Researching a Best-Practice End-of-Life Care Model for Canada*

Donna M. Wilson,[1] Stephen Birch,[2] Sam Sheps,[3,4] Roger Thomas,[5] Christopher Justice,[6,7] and Rod MacLeod[8]

RÉSUMÉ

De nos jours, la majorité des 220 000 Canadiens qui meurent chaque année, principalement de vieillesse ou des suites de problèmes de santé dégénératifs, n'ont pas accès à des centres de soins palliatifs ou spécialisés en fin de vie. Les programmes de soins palliatifs et d'hospices sont inégalement répartis au Canada, la plupart n'ont qu'une faible capacité de services, et ces services varient considérablement d'un programme à l'autre. Les services de fin de vie sont « les services qui permettent aux familles et aux amis d'aider une personne en phase terminale à vivre ses dernières semaines, ainsi que des services de soutien aux personnes en deuil. » Bien que des services de santé et des services sociaux soient disponibles, la plupart des Canadiens en phase terminale n'ont pas facilement accès à un ensemble complet de services qui pourraient les aider à traverser cette période difficile. La plupart risquent donc d'être soumis en fin de vie à des soins non coordonnés et potentiellement inadéquats. Les personnes en phase terminale sont les plus vulnérables de toutes. Le passage de la vie à la mort est souvent difficile en raison des défis émotionnels et physiques que cela engendre. Bien que le soutien des parents et des amis soit irremplaçable, les soins de fin de vie constituent une obligation publique importante.

Un projet de recherche de synthèse a été mené dans le but de déterminer un modèle des meilleures pratiques de prestation de soins de fin de vie qui favoriserait la coordination et l'intégration de ces soins au Canada. Par le truchement de visites, d'analyses documentaires, de sondages sur le web, et d'une analyse des données sur les soins à domicile, quatre éléments essentiels d'un modèle intégrant les meilleures pratiques en matière de soins en fin de vie au Canada ont été dégagés : 1) universalité, 2) coordination des soins, 3) accès assuré à un vaste éventail de soins de vie de base et spécialisés, et 4) assurance de services de fin de vie peu importe où les soins sont prodigués. Le présent modèle est proposé comme guide pour l'établissement de soins intégrés de fin de vie au Canada.

ABSTRACT

The vast majority of the 220,000 Canadians who die each year, principally of old age and progressive ill health, do not have access to specialized hospice or palliative care. Hospice and palliative care programs are unevenly distributed across Canada, with existing programs limited in capacity and services varying considerably across programs. End-of-life (EOL) care is defined as "The services that may be needed by dying persons and their families or friends in the last year of life, as well as bereavement services following death." Although some health and social services may be available, most dying Canadians are in the difficult position of not having ready access to a full range of services that could ease their final days of life. Most are thus at risk of uncoordinated and potentially inadequate EOL care. Among all persons, dying persons are arguably the most vulnerable. The dying process is often difficult as a result of emotional and physical challenges. Although the loving support of family and friends for dying persons is irreplaceable, EOL care is an important public obligation. A synthesis research project was conducted to identify a best-practice EOL care model for Canada, one featuring coordinated or integrated EOL care. Through site visits, literature reviews, Web-based surveys, and a home care data analysis, four essential components for a best-practice integrated EOL care model for Canada were identified: (a) universality, (b) care coordination, (c) assured access to a broad range of basic and advanced EOL services, and (d) EOL care provision regardless of care setting. This model is offered as a guide for the development of EOL care services across Canada.

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[1] Faculty of Nursing, University of Alberta
[2] Centre for Health Economics and Policy Analysis, McMaster University
[3] Western Regional Training Centre for Health Services Research
[4] Faculty of Medicine, University of British Columbia
[5] Department of Family Medicine, Faculty of Medicine, University of Calgary
[6] Centre for Leadership in Learning, McMaster University
[7] Department of Public Health Sciences, University of Toronto
[8] School of Population Health, University of Aukland

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Nine additional researchers contributed actively to this research study: Margaret Brown (Hawke Institute, Australia), Dr. Katherine Froggatt (University of Sheffield, UK), Dr. Janice Kinch (University of Calgary, AB, Canada), Karen Leibovici (City of Edmonton, Edmonton, AB, Canada), Dr. Margaret MacAdam (Toronto, ON, Canada), Dr. Tom Noseworthy (University of Calgary), Pam Reid (Nova Scotia Community College, Halifax, NS, Canada), David Shepherd (County Durham, UK), and Dr. Corrine Truman (Capital Health Authority, AB, Canada).

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Requests for offprints should be sent to: / Les demandes de tirés-à-part doivent être adressées à :
Donna M. Wilson, R.N., Ph.D.
Caritas Nurse Scientist and Professor, Faculty of Nursing
Third Floor Clinical Sciences Building
University of Alberta, Edmonton, Alberta T6G 2G3
(donna.wilson@ualberta.ca)

Over 90 per cent of the 220,000 Canadians who die each year, principally of old age and progressive ill health (Thomas & Hrudey, 1997; Wilson et al., 2001), do not have access to specialized hospice or palliative care (Special Senate Committee on Euthanasia and Assisted Suicide, 1995; Subcommittee to Update ''Of Life and Death'', 2000). Although hospice/palliative care programs have been valued since their inception in the mid-1970s, they remain unevenly distributed across Canada, with small service capacity and considerable variation in service mix (Subcommittee to Update ''Of Life and Death'', 2000). This scarcity of hospice/palliative care, a specialty service that is currently reserved for terminally ill persons with difficult dying processes, together with discontinuities in the types and availability of other health or social services, means most dying Canadians are at risk of uncoordinated and therefore inadequate end-of-life (EOL) care. Dying persons are arguably the most vulnerable among us, as a result of emotional and physical challenges that are often unique to the dying process. Although the loving support of family and friends when available is irreplaceable, EOL care is an important public obligation (Wilson & Ross Kerr, 1998).

This obligation is not new. The importance of addressing the needs of dying persons has been recognized for over 30 years now (Kubler-Ross, 1973). The Commission on the Future of Health Care in Canada (Romanow, 2002) clearly recognized this obligation by recommending a large-scale expansion of publicly funded palliative home care. This recommendation is extremely important, as a growing proportion of dying persons desire home-based EOL care (Burge, Lawson, Johnston, & Cummings, 2003). It is also becoming obvious that more assistance is needed to support aging-in-place (Cheek, Nikpour, & Nowlin, 2005; Ritchie, 2003), a goal that could include dying-in-place. As only 20–25 per cent of deaths occur suddenly and unexpectedly (Thomas & Hrudey, 1997), 75–80 per cent of decedents have a dying process that typically occurs over a few weeks to many months in length. More assistance is needed to prevent caregiver burnout and the effects of this on caregiver health and well-being because much EOL care is provided at home and by informal or family caregivers. (Brazil, Bedard, Willison, & Hode, 2003; Grunfeld et al., 2004; Hollander, Chappell, Prince, & Shapiro, 2007). Greater home-based support is also needed because of a major shift that began in the mid-1990s from in-patient to out-patient health care provision (Wilson, Truman et al., 2005). Although this shift has primarily been understood as having resulted in most diagnostic tests and surgeries being done on an ambulatory care basis now, location-of-death research also shows a reduction since 1994 in hospital-based deaths (Wilson et al., 2001, 2002). This reduction suggests that the societal obligation to assist dying persons is changing in a number of ways. As such, it is important to consider how this obligation can be better met now and in the future as the number of decedents will increase substantially with population aging and growth.

As a developed country, Canada has considerable means by which to address the societal obligation to help dying persons. Current Canadian EOL supports can be compared against those in other developed countries, including the USA – a country where health care is not normally considered a public responsibility (Committee on Care at the End of Life, 1997; United States Department of Health & Human Services, 1999). Since the mid-1980s, all dying Americans have been able to receive EOL care as a consequence of the Medicare Hospice Benefits program (Centers for Medicare & Medicaid Services, 2005), a program that emphasizes non-hospital care. In contrast, Canadians are only assured, through the 1984 Canada Health Act, of medically necessary health care in hospitals or physicians' offices. Canada does not yet have legislation or EOL care programs specifically designed for all dying persons (Health Canada, 2005). The 2001 Employment Insurance Act amendment known as Compassionate Care Benefits enacted a program that only partially compensates employed persons who take time off work to provide care for a few weeks to dying family members (Williams, Crooks, Stajduhar, Allan & Cohen, 2006). To further the development of EOL care services across Canada, particularly in light of the difficulties inherent in developing new national legislation and pan-Canadian programs, a multi-faceted 18-month research investigation was conducted. This study sought to identify key components of a best-practice integrated EOL care model for Canada. This model should be useful for assisting or guiding EOL care developments that address the need for integrated care.

Methods

A synthesis research approach was chosen over all others to identify key components of a best-practice integrated EOL care model because this approach methodically seeks and critically reviews both newly acquired and existing evidence, including evidence gained through literature reviews, secondary data analysis, and expert testimonials (Ferrell et al., 2005). Synthesis research is similar in intent and methods to integrative literature reviews and meta-analyses, as all systematically seek, critique, and consolidate evidence from multiple sources (Stevens, 2001). The synthesis approach chosen for this study differs from a meta-analysis in that quantitative data analysis was not used to consolidate findings. Instead, constant-comparative data assessment and then data categorization, in keeping with the well-established methods of Grounded Theory research (Cutcliffe, 2005), were used to consolidate findings. More specifically, as the study progressed, specific data were sought and acquired, data were assessed in relation to previous data, with additional new information sought when it was evident that further data were needed to fill a knowledge gap or an improved understanding of an emerging concept was required. Over time, data were grouped into data categories and then larger categorical themes showing relationships between data categories, with these themes becoming the integrated EOL care model components. Monthly team discussions were used to discuss and validate the data categories and each emerging theme, and to ensure continued planning for data saturation.

As indicated previously, the purpose of this study was to identify key components of a best-practice EOL care model that would address discontinuities and gaps in existing EOL services for dying Canadians. This identification had to take into consideration a wide range of factors affecting EOL care in Canada, including differences in care setting (e.g., rural/urban, care in private dwellings vs. that in hospitals or continuing-care facilities), age, marital status, informal or family caregiver availability, ethnicity and culture, cancer versus non-cancer diagnoses, and slow or other dying trajectories. Evidence was gathered through four modes: (1) site visits to established EOL care programs across Canada and in other developed countries, (2) integrative literature reviews on topics identified as important both prior to and over the course of the study, (3) Web-based surveys of Canadians to gain current viewpoints on specific issues, and (4) an analysis of one accessible home care database to gain information on palliative home care clients and service provision in one province. Additional information about these modes follows.

Site visits

Site visits to hospice or palliative care programs and continuing-care facilities with EOL care services were undertaken to gather information on EOL care provision and care integration in nine developed countries: Canada (23 sites), the USA (eight sites), New Zealand (eight sites), Australia (eight sites), and England, Northern Ireland, the Republic of Ireland, Wales, and Scotland (23 sites). Prior to the site visits in each country, extensive preparations were undertaken to gain a foundation of country-specific information on EOL care, such as government policies and programs (as well as the influences for their development), existing or expected hospice/palliative care standards and other EOL program requirements, and EOL care developments such as those occurring in continuing-care facilities and through home-based EOL care. Information on each specific site was also reviewed to gain an understanding of the EOL care services provided and any other information relevant to care integration. Potential sites were identified through Internet searches, and sites were sent a letter requesting a site visit. Approval for each site visit was obtained in advance from the chief administrator at that site, who later signed a research consent form prior to on-site data gathering. All site visits involved a tour and a semi-structured interview of the chief administrator and often other employees to gather information that largely focused on what is needed for best-practice integrated EOL care (see Appendix A for a list of the questions asked at all site visits). The principal investigator or a research assistant undertook all site visits, with the semi-structured interviews tape-recorded and transcribed. Interview data and additional site observations were outlined in a written report that was completed immediately after each site visit. This report was shared with the chief administrator and corrected if needed. The person who had undertaken the majority of the site visits then completed a summary report for each country. Each country-specific summary report was reviewed and approved by the research team prior to it being uploaded to the team's Website for dissemination purposes.

Literature reviews

A total of 27 integrative literature reviews were completed on key topics that were either considered important at the beginning of the study for integrated EOL care or determined later to be important through one or more site visits (see Appendix B). Each review primarily involved identifying and systematically reviewing all research articles published in the previous fifteen years (1988–2003) in nine primary health library databases (EMBASE, Medline, CINAHL, AHMED, PsycINFO, ERIC, HealthSTAR, Sociological Abstracts, and Cochrane, including the Cochrane Central Register of Controlled Trials and the Library of Systematic Reviews). Each search involved the terms "palliative care", "terminal care", "hospice", "dying", and "end of life", combined with the keyword of interest, and was limited to English- and French-language articles. Research articles were mainly sought, although other articles and books or Internet materials were used for background information. Each published research article was systematically reviewed to identify clearly its findings, and to permit a constant-comparative analysis that would group findings across articles into categories and then themes. For each topic, a report was drafted by the principal investigator and the research assistant who had been involved in that review, with this report circulated for research team discussion. Each report needed 100 per cent group consensus before it was considered complete. Six reports that fully outline the review methods used have since been published (Froggatt et al., 2006; Thomas & Wilson, 2005; Thomas, Wilson, & Sheps, 2006; Wilson, Justice et al., 2005; Wilson, Kinch et al., 2005; Wilson et al., 2006).

Surveys

Three Web-based questionnaires were designed to gather current or previously uncaptured information from: (a) persons who reported themselves as being near the EOL, (b) families/friends of persons near the EOL, and (c) people who responded as EOL care providers. Following a review of other EOL care survey tools and a careful appraisal of the desired information, the principal investigator and a research assistant drafted each questionnaire. The research team revised the draft questionnaires with the assistance of palliative care experts (see Appendix C). All three questionnaires were translated into French, and both language versions were uploaded to an Internet site for a period of seven months. Notices to encourage voluntary participation were circulated at four large Canadian healthcare conferences and via 12 Web or print-based distribution sources (including the Canadian Hospice Palliative Care Association Website and the journal *Canadian Nurse*). Questionnaire data were sampled at mid-point to ensure that persons situated across Canada were completing the questionnaires. A total of 32 persons who were near the EOL, 154 family members/friends, and 554 EOL care providers completed questionnaires. Questionnaire data were summarized through descriptive statistics, with a report of findings drafted by the principal investigator and a research assistant. This report was reviewed by the research team and then approved for uploading to the Website following revisions. As the questionnaires were simple and the data not generalizable, since contributors were not representative of the larger populations of persons sought, a publication outlining the findings from these surveys was not considered.

Home care data analysis

An analysis of population-level home care data, reflecting home care clients and service provision in one province from April 1, 1991 through March 31, 2001 was undertaken. This analysis was undertaken because few reports on home care provision and home care clients are available for Canada, despite an increasing number of deaths at home and much EOL care taking place in the home even when death occurs in hospital (Wilson et al., 2001). To this end, complete individual-anonymous data were purchased from Alberta Health and Wellness, and analyzed by a graduate student supervised by the principal investigator and a co-investigator with expertise in health services data analysis. Palliative clients, services, and service providers were described and compared over the 10 study years and compared to other non-palliative home care clients, services, and service providers. A report was drafted, and then reviewed and ultimately approved by the team after suggested revisions were completed. Two articles that outline the data, data analysis, and findings have been published (Wilson, Truman et al., 2005, 2007).

Information synthesis methods

Through the four data-gathering methods described above, much information relevant to a best-practice integrated EOL care model was identified. As the information emerged, it was tested and validated through one or more methods. In most cases, information obtained at one site visit was tested and validated through subsequent site visits and/or through one or more literature reviews. The home care data and Web-survey data, which provided additional information after the majority of the site visits were completed, were mainly used to validate previously collected data, and in some instances identify key information to be validated through literature reviews. As information was validated, it was grouped into categories and then themes using a standard Grounded Theory data analysis method, which builds a theory of key concepts and their relationships over time. Through this synthesis method, four themes or key model components for integrated EOL care emerged, as well as a definition of EOL care.

Results

EOL care came to be defined as the services that may be needed by dying persons and their family or friends in the last year of life, as well as bereavement services following death. The four key components for a best-practice integrated EOL care model for Canada were determined to be: (1) universality, (2) care coordination, (3) ensured access to a broad range of basic and advanced EOL services, and (4) EOL care provision regardless of setting. Each of the four components is further described below.

Universality

All persons can be expected to have psychosocial, spiritual and physical care needs following a terminal diagnosis and as they progress through their dying process. Although these needs vary considerably among individuals as a result of differences in age, marital status, the terminal illness and any co-morbidities, the speed and type of dying trajectory, and many other factors, all persons who are nearing EOL will need support. As such, a best-practice EOL care model for Canada would consider all dying persons as having support needs.

Care Coordination

The second key component of a best-practice integrated EOL care model for Canada is care coordination. More specifically, a care coordinator or case manager is essential for ensuring the access of dying persons and their family or friends to needed care across service sectors and care settings.

Assured Access to a Broad Range of Basic and Advanced EOL Services

The third component of a best-practice integrated EOL care model for Canada is assured access to a broad range of basic and advanced EOL care services. Most dying persons only require basic supports such as with transportation, walking, toileting, bathing, and meal preparation during the last days or weeks of life (Wilson, 2002). While basic services can be provided by many different formal care providers and also by family members or friends, advanced services can only be provided by persons or organizations specializing in EOL care. Since it is impossible to predict which persons will need advanced EOL care or even basic support because of informal caregiver burnout or other factors, such as a person not having a family or friends available to provide basic EOL care, the assurance of a full range of accessible basic to specialized hospice/palliative care is necessary at all times for dying persons.

EOL Care Provision Regardless of Setting

The fourth component of a best-practice EOL care model is the assurance of EOL care regardless of the care setting. Although terminally ill persons typically reside in private dwellings throughout the majority of their dying process, many deaths take place in hospital and some in continuing-care facilities. EOL care may thus be required in any setting where a dying person temporarily or permanently resides. EOL care needs can change rapidly in any care setting, and the needs of dying persons are often best served in the existing care setting as opposed to moving to receive care. EOL care provision in any location where a dying person temporarily or permanently resides is thus an essential component of best-practice integrated EOL care.

Discussion

Care integration is increasingly being identified as a key area for Canadian health services and policy development (Hollander et al., 2007). As outlined above, a definition of EOL care and four components for best-practice integrated EOL care in Canada were developed through a synthesis research investigation. The definition and each component was determined through one or more data-gathering methods and validated repeatedly through subsequent data-gathering and analysis methods to ensure its importance for integrated EOL care. Our systematic literature review of published hospice/palliative care models revealed that some of these components have previously been identified in whole or in part as important for care planning or provision (Centeno & Heller, 2000; Centeno et al., 2000; Cohen & Leis, 2002; Ferraz Gonçalves, 2001; Gilmer, 2002; Gotay, 1983; Ingleton, Skilbeck, & Clark, 2001; Janssens & ten Have, 2001; Janssens et al., 2001; Johnston & Daly, 2001; Luczak, 1993; Maltoni, Derni, Fabbri, & Sansoni, 2000; O'Neill, O'Connor, & Latimer, 1992; Sbanotto & Burnhill, 1998; Singer, Martin, & Kelner, 1999; Stead, 1998; Walsh, 2001; Zhukovsky, 2000). As such, these models provide additional support for the four components.

The definition of EOL care that was developed through this study differed substantially, however, from all previously published hospice/palliative care definitions. Through this synthesis research study, EOL care came to be defined as the services that may be needed by dying persons and their family or friends in the last year of life, including bereavement services following death. This definition differs from hospice/palliative care definitions in three crucial regards. First, it is much broader, as it is oriented to the care of all persons who are dying, not just those needing specialized hospice/palliative care. Second, EOL care services are not specified as to their type, as needed services will vary considerably in keeping with the unique circumstances of each dying person. Finally, a 12-month timeframe for EOL care was chosen over the six-month eligibility criteria for U.S. Medicare Hospice Benefits and the six-month recommendation for home palliative care made by the Commission on the Future of Health Care in Canada (Romanow, 2002). A 12-month timeframe was identified as current practice in hospice/palliative care programs with regard to planning and providing EOL care services. Site visits repeatedly revealed that care providers commonly use the program-admission criterion that the dying person is not expected to be alive in one year. Our integrative literature review on EOL prognostication also revealed considerable ongoing difficulty, despite advancements in diagnostic tools, for accurately predicting life expectancy, with dying persons often living much longer than expected.

Universality as a Key Component of Integrated EOL Care

The Special Senate Committee on Euthanasia and Assisted Suicide (1995) and the Subcommittee to Update "Of Life and Death" (2000) twice estimated that only five per cent of dying Canadians receive specialized hospice/palliative care, with the vast majority of dying Canadians thus not receiving advanced care from hospice/palliative specialists nor through one EOL care program. A literature review of the needs of dying persons also revealed that they normally have care needs prior to death (Addington-Hall & Karlsen, 1999; Anderson et al., 2001; Baker & Seager, 1991; Chow et al., 2001; Costello, 2001; Evers, Meier, & Morrison, 2002; Maguire, Walsh, Jeacock, & Kingston, 1999; Morasso et al., 1999; Myers & Trotman, 1996; Raynes, Leach, Rawlings, & Bryson, 2000; Singer et al., 1999; Steinhauser et al., 2000; Vig, Davenport, & Pearlman, 2002). Although not all dying persons have difficulty with symptoms or dying processes that need hospice/palliative care specialist support, the usual discontinuity that exists with regard to health and social service provision means that most dying Canadians are at risk of receiving minimal or inappropriate EOL care, with unmet care needs a common problem.

Despite considerable concern since at least 1995 about the need for quality EOL care in Canada (Special Senate Committee on Euthanasia and Assisted Suicide, 1995; Subcommittee to Update "Of Life and Death", 2000), the site visits to programs across Canada revealed that existing hospice/palliative care programs are largely the result of grassroots and voluntary efforts, with an uneven distribution of programs, limited service capacity, and varying services the result. The site visits and Web-based questionnaires also revealed that public funding for hospice/palliative care differs across Canada, with most programs relying in large part (50 per cent or more) on charitable donations. Similar historical development issues were evident in all other countries visited, although, in these countries, considerable government involvement in the form of care standards and ensured funding had occurred to increase both access to EOL care and the quality of this care. Government support for EOL care is in keeping with the social values underlying the universality criterion of the Canada Health Act (1984). As all Canadians can be expected to have health care needs, so too can all dying Canadians be expected to have EOL care needs. Furthermore, given that the ability to purchase EOL care services varies considerably among dying persons and their families, public funding is required to ensure universal coverage of needed EOL care services.

Care Coordination as a Key Component of Integrated EOL Care

The site visits, an integrative literature review of case management, the three Web-based surveys, and the home care data analysis all illustrated the significance of care coordination. Although the review of the case management literature did not clearly establish the outcomes of EOL care coordination or case management, care coordination was found to be a common and well-regarded phenomenon in the USA, the country where most of the research on EOL case management has taken place. Care coordination was also found to be a common and highly valued feature of all visited hospice/palliative care programs, both in and outside of Canada.

It is also notable that most hospice/palliative care programs in New Zealand were initiated after community fundraising had enabled the employment of a care coordinator for assessing care needs and then arranging EOL care. Some programs in the UK consist solely of EOL care coordinators, with these persons often community-based Macmillan nurses, who are registered nurses with advanced EOL care skills and knowledge, if not palliative care credentials. In all countries visited, care coordinators typically performed an intake assessment and developed the initial care plan. Care coordinators then maintained an ongoing working relationship with the dying person and their family. Care coordinators also typically provided specialized EOL care, such as periodic or regular symptom assessment. Care coordinators were thus identified as reducing the workload of palliative care specialists, and these specialists could focus on the clients who required their level of expertise. Few care coordinators, however, could prescribe medications, order diagnostic tests, or admit a client to hospital; limitations that were cited as important to overcome.

Regardless, improved care planning and integration were considered to be positive outcomes of having one clearly identified person who was responsible and accountable for assisting select dying persons and their families. Persons near the EOL and their families were also thought to benefit from having a consistent care coordinator through the anticipation of EOL care needs as opposed to care being arranged reactively when needs had already arisen. As EOL care coordinators were readily available by telephone to dying persons and their families, more timely care was another reported benefit. Care coordinators were considered particularly crucial for addressing the communication needs of persons near the EOL, their significant others, and their health care providers. More accurate identification of actual or potential problems, problem prevention, and earlier as well as more successful resolution of problems were additional commonly reported impacts of care coordination. It was also notable that all of the EOL care coordinators, most of whom were registered nurses, were in salaried positions, a deliberate arrangement as the fee-for-service remuneration of family physicians was said to provide little incentive for undertaking the time-consuming tasks of planning and arranging EOL care. As such, many positive outcomes of care coordination were identified, with the outcomes often related to care integration by registered nurses.

Assured Access to a Broad Range of Basic and Advanced EOL Services as a Key Component of Integrated EOL Care

An integrative literature review on the needs of dying persons, an integrative literature review on the needs of families of dying persons, all three Web-based questionnaires, and all site visits identified the importance of ensuring ready access to a comprehensive range of basic through to advanced EOL services. Although it was evident that many factors may contribute to a good death, and many factors are considered relevant to high-quality EOL care, assured access to basic and/or advanced EOL services when needed is essential for dying persons.

Basic and advanced support are both important. Basic support is the support that can be provided to dying persons in any care setting by people who do not have nursing or other credentials, although this provision is not without challenges. The integrative literature review on the needs of dying persons revealed five basic needs that are common throughout most dying processes: (a) pain and symptom management; (b) assistance with activities of daily living; (c) good communication, including the provision of timely and relevant information; (d) spirituality; and (e) help with psychosocial or emotional concerns. The integrative literature review on the needs of family members similarly revealed six basic needs that are common across families: (a) timely and compassionately delivered information about their family member's state of health, (b) emotional support prior to and following the death, (c) knowing that they ensured their dying family member's comfort, (d) feeling satisfied with the formal care services that were provided, (e) having their work as informal caregivers enabled and recognized as important, and (f) additional needs that arise largely from cultural backgrounds and/or family dynamics.

Advanced support was identified as needed by only a small proportion of dying persons, normally persons dying of cancer, a disease that is often associated with symptoms that are difficult to manage or control. Furthermore, in cases where dying persons are admitted to a continuing-care facility with considerable ongoing EOL dependency, this type of advanced EOL care is also normally only needed by a very small proportion of dying persons. In contrast, the needs of all persons who are nearing the EOL can vary from day to day, with increasing dependency as death nears, and with their needs potentially ranging from minimal to complex. Other than those dying suddenly or unexpectedly, all persons with dying processes will have basic and sometimes advanced care needs. Furthermore, these needs should be met – and met as quickly as possible for quality care purposes.

EOL Care Provision Regardless of Setting as a Key Component of Integrated EOL Care

Our integrative literature review on Canadian EOL care programs, models, and approaches revealed that the majority of deaths in Canada since 1950 have taken place in hospitals, although the EOL care that precedes death typically occurs at home (Wilson et al., 2001; Wilson, MacAdam et al., 2003). Our home care data analysis and the literature review to inform our discussion of these findings revealed widespread consensus and growing evidence that death in hospital now is often a result of minimal formal home care and subsequent informal caregiver burnout (Wilson et al., 2001; (Wilson, Truman et al., 2005). Indeed, the home care data for Alberta revealed that, in this economically advantaged province, 90 hours of home care assistance had been provided on average to palliative care clients over the last three months of life (Wilson, Truman et al., 2005; Wilson et al., 2007). It is unlikely that the equivalent of one hour of assistance from a nursing aide each day in the last three months of life, a time when care needs are typically the highest, would prevent informal or family caregiver burnout, nor would it ensure quality EOL care.

Although hospital-based EOL care may improve access to pain specialists and to diagnostic or treatment services to address discomfort and other unpleasant symptoms, a considerable number of issues, including the risk of cure-oriented care being provided as opposed to comfort-oriented care, were identified through our integrative literature review of acute care hospital death and dying. This review also clarified the current Canadian health system state as one in which hospitals are the only care site that is available on a 24 hour and seven-day-a-week basis for the vast majority of dying persons. Greater home-based support and the development of alternative sites to hospital-based EOL care are thus important to ensure that hospitals are not the sole setting where end-stage dying can take place. Free-standing hospices that provide 24 hour and respite care, palliative day-care programs that offer full-day and full-service care, and continuing-care facilities with recognized palliative care expertise were common examples of alternatives found in other developed countries, but not within Canada.

Conclusion

The proposed care-integration model extends both the breadth and scope of EOL care, and it also increases the potential recipients of care. These extensions are needed, as specialized hospice/palliative care is currently reserved for persons who are actively dying and experiencing difficult-to-manage symptoms or dying processes. Given the scarcity of hospice/palliative care experts and also established hospice/palliative care programs across Canada, hospice/palliative care has understandably been rationed to date on the basis of specialist need. The four model components identified above are relevant for all dying Canadians who are identified as being in the last year of their lives, a time when basic care needs become evident and when some persons develop a need for advanced care. The assurance of both basic and advanced EOL care across all possible care settings, as assisted by care coordinators and through public funding, is critical to fulfilling the societal obligation to assist all dying persons.

The four components for best-practice integrated EOL care are relevant for guiding developments in EOL care on both a pan-Canadian basis and also within provinces or communities. These components may be employed by governments at any level and by regional health authorities, or by the administrators of rural or urban hospitals and all other health care organizations, to plan and provide for integrated EOL care. Although many different organizations can cooperate to ensure integrated EOL care, it is also possible for one organization to provide the full range of basic and advanced EOL care services. Care coordination is the key for ensuring the comprehensive package of EOL care services is truly accessible, in all care settings and in all cases of impending death.

The timing for the development of EOL care is excellent, as the philosophy of excellence in comfort-oriented care is starting to extend beyond specialized hospice/palliative care programs (Health Canada, 2005). Much must be done, however, to ensure that all dying persons receive the care that they need in the last year of life. Work at policy and service levels is important now and in the future, as population growth and population aging will increase demand for integrated EOL care.

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Appendix A. Semi-Structured Site Visit Interview Guide

Questions asked of all chief administrators:

1. What is the aim (or purpose/mission) of your organization? In addition: What services do you offer, what services are available to clients now or as planned, are any services for family members, how do clients get your services, does a client or family have to pay for your services, how many clients are served each year, are you at full capacity, who are your clients primarily, and is there a limitation on the length of time that services can be received?
2. Is the program integrated, such as having care provided in different settings? In addition: Where can your services be provided, how is the program integrated, does the program use a case manager or care coordinator, who is employed, are volunteers used, can we see your forms and other recording tools, can we talk to your staff and other available persons?
3. What are the impacts or outcomes of your program? In addition: Has there ever been a research study of the impacts or outcomes, has there ever been an evaluation of the impacts or outcomes, are there client satisfaction or staff satisfaction survey results to view?
4. How or why did your program develop? In addition: Did it develop as a result of health system regionalization or integration and, if so, did these initiatives continue to impact the program?
5. What policy implications are there for starting a program such as yours and for operating a program such as yours? In addition: What policy implications are there for starting and/or carrying out this program, how is the program funded, do you fundraise, what is the annual budget, how does this program relate with hospitals and health care organizations in the area, how does the program work with doctors and other providers in the area, do you advertise, how do you otherwise promote the use of your services, what is your government's stance on hospice palliative care and seniors care, and what information do you share with government or others?

Appendix B. Completed Literature Reviews ($n = 27$)

Canadian end-of-life care programs, models, and approaches

International end-of-life care-delivery models or approaches

The needs of dying persons

The needs of the families of dying persons

Pediatric end-of-life care

Gender differences in the experience of the dying process

Culture and end-of-life care

Aboriginal end-of-life care

End-of-life spiritual and psychosocial issues

Bereavement

Managing end-of-life pain and other symptoms through non-pharmacological means

End-of-life prognostication

Literature reviews that have focused on end-of-life care

End-of-life topics in randomized controlled clinical trials research

Continuity of end-of-life care

End-of-life case management

The home as a place of end-of-life care

End-of-life care in acute care hospitals

End-of-life care in intensive care units

End-of-life care in residential continuing-care facilities

End-of-life care in rural or remote areas

Palliative day care

End-of-life respite care

Volunteers involved in end-of-life care

Outcomes and evaluation of end-of-life care

Education in Canada for end-of-life care

New developments in end-of-life care

Appendix C. Three Web-based Questionnaires

Questionnaire for persons facing the end of life:

1 What part of Canada do you live in?
2 Where do you live? (Urban, suburban, rural/remote)
3 Are you a female or male?
4 What is your age?
5 Do you live with or near family/friends who can help you?
6 How are your finances? (Well off, comfortable but must watch spending, having difficulty paying for essentials)
7 What life-threatening illness or health condition do you have?
8 How long ago did you learn you had this life-threatening condition?
9 Since the day you learned you had a life-threatening illness, have you needed any of the following services (list of 16 common services)?
10 Since the day you learned you had a life-threatening illness, have you had any difficulty getting any of the following services (list of 16 common services)?
11 Since the day you learned you had a life-threatening illness, have you had to pay privately (out of pocket) for necessary health care?
12 Since the day you learned you had a life-threatening illness, how well have you been served by the public health care system?
13 Since the day you learned you had a life-threatening illness, have you had any help from a care coordinator or case manager?
14 How important are integrated end-of-life care programs (these provide care in and outside of hospital)?

Questionnaire for the family members and friends of people facing the end of life:

1 What part of Canada do you live in? And what part does your family member live in?
2 Where do you live? And where does the family member live?
3 Are you a female or male? Are they male or female?
4 What is your age? What is their age?
5 Do you live with or near the family member/friend?
6 How are your finances? And the finances of your family member/friend?
7 What life-threatening illness or health condition does your family member/friend have?
8 How long ago did they learn they had this life-threatening condition?
9 Since the day they learned you had a life-threatening illness, have they needed any of the following services (list of 16 common services)?
10 Since the day they learned they had a life-threatening illness, have they had any difficulty getting any of the following services (list of 16 common services)?
11 Since the day they learned they had a life-threatening illness, have they had to pay privately (out of pocket) for necessary health care?
12 Since the day they learned they had a life-threatening illness, how well have they been served by the public health care system?
13 Since the day they learned they had a life-threatening illness, have they had any help from a care coordinator or case manager?
14 How important are integrated end-of-life care programs (these provide care in and outside of hospital)?

Questionnaire for end-of-life care providers or planners:

1 What part of Canada do you work in?
2 Please tell us your end-of-life care role (manager, direct care provider, other).
3 How long have you been involved in planning or providing end-of-life care?
4 Your program has services that are province wide, regional, city or town specific, other?
5 Your program provides which of the following six services?
6 Which of the following 16 services does your program offer?
7 Is your program publicly funded?
8 How would you rate the end-of-life care services provided by the public health care system in your province?
9 How would you rate the end-of-life services provided by your program?
10 How important are integrated end-of-life care programs (these provide care in and outside of hospitals)?