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Bereavement Programs and Services in the Province of Alberta: A Mapping Report*

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RÉSUMÉ

Cet exercice de cartographie en 2014 avait comme but d' identifier et de décrire tous les programmes et services de soutien pendant le deuil dans la province entière de l'Alberta, et de les comparer aux ceux-ci disponibles quatre années d'avant. Le deuil est une expérience commune dans la vie, en particulier chez les personnes âgées, et le soutien est souvent nécessaire pour aider leur récupération. Nous avons cherché des informations sur les programmes et les services par le biais de recherches systématiques et la technique «boule de neige» est utilisée pour identifier les fournisseurs et les interviewer. Bien qu'une croissance considérable (330%), et une plus grande diversité parmi les fournisseurs, les programmes et les services, étaient évidente, nous avons découvert que les programmes de deuil ne sont plus encore financés par l'État. Au contraire, les programmes et les services existants proviennent maintenant de la base, avec des individus et des groupes communautaires offrant, pour la plupart, la conception et la fourniture de services de soutien aux personnes en deuil. Les programmes de deuil sont importants, en particulier pour les personnes âgées qui peuvent être les plus touchées par la mort d un être cher. Les résultats de ces programmes nécessitent une évaluation comparative. Si les gouvernements devraient fournir et / ou financer de tels programmes est une question qu'on doit également prendre en compte.

ABSTRACT

This 2014 mapping exercise sought to identify and describe all bereavement support programs and services in the province of Alberta, and compare these to those available four years previously. Bereavement is a common life experience, especially among older persons, with support often needed to assist recovery. We sought program and service information through systematic searches and the snowball technique to identify providers and interview them. Although considerable (330%) growth, and more diversity in providers, programs, and services was evident, bereavement programs were no longer publicly funded. Instead, programs and services were now grassroots in origin, with individuals and community groups largely designing and providing bereavement support services. Bereavement programs are important, particularly for elderly persons who may be the most impacted by the death of a loved one. Whether governments should fund and/or provide these programs is a question that also needs to be addressed.

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In Alberta, a Canadian province populated by just over four million persons, around 22,000 deaths take place each year (Alberta Vital Statistics, 2014). According to the Parliamentary Committee on Palliative and Compassionate Care (2011), four persons are bereaved on average for every death, with 88,000 persons annually thus expected to grieve these deaths. Grief is the emotional reaction to bereavement, and it includes diverse physical and psychosocial impacts (Stroebe, Hansson, Stroebe, & Schut, 2001; Stroebe, Hansson, Schut, & Stroebe, 2008). The death of a spouse is a major risk factor for early mortality (Manor & Eisenbach, 2003). Although people of all ages may be bereaved, older people are the most familiar with the death of a loved one. Among people aged 65 and older, 45 per cent of women and 15 per cent of men are widowed (Hansson & Stroebe, 2003). Comparatively, only 3.4 per cent of children 18 years of age or younger have had a parent die (Christ, Siegel, & Christ, 2002). One study found 4.8 per cent of adults aged 55 and older were experiencing grief, with 25.4 per cent of these having complicated or extended grief (Newson, Boelen, Hek, Hofman, & Tiemeier, 2011).

The World Health Organization's (2016) definition of palliative care indicates that efforts should be directed at quality of life for the dying person and their family, with such efforts needed both before and after the death. A recently completed research study revealed 42 per cent of bereaved persons sought and obtained some type of bereavement support, with those who rated the quality of death of their loved one as low and those with higher levels of grief significantly more likely to seek and obtain help for their bereavement grief (Wilson et al., in press). Bereavement programs have been found effective for ameliorating grief symptoms (Kang & Yoo, 2007; Holland, Currier, & Gallagher-Thompson, 2009). The need for bereavement programs and services to exist and be accessible to a considerable proportion of grief-stricken people, especially older adults who experience bereavement grief more often, is evident.

A literature search for Medline and the Cumulative Index for Nursing and Allied Health Literature (CINAHL) articles revealed no descriptions of all existing bereavement support programs or services in any region or country. This information gap is surprising, as bereavement is a centuries' old social phenomenon. However, an environmental scan has been done of bereavement services that are available in North American pediatric and maternity hospitals (Ma, Webber, & Crowell, 2014). That scan revealed that most hospitals had a formal bereavement program with a bereavement coordinator. In 2014, we sought information to map bereavement programs and services in Alberta.

Search and Information Analysis Methods

This 2014 mapping exercise was initiated after a review of an existing online open access directory of bereavement programs and services within the province of Alberta (Alberta Hospice Palliative Care Association [AHPCA], n.d.). The directory contained contact information for 24 organizations. Although it had only been four years since this directory was developed, Alberta's health care system had experienced funding cutbacks since then, with what appeared to be the subsequent closure of many bereavement programs. The regional health authority was thought to have focused funding on mental health services for depression treatment and suicide prevention instead of bereavement services.

The lead author (DW) was involved in the previous search for bereavement programs, and so was familiar with the search methods and results. As with the previous search, the 2014 mapping exercise sought to gather publicly available information. Accordingly, it was not considered a research study, and research ethics approval was not obtained for it. To gather consistent relevant information, a list of questions was developed for use by a research assistant who was a registered nurse and university graduate student (see Table 1). These questions were emailed to all of the 24 previously identified organizations with working email addresses, and this same set of questions was used to collect information by telephone from those organizations without a current contact email address and those where the informant preferred to provide information verbally. The questions were designed not only to gather current contact information for existing bereavement programs, but also to identify the number and types of services provided, the number and types of clients using these services, and to determine if any evaluations of their services were being conducted or had been conducted for quality improvement or other purposes. One question was also designed for "snowballing" purposes; each respondent was asked to identify other bereavement programs, services, and/or providers that they knew of.

In addition to the initial search for current programs and services starting with the 24 previously identified programs/services, we contacted all of the bereavement program/service providers that were identified through multiple Internet searches. Additional searches for programs to contact included the directories and webpages of potentially relevant government, quasi-government, and not-for-profit organizations; these included the Government of Alberta, Alberta Health, Alberta Health Services, and Family and Community Support Services (FCSS). We also checked local and provincial newspapers and other paper sources for advertisements and notices to identify additional bereavement programs/services. Each possible program/service provider was

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Table 1: List of questions formulated for use in the mapping report on bereavement programs in Alberta

Questions:
1. Name of program/organization and contact information?
2. A general description of the bereavement grief supports/services offered?
3. When did you start and how long have you been in operation?
4. How many bereaved people (approximately) do you assist each year?
5. What types of evaluation information is collected and how is it collected?
6. How are you funded?
7. How many people are employed and how many volunteers are involved in your program/services?
8. Do you have any other information you feel is important to share with us about your services/program?
9. Do you know of any other bereavement programs or services in the province, as we are using a snowball technique to try to get a list of all programs/services/providers in the province?
10. Are you OK with your information appearing in the Alberta Hospice Palliative Care Association (AHPCA) database and website for the public to see?
11. Are you OK with your information being summarized in a published report of bereavement services?

contacted through a telephone call or email up to three times in our attempt to map the full spectrum of bereavement programs and services in the province.

Despite much effort over a three-month period (February–March 2014), we anticipate that some programs or services were missed as considerable growth in small local-area programs and online programs or services over the four years was evident. The information gained was also limited to each informant's knowledge of and willingness to share information. Informants were typically very informed about their program or service, however, as they were most often the executive director, program coordinator, or – in some instances – the sole provider of the bereavement support services. All informants readily provided information, and each gave their consent for this information to be shared openly, such as with the AHPCA to update their open access directory of bereavement programs/services in the province.

Once no additional new organizations or individual providers were identified, and all the required information from the ones responding had been gathered, the two persons who conducted this search met to review and summarize the findings. We compared the summarized findings, when possible, to the programs and services in existence four years previously.

Discussion

Two major findings were noted when we reviewed the gathered information: (a) considerable growth over four years in the number of bereavement programs and services across the province, and (b) much greater diversity in bereavement programs and services. Many implications and other considerations are evident in relation to these two findings.

Growth in Bereavement Programs/Services

One of the most immediate and significant findings was a very large (330%) growth in the number of distinct bereavement programs and services existing across the province, with 79 distinct programs and services identified compared to the 24 identified back in 2010. Of all 79 current programs or services; 60 (76%) had come into existence at some point within the past four years. It was also common to find among previously established organizations – notably, free-standing hospices and funeral home chains – a recent extension of services to include one or more designed specifically to support bereaved persons. More than half of the original 24 programs or services were no longer in existence, including the 11 that had been funded and operated through the province's health care system. As a result of this change – or, perhaps unrelated to this change – many grassroots community groups and individuals had started programs or services to help those in need of bereavement support.

Most of the current programs or services were situated in cities, including the hospice-based bereavement programs and services, although all respondents indicated that they did not confine or restrict their services to local-area urban persons. A small number were identified in rural or remote areas of the province, including ones developed in areas where the driving time to a city program or service was viewed as prohibitively long. In addition, new online programs and services were available to people regardless of where they lived. This growth in programs and services was not, therefore, confined to cities and urban people.

Some of the informants for the new programs and services, as well as all those for the previously established ones, indicated they thought there had been dramatic growth in the past few years in the demand for bereavement services. It was not surprising, then, to find considerable growth in the total number of programs across the province, and to hear from many informants that there had been growth over time in the number of persons served by their programs and services. Unfortunately, many informants were unable to provide comparative information on the numbers of clients served.

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Most informants indicated that the demand for their services was continuing to grow, and that some bereaved people now needed to be told to wait and apply for a future class, course, or other offering. Some catalysts for this growth were identified, with these factors grouped into three categories: (a) increased public and professional awareness of their services, as indicated by more calls about and direct requests for services; (b) increased acceptance of their services by a wider or more comprehensive range of individuals and organizations, with health care providers such as physicians, nurses and other people increasingly suggesting to bereaved persons that there is bereavement support available to them; and (c) increased desire among bereaved individuals to obtain help. Most informants indicated that "word of mouth" was the primary reason for continued growth in the use of their programs or services, with bereaved persons who had used their services recommending that others use them. Additional reasons for growth included the fact that most organizations advertised in newspapers and other public access venues such as through an organizational website. The organizations were also now more visible in their communities because they often made presentations to community groups and carried out other activities to be both useful and noticed. Many also worked directly with local-area nurses, physicians, psychologists, and other therapists by providing telephone support to them or through offering them bereavement training programs.

Most providers of bereavement support services in Alberta attributed at least some of their success, however, to "constant" evaluation of the services they provide. Some assessed the quality or outcomes of services they provide by asking their participants to complete a questionnaire or survey form either at the beginning and end, or at the end of individual or group sessions, while others said they use unsolicited reports from family or clients as their evaluation approach. Self-evaluations by staff or volunteers are also often used for quality assurance and quality improvement purposes.

Some programs were oriented to one service only; most, however, provided a variety of services. Although all bereavement counseling service providers reported that the need for their services has grown over time, the greatest growth and thus expansion of services was through new providers. In many instances, the new programs and services were started by individuals who had suffered personally throughout a bereavement, and who then alone or as a part of a small group had sought to fill what they saw as a service gap. The funding needed for most of these new programs and services, as well as the established ones, was raised privately, with the majority of bereavement support workers unpaid volunteers. These volunteers were typically people who had experienced one or more bereavements, and many of these individuals had already used the bereavement program/service for which they were now volunteering. Consequently, for the most part, the programs and services now available in the province appear to be largely provided by individuals who themselves have suffered through a death and who had decided to help others who had similarly suffered. These individuals represented people from all walks of life, including pastors affiliated with a church group, funeral directors, and mothers or fathers who had lost a child.

In summary, a much larger number of bereavement programs and services were identified in 2014 as compared to four years previously. Collectively, these programs and services are less "formal" now and more grassroots in origin. The health care system for the province had shifted from bereavement support to the mental health issues of depression treatment and suicide prevention. Many more individuals and community groups were now working to increase bereavement support to those needing it.

Greater Diversity in Bereavement Programs/Services

A related finding associated with this growth in the number of programs and services was a much greater diversity or variety now available among bereavement programs/services. Although these included the more traditional formal counseling and group or individual grief therapy sessions, many more informal and highly personalized bereavement support programs/services were evident. These non-traditional offerings were often designed specifically for a select and clearly defined client group, and were consequently targeted for children, teenagers, or adults with specific bereavement support circumstances and needs, such as programs designed for those who had lost a child through stillbirth or suicide. Other programs or services were designed specifically for the remaining spouse or the remaining child/teenage siblings. Some were designed for individuals, while others were designed for family groups or communities, such as when services were provided in a school after the death of a student or teacher and in small to large workplaces after the death of a co-worker. Some of the programs or services were thus provided through a "grief support community" orientation.

The services provided – for the most part, peer-support individual or group counseling – included candlelight vigils, annual memorial events; day, night, and/or weekend retreats; education and training so others could provide additional bereavement support; and social gatherings such as "group support party" nights and potluck dinner gatherings. Many of the bereavement

support social gatherings were planned by the participants. Accordingly, we found the services now available were designed to provide support either through a one-on-one capacity or in small to large group formats; moreover, support exists for almost every kind of grief experience possible, including grief due to a death from a sudden accident or homicide, dementia, and separation or divorce – even the grief resulting from the death of a beloved pet.

The format of these bereavement programs and services was also highly varied. Services were available as oral education presentations, in the form of books and DVDs which could be borrowed or purchased, and online tools or services such that the bereaved person or the family members of bereaved persons could receive daily or weekly supportive and educational emails. Services now also included text messages and short video messages sent to those who were subscribed to them. Some of the programs/services were designed to be short-term, such as one- or two-week summer camps for bereaved children, whereas others had no time or length of service expectation; bereaved people could continue to receive services for as long as they were needed.

This diversity in programs and services also included a wider range of providers. As we have indicated, the formal health care system had shifted focus from bereavement support, which could be viewed as a health promotion or wellness initiative, to depression treatment and suicide prevention and was, therefore, more oriented to mental illness care. The majority of current bereavement programs and services appeared to be oriented, instead – as indicated by the information on their websites and/or from their spokespersons – to bereavement being understood as a major normal and expected life event, for which support from peers and others is helpful.

Regardless of this greater diversity in providers, most were not-for-profit in orientation. This included the individually started small programs and services; none of these sought a profit from their activities. The funeral home chains were the exception; as might be expected, these are all typically for-profit organizations, although no fees were identified for their bereavement services. Another interesting note is that not-for-profit, free-standing hospices appeared to be serving the greatest number of bereaved persons, with hospices thus having become the most common provider of bereavement support as compared to the health care system in place four years previously. Most funding for the hard costs associated with hospices was obtained through a variety of sources, including donations from individuals; memorial events; small grants from government, corporate, or other not-for-profit organizational donations; or sponsorship arrangements, community fundraising events, and, at times, a fee for service. This fee was generally on a sliding-scale basis, one that took into account the individual's financial situation; although all informants stated that no one would ever be "turned away" or refused bereavement support services.

Conclusion

This mapping of bereavement programs and services in Alberta was helpful for identifying considerable growth in the number, and much greater diversity among, the available programs and services. As publicly funded bereavement programs provided at no charge through the health care system had been closed in response to government funding cutbacks, bereavement programs were now being developed privately and with these most often staffed by volunteers. These comparative mapping results are significant to consider as an American policy report similarly noted that the 2008–2009 recession resulted in state budget cutbacks which reduced necessary health and social services (Johnson, Oliff, & Williams, 2011).

Funding cutbacks can most directly affect the vulnerable, and in the case of bereavement, this is often older persons. As Canada's population continues to age, programs for older people must be considered a top priority, particularly bereavement programs because the death of a spouse increases the risk for the surviving spouse of early mortality (Manor & Eisenbach, 2003). Consequently, bereavement programs/services should be considered an important health promotion or illness prevention intervention. The question remains whether these programs are best left to individuals and private organizations or if governments should instead fund and provide bereavement programs and services. Moreover, the outcomes of all types of bereavement support programs and services need to be determined, with evaluations conducted on them to determine and compare outcomes.

In Alberta, the changes that took place over four recent years have resulted in many more bereavement support programs and services, including online ones, which suggests bereavement support is now more accessible to citizens needing such support. In addition, the providers of bereavement services have changed substantially, offering a much greater variety of bereavement services to Albertans. This is a positive development as death, dying, and bereavement circumstances are highly variable; so generic or "one size fits all" programs and services are unlikely to meet the needs of all persons experiencing grief. Those in need of bereavement support are most often now being assisted by persons with first-hand experience in suffering and recovering from a death. In short, grass-roots individual

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and community-based bereavement programs and services are common now in Alberta. It would be informative to learn if this trend is occurring elsewhere.

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