

Linkage to community bereavement support groups and services (as mentioned earlier in this report), is also essential. One role the centre could play as a community service agency is to support non-profit organizations with space to host meetings, combining assets/resources for manpower and materials, expanding access to resources and training for volunteer facilitators.

An immediate recommendation is for bereavement centre partners to host an invitational, informational community meeting for community-based, bereavement service groups. In the course of completing the field work for this study, we learned that while some of the groups have been aware of the bereavement centre concept, none have been invited or involved in early bereavement centre development and planning.

As territorialism and service duplication have been identified as potential barriers to success (Melvin, 2002), informational community meetings with these representatives of groups are essential to clarifying what the centre may provide, maintaining a positive working relationship, cross-referrals and articulating the positive opportunities of a centre.

Recommended Direction 4 – Diversity and under-served populations. As stated earlier, several populations have been identified as needing more focused bereavement services. A Bereavement Centre might investigate rural outreach services, such as individual bereavement counselling and grief groups within rural communities, perhaps in conjunction with local health region services, DCRE services, funeral service providers and church groups. Other under-served populations include marginalized people, such as the homeless.

Connection also needs to be made with First Nation bands and Metis groups, initially within Southern Saskatchewan. It is prudent to consult early with Elders from various Aboriginal traditions (e.g., Cree, Nakota, etc.) about traditional protocols, including holding or releasing of the spirit, healing, smudging, talking circles, sweat lodges, etc.

Bereavement centre staff would need proper preparation for cultural counselling beyond traditional “western” grief support practices. This is perhaps another area where the partnership with the University of Regina and a bereavement centre could provide professional education.

Recommended Direction 5 – Participation in research/scholarly activities. A bereavement centre could be a partner in original research and scholarly activities. It could facilitate western Canada research helpful to support bereavement, grief, dying and death. Building a strong research base is also helpful in supporting an identified key component of a bereavement centre.

Recommended Direction 6 – Continued bereavement centre concept development. Recommended directions for development of the Centre include: 1) informing the public

about available services, 2) public education on the definition of bereavement, 3) overall death education, 4) determining an appropriate name for the centre, and 5) determining how services will be funded.

Public education addresses common misunderstandings about bereavement programs and services. This will address a continuing concern that bereavement service is available beyond those on the RQHR Palliative Care Services patient roster, which remains a common misperception. It is also important to recognize “bereavement” is poorly understood by the general public. The bereavement centre will want a name to reflect its purpose and services, while promoting a public understanding of its mission and main objectives.

There are mixed opinions about whether a sustainable bereavement centre business model takes the form of a fee-for-service model, a community-funded model, a public funded (e.g., RHA) model or combination thereof. Fee for specialized services is common in private practice counselling and therapy, with sliding fee scales and some pro bono services. Sustainable resource models are something that the management of the Regina Bereavement Centre project will need to further consider.

Limitations

There are methodological limitations to this study. The time for data collection and initial write up was limited to a six week window of January 25 – March 15, 2006. This limited the potential number of key informants and the total possible data set of key informants.

As with any qualitative research based on a purposive sampling strategy, not all potential key informants may have been known to, or identified by, the research team. As such, the

insights of significant individuals or organizations may have been excluded in primary data collection. There was, however, no purposeful or deliberate exclusion of any group, organization or individual. The limitation of not engaging some potential key informants required use of secondary source information for obtaining data regarding services, timelines and organizations, so accuracy of current programming, operations and context also cannot be fully assured.

Website information was re-verified in November 2006 prior to re-publication of this manuscript in The Pallium Project's, *Knowledge for Action* occasional paper series and was accurate at that time.

For those key informants who did participate in this retrospective study, there is also the potential for recall bias. That is, informants recall and cognitively reconstruct past experiences through their own interpretative lenses. Hence the saying "what you see depends on where you stand." This limitation is addressed, in part, by use of secondary source information and triangulation of insights and information derived from a broad-base of key informants.

Another limitation about the key informant base is that the demographics are not as widely representative as they could have been. The main under-represented populations are rural and Aboriginal populations. Considering these are two of the four identified component areas of focus for the bereavement centre, it would seem more contact with these populations may have been useful to fully informing the current study.

Study design also did not directly engage bereaved persons about their opinions and insights about prospective types of bereavement services they would like to see available, which is consistent with the retrospective design of the current study.

Conclusion

The Regina Bereavement Centre development project was well underway at the time of this retrospective study and has made significant progress since spring 2005. It is being built upon a strong history and foundation of bereavement programming as part of a comprehensive palliative care service.

The community grief-related services have existed for many years and have progressive, if at times somewhat turbulent, success as is common with many non-profit organizations and community-based initiatives.

A centre that provide linkages between many different groups and acts as a hub for quality service provision, research and education appears to largely be welcomed by community service providers and the bereavement community generally, with the noted reservations about duplication of service provision.

Contact

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APPENDIX A



KEY INFORMANT INTERVIEW SCHEDULE *Community-based Review of Accomplishment*

Purpose: The purpose of this project is to conduct a community-based review of local accomplishments and developments in bereavement and clinical care in the Regina area over the past 15 years. I am conducting interviews with members of the local palliative and bereavement care community in order to identify noteworthy local accomplishments and projects. I will then organize this review into a retrospective that highlights local developments, challenges and successes. With your help, I will be able to make comments and recommendations about future directions in the area with a specific focus on how grief and bereavement services should be organized and delivered in order to best meet the needs of our local community. This project is sponsored by the Pallium Project and the University of Regina. If this sounds good to you, I'd like to talk with you for about 20 minutes and get your feedback on a number of areas.

1. First of all, let me get some background information:

Your name is: _____

(You fill in) Gender: _____ Ethnicity: _____

Contact information: Phone number: _____

E-mail address: _____

Address: _____

Your job/position: _____

2. Bereavement Centre

a. What has your role been in working towards creating a Bereavement Centre in Regina?
 How long have you been involved?

b. Can you talk about the idea for the Centre: why, what's the purpose, the vision, etc.

- c. What are some of the "critical moments" or "key activities" or "key decisions" that have led to where we are now in January 2006
-

3. Accomplishments in Bereavement and Clinical Care:

- a. What are the special accomplishments in the area of bereavement care and clinical care that our community has to offer:
-

- b. In your opinion, what future directions should we go in the way grief and bereavement services are organized and delivered in our community?
-

4. Anything else:

- a. Is there anything else that we've missed or that is important for us to know?
-

- b. Who else should I speak with:
-

Thank you very much for your time.

**Building Community Capacity
A Retrospective of Bereavement Services in Regina, Canada**

APPENDIX B

Figure 1.1

Regina Bereavement Services Retrospective Timeline 1983 - Present

Regina Palliative Care Bereavement Services

The Compassionate Friends support group established in Regina	1983	Founding of Regina Palliative Care Incorporated (first annual meeting in 1984)
Survivors of Suicide support group established in Regina	1985	1983-1988 RPCI took a role in bereavement education providing internationally known speakers in the area of bereavement clinical care and research
	1988-99	Implementation of Adult Bereavement Support Group (originally Bereavement Follow-up Groups)
	1990-93	
	1994	Childhood and Teen Grief Groups started
Arborcare grief aftercare program available via Regina Funeral Home	1995-96	
	1997	Caring Hearts Camp Children's Grief Camp Ages 6-18 yrs
	1998	Bereavement Coordinator position introduced in the fall
Family Service Coordinators providing grief aftercare via Lee Funeral Home	1999	First Walking Group, "Miles and Memories" started in the spring
GriefShare starts via Faith Baptist Church First annual Infant Loss Memorial Gathering	2000	
	2001	Young Adult Bereavement Group started (initially in conjunction with U of R Counselling Services)
	2002	Melvin (2002) Research Project Completed
	2003	
	2004	Daytime Support Group started in February
Bearing Loss Perinatal Grief Group started via YMCA	2005	Initial planning for Bereavement Centre with RPCI and Pallium Project * Sakundiak (2005) Research Completed
	2006	Continued Bereavement Centre planning*

**Figure 1.2
Bereavement Centre Development Retrospective Timeline
Bereavement Centre Development Timeline January 2005 – March 2006**

Jan – Feb	Initial interest and planning for the March meeting
March	Initial Bereavement Centre Stakeholder Process Development meeting sponsored by Pallium Project, RPCI, RQHR PSC and various community members
April – May	Ongoing planning and business planning research
June – Aug	RPCI committed to funding space for a three year term
July	Budget template developed by M. Komick for the Bereavement Centre
July – Sept	Project development plan review/business model discussions
September	Project Development Plan Draft #6 available from Marilyn Komick. RPCI Board created a fundraising committee to solicit sponsorship in the community.
October	Start of lease for space at the Western Christian College in Regina for the Bereavement Centre
November	Secondment by RPCI of Debra Wiszniak as the Bereavement Centre Project Manager for a six month period. Mission Statement report “Toward a Bereavement Centre of Regina” led by Dr. Michael MacLean
January	Second Bereavement Centre Stakeholder meeting hosted by RPCI, RQHR PCS and the Pallium Project, including various community members
March	Research completed for Pallium Project/University of Regina by S. Melvin and J. Nutini.

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 under the Marketplace link. This paper should also be used with *Select bereavement programming in western Canada and a discussion of current scholarship*, which is accessible at www.pallium.ca/infoware/KFA_2006-01_BereavementActivity.pdf

Taking Stock

- Do your local palliative and end-of-life care stakeholders, including health delivery system management, understand the importance of well-designed and linked community bereavement supports to mitigate “hidden” personal, family and health system costs of under-developed, poorly-linked/integrated or no local community survivor supports?
- 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 know “who and how” to refer family and friends of dying persons to community bereavement support services as appropriate?
- Do your local primary health care stakeholders have a “map,” list or inventory of available grief and bereavement supports available in your local community?

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.
- Identify those stakeholders in your community that you feel might have an interest in advancing the status quo (e.g., local church leaders, funeral home, RCMP Victim Services, Family & Community Support Services, school leaders, Aboriginal friendship centres, service groups, seniors organizations, chamber of commerce, library, volunteers, etc.).
- Hold an initial community stakeholder meeting to examine issues as they pertain locally.
- If there is a bona fide concern and interest warrants, strike a small working committee/study group to address the key questions/issues that arise around loss and bereavement, establish some key priority questions and set a date to report back to stakeholders.