

Twentieth-Century Social and Health-Care Influences on Location of Death in Canada

Donna M. Wilson, Susan L. Smith,
Marjorie C. Anderson, Herbert C. Northcott,
Robin L. Fainsinger, Michael J. Stingl,
and Corrine D. Truman

Des soins adéquats, prodigués dans des lieux appropriés, ne peuvent être offerts aux mourants en raison d'un manque de compréhension quant aux lieux habituels où se vivent la phase terminale et le décès, et quant aux facteurs influant sur les lieux de décès. Cet article présente les résultats d'une étude historique multidisciplinaire des éléments du 20^e siècle qui influent sur les lieux de décès au Canada. Il s'appuie sur une recherche qui révèle qu'au Canada, pendant la plus grande part du 20^e siècle, les décès surviennent surtout en milieu hospitalier, et que ce taux est à la baisse depuis 1994. Cette étude a identifié deux facteurs clés en ce qui a trait au lieu de décès : (1) des transformations dans le domaine des soins et du système de santé ont relégué les soins aux hôpitaux et suscité chez le public des attentes de soins en milieu hospitalier qui sont efficaces et curatifs – l'augmentation du taux de décès en milieu hospitalier au 20^e siècle peut donc être attribuée au fait que les soins, jadis prodigués à domicile, ont été transférés dans les hôpitaux; et (2) la diminution de la disponibilité des soignants naturels. Pour les malades chroniques et les personnes en phase terminale, plusieurs changements ont réduit les possibilités d'être soignés en milieu familial, notamment la participation croissante des femmes au marché du travail et le fait que l'exercice de la profession infirmière est passé du foyer aux hôpitaux. Bien que des services sociaux et des soins de santé ont été mis sur pied dernièrement pour la clientèle à domicile, ce soutien n'est pas, de toute évidence, aussi important que celui accordé aux soins hospitaliers. Les résultats de cette recherche indiquent que le lieu de décès constitue un facteur important dans l'étude et la planification d'améliorations au bénéfice des personnes en phase terminale.

Donna M. Wilson, RN, PhD, is Associate Professor, Faculty of Nursing, University of Alberta, Edmonton, Canada. Susan L. Smith, PhD, is Associate Professor, Department of History and Classics, Faculty of Arts, University of Alberta. Marjorie C. Anderson, RN, PhD, is Associate Professor, Faculty of Nursing, University of Alberta. Herbert C. Northcott, PhD, is Professor, Department of Sociology, Faculty of Arts, University of Alberta. Robin L. Fainsinger, MD, is Director, Division of Palliative Care Medicine, Department of Oncology, University of Alberta. Michael J. Stingl, PhD, is Associate Professor, Philosophy Department, University of Lethbridge, Alberta. Corrine D. Truman, RN, PhD, is Information Analyst, Alberta Health and Wellness, Edmonton.

Providing the right care, in the right place, to dying persons is hampered by a lack of understanding of where death and dying normally take place and ignorance about what influences location of death. This paper reports the findings of a multidisciplinary historical investigation of 20th-century influences on location of death in Canada. It builds on a study that found a hospitalization-of-death trend in Canada over much of the 20th century but a reduction in hospital deaths beginning in 1994. This study found 2 key influences on location of death: (1) health-care and health-system developments that consolidated care in hospitals while also raising and sustaining public expectations of beneficial if not curative hospital care — the rising hospital-death rate throughout the 20th century can thus be considered an outcome of the shift of illness care from the home to the hospital; and (2) reduced availability of home-based caregivers. A number of developments limited the availability of home care for chronically ill and terminally ill persons, including the increased participation of women in the workforce and the shift in nursing from private home duty to hospitals. Although some health and social support for home care has developed recently, this support clearly does not match that for hospital care. These findings indicate that location of death is an important focal point for studying and planning improvements in end-of-life care.

One of the most serious concerns today about death and dying is extensive and expensive treatment-oriented care. Although some Canadian research indicates that terminally ill people are often recognized as such and treated compassionately (Wilson & Truman, 2001), a recent large-scale study of hospital care found aggressive care until death to be the norm in the United States (SUPPORT Principal Investigators, 1995). The impact of extensive cure-oriented diagnostic testing and treatment has led one nurse to conclude: "first you suffer, then you die" (Curtin, 1996, p. 56). Futile, cure-oriented end-of-life care is particularly troublesome in light of the considerable palliative-care advances that have been made. Palliative care has become an effective, comprehensive, comfort-oriented, broad-based approach, irrespective of the location of care, for improving the quality of life of dying individuals and their families (Canadian Palliative Care Association, 1997).

Yet palliative care has not exactly flourished in Canada. Most hospitals still do not have palliative-care teams or programs to plan and provide care to dying persons (Health Canada Working Group, 1997; Roy, 1999). Community-based palliative-care programs are increasing in number but are inadequate to meet current needs (Health Canada Working Group; Wilkins & Park, 1998), let alone the future needs of a growing and ageing population (Chui, 1996; Statistics Canada, 2000).

Providing the right care, in the right place, to dying persons is made all the more difficult by considerable knowledge gaps. Although death in hospital is a common occurrence (Heyland, Lavery, Tranmer, Shortt, & Taylor, 2000), no comprehensive reports on location of death in Canada exist for planning or policy purposes. Health-services planning for dying persons is hampered by a lack of understanding of

where death and dying take place, the factors that influence location of death, and whether important shifts in location of death and dying are occurring. To address these knowledge gaps, an investigation of 20th-century Canadian trends in location of death and factors influencing location of death was undertaken.

Research Methods

The first phase of the investigation involved an analysis of three Canadian mortality databases to identify 20th-century trends in location of death. The findings of this analysis are reported elsewhere (Wilson et al., 2001). Two findings are critically important: a longstanding hospitalization trend (culminating in a peak incidence of 80.5% of all recorded places of death in 1994), and a reduction in hospital deaths following 1994.

The second phase involved an historical study of 20th-century social and health-care influences on location of death. To ensure broad-based, comprehensive data collection and diverse disciplinary perspectives on group data analysis and synthesis, the project was undertaken by a multidisciplinary six-member team: a nurse, a palliative-care physician, a health-care historian, a nurse gerontologist/psychologist, a philosopher/ethicist, and a sociologist. Each researcher had a distinct focus of inquiry and committed to searching a distinct selection of library databases (see Appendix 1). To enhance trustworthiness of data collection and analysis, all members of the team attended a workshop on historical data collection and historical-comparative data-analysis methods.

Extensive quantitative and qualitative data were sought by each researcher and his or her research assistant(s), with historical-comparative methods being used to organize, critique, compare, and synthesize data (Hamilton, 1993; Sarnecky, 1990). As influences can vary greatly from one country to another, only Canadian information was sought.

More specifically, after data from the first phase of the investigation and preliminary data had been reviewed, the data search was divided into four eras: the early 20th century (1900–39), the development of Medicare era (1940–69), the initiation of palliative-care era (1970–89), and the contemporary era (the 1990s). This division permitted a contextualization and categorization of influences that proved to be impossible when a decades-based approach was attempted. Historical research is often undertaken and reported in such a chronological

context, as developments in one period can influence those in subsequent periods (Colton, 2000).

Each researcher used data triangulation and judgements about the dependability of data to prepare four reports, one for each era, on location-of-death influences. The reports were circulated to all researchers prior to group meetings, with meetings taking place after all reports for an era had been prepared. Each researcher thus developed a discrete database and understanding of era-based influences on location of death. The researchers also came to a common understanding, through group analysis and synthesis of findings, of location-of-death influences first for each era and then for all eras combined. The group thus consensually approved and validated the findings presented below.

Findings

Early 20th Century (1900–39)

Many early developments facilitating hospital-based health care were identified. Two critical location-of-death influences became apparent: increased availability of hospital-based care, and an increased need for and acceptance of hospital-based care.

The increased availability of hospital-based care was due in part to rapid growth in the number of hospitals. Agnew (1974) notes that in 1870 there were only a few hospitals across Canada but in 1929 there were 886 (with 74,882 beds). Another example of rapid hospital growth was provided by the principal investigator through an analysis of annual hospital reports housed in the Provincial Archives in Edmonton. In 1905, there were only 11 hospitals in Alberta, but by 1939 there were 93 (compared to 120 currently for a much larger population).

Hospitals at the turn of the 20th century were often private homes converted to hospitals by charitable or religious groups (Agnew, 1974). Although most were small, hospitals were considered necessary for a variety of reasons, such as to attract settlers, but the most common reason was to meet the health-care needs of people living in the immediate area (Agnew, 1974; Middleton, 1919). As most early hospitals in Canada were voluntary enterprises, they often provided care even when there was little possibility of payment (Agnew, 1974). Hospitals tended to provide care only when it was not available in the home (McGinnis, 1988).

There is considerable evidence that hospital care was increasingly needed during this era, one reason being rapid population growth as a result of immigration (MacDougall, 1994), with single immigrants, and married immigrants who arrived in advance of their families, having to rely on hospitals when ill. Industrialization and urbanization, two developments in the early to mid-1900s (Ostry, 1994), disrupted the family unit and thus reduced the ability of families to provide care in the home. The conscription of men during the two world wars also served to reduce the ability of families to provide health care in the home (McPherson, 1996). Not only were able-bodied men removed from the home, but able-bodied women were often employed outside the home. In addition, the wars produced many injured veterans. At the end of World War I alone, 173,000 disabled and wounded men returned to Canada (MacDougall). These veterans could not always be cared for at home, and governments felt a responsibility to them (MacDougall; Ostry). Municipal governments were the first to take concrete steps to ensure the availability of hospital care. By 1924, many hospitals had come under the control of municipal governments as a result of their providing secure funding (Middleton, 1919).

Regardless, most sick people in the early 1900s received care in private residences (McGinnis, 1988). Home care for both the sick and the dying was considered the norm (McPherson, 1996). Care by family members also eliminated the need to pay for hospital care or for private care in the home. Significant limitations on the efficacy of health care also served to temper public reliance on and demand for hospital care. Despite advances in surgical techniques and in radiation (George & Gerber, 1915), few serious illnesses or diseases were curable in the 1900–39 era (Bell, 1900; Munroe, Hoare, & Cristall, 1939). The hospital was considered a place of death, as indeed death commonly occurred there (Agnew, 1974; Buckley, 1988; MacPhail, 1904; Rozovsky, 1974), partly due, perhaps, to a lack of effective medications (Blackader, 1916): antibiotics did not become available until after World War II (MacDougall, 1994; McGinnis), and anaesthesia and pain medications were not in common use (Roland, 1985).

Yet the public's faith in health care increased in this era. Public-health measures initiated by government greatly reduced infectious disease and death rates (Harding le Riche, 1979). Immunization was almost routine across Canada by the time of World War I (Harding le Riche). Similarly, by 1920 milk pasteurization and other public-health measures had greatly reduced the incidence of tuberculosis, a major cause of death until then (MacPhail, 1904; Zilm & Warbinek, 1995).

X-ray technology, electrocardiography, and laboratory testing of blood and bodily fluids also came to be used widely (Agnew, 1974). Hospitals served as the physical location of these technologies, along with the experts required to operate them. Early diagnosis became a medical preoccupation (Bell, 1990). Insofar as early detection helped to save lives, the hospital was transformed, in the 1920s and 1930s, from a place where one went to suffer and die, to a place where one's life might be saved (Agnew, 1974).

Nursing developments also raised public confidence in hospitals, thereby promoting a shift of care from the home to the hospital. Stringent nursing programs were instituted in hospitals at the turn of the 20th century, with staffing composed primarily of student nurses (McPherson, 1996). Graduate nurses normally provided care in the home (McPherson). Often, this care was palliative, or comfort-oriented (McIlveen & Morse, 1995). For instance, early records of the Victorian Order of Nurses indicate that half of its home-care clients were dying ("What is the V.O.N.?", 1943). Private home visits could be of short duration, but long-term home nursing care was also common (McPherson). The 1920s recession and 1930s Depression, however, made hospitals a much more attractive work setting for nurses, as for physicians, due in part to the dependability of public versus private funding (McPherson; Weir, 1932). This shift in work setting served to reduce the number of persons available to provide skilled health care in the home, while increasing the quality and desirability of hospital-based care.

Other, less tangible, developments also influenced the hospitalization trend. The dual development of health-care professionalism (Rozovsky, 1974) and technological advances reflected, as well as fuelled, the emerging ideology of logical positivism — that science and technology can understand and control the natural world (Ostic, 1940). The increased faith in science was accompanied by a decrease in the social power of religion (Stingl, 1997). One of the most significant outcomes of these changes was a shift in medical focus, from the patient as a subject of observations (about his or her condition) made by the physician, to the patient's body as a subject of observations made by machines (Stingl). The subjective meaning of illness and death began to be eclipsed in significance by their technological management in a hospital setting. In summary, many developments in the 1900–39 era influenced a shift in care from home to hospital, and these same developments would support a shift in death and dying from home to hospital.

Development of Medicare Era (1940–69)

Prior to the early 1970s, when access to hospitals and medical care was assured across Canada, two federal government initiatives supported hospital-based care. The first was the National Health Grants, aimed, during the 1940s and 1950s, at increasing the number of hospital beds and raising the quality of hospital care (Vayda & Deber, 1984). These funds were often used to upgrade hospital laboratories and radiology departments. The second development was the passage, in 1957, of the *Hospital Insurance and Diagnostic Services Act*, making hospital care accessible to all Canadians. Yet, while hospital care began to be provided at public expense, home care continued to involve private costs (Donahoe, 1961; Special Report, 1970).

There was considerable demand for nurses and other health-care workers during this era of hospital expansion (McVey & Kalbach, 1995). Employment in the financially secure, familiar hospital environment became the norm for nurses (Canadian Nurses Association Research Unit, 1966; McPherson, 1996). The rising incidence of hospital care and the shift of nurses to the hospital setting increasingly made nurses, as opposed to lay family members, the primary caregivers in cases of serious illness, dying, and death. The public was thus assured of expert care for the ill and dying (Rozovsky, 1974).

Yet the age-old duty of nurses to provide comfort-oriented care to dying persons was at odds with a medical emphasis on cure or life prolongation (Quint, 1967). Comfort-oriented or palliative care did not advance much during this era, perhaps due in part to nurses having come under the control of physicians and hospital administrators (McIlveen & Morse, 1995). In addition, nurses were not united: some advocated for palliative care and publicly funded home care, some for keeping pace with rapidly changing technologies (Miller, 1960).

Three additional interrelated developments influenced the pre-1970 rapid rise in hospital deaths: industrialization/urbanization, changing gender roles, and the social disruption caused by World War II (Guest, 1985; McVey & Kalbach, 1995). During this larger war, more women were needed to work outside the home. Following the war, married women continued to seek paid work outside the home (Chisholm, 1944; McVey & Kalbach), and long-term, home-based caregiving became increasingly less possible as their employment rates grew. The reduced availability of female family members to provide home care is only one explanation, however, for the growing demand for hospital care (Agnew, 1947, 1974).

Open-heart surgery, intubation and ventilation, and cardiopulmonary resuscitation were all pioneered in this era (Grondin, Lepage, & Castonguay, 1964; Minuck & Perkins, 1969). Antibiotics and other advances in drug therapy also raised public expectations about the efficacy of health care. Most advances required care in hospital by physicians, nurses, and other trained specialists (Agnew, 1947). Technological intervention became standard practice in the treatment of life-threatening illnesses (Mair, 1967; Postman, 1993) and the fight against death (Stevenson, 1963).

Health-care advances also served to change the personal impact and meaning of death and dying. Growing awareness that most people could live into old age (Sellers, 1951) helped to replace a centuries-old fear of dying (Wallace, 1951) with the hope of avoiding death (Mair, 1967; Rozovsky, 1974). This hope, coupled with the emotional and practical difficulties of caring for dying persons, contributed to the emergence of an avoidance-of-death phenomenon (Wallace, 1951). No longer was death anticipated or acknowledged. This phenomenon became the norm among physicians and nurses, whose education was now oriented to saving lives (Lindabury, 1969). It was not until 1969 that Elizabeth Kubler-Ross defined this as inappropriate treatment and advocated for open discussion of dying and death.

All of these developments meant that alternatives to hospital-based care either were not developed or became less available. In short, palliative care was not recognized as an option in the excitement generated by many life-saving developments within the hospital setting. Expert care in accessible, high-quality hospitals had become more desirable than care in the home.

Initiation of Palliative-Care Era (1970–89)

Numerous health and social developments in the 1970s and 1980s reinforced the hospitalization-of-death trend. One of the most significant was a steady increase in the number of hospital beds (Health Canada, 1996). Developments in hospital technology also continued, particularly for cardiovascular surgery, organ transplantation, and drug therapy (Nicholls, Jung, & Davies, 1981), all enormous strides in preserving and extending life. More highly educated nurses, physicians, and other health professionals also strove for higher quality care. The rising employment of women (McVey & Kalbach, 1995) continued to reduce the possibilities for family caregiving in the home (Siebold, 1992).

However, the health system also began to be criticized as hospital-based and cure-oriented (Vayda & Deber, 1984). The need for disease prevention and health promotion became evident (Canadian Nurses Association, 1980; LaLonde, 1974). The cost of the health system as a result of the 1970s recession was also problematic. Governments actively sought ways to reduce spending, and health care was not exempt. The *Established Programs Financing Act* of 1977 was the first of many federal acts aimed at reducing Ottawa's share of health spending by the provinces (Vayda & Deber). Yet public funding for health promotion, long-term care, and home care was increased (Adams, 1989; Clarfield, 1983). For example, in 1977 the federal government initiated the Extended Health Care Services for Long Term Care program to enable provinces to provide more home care and long-term institutional care (Soderstrom, 1978). These changes were directed at reducing hospital use by elderly people, as research was demonstrating an ageing of the population and extensive use of the hospital system by the elderly (Roos, Montgomery, & Roos, 1987; Shapiro, 1983).

Another health-care issue became evident: an inability to treat all illnesses successfully (Hale, 1989). The most problematic issue was the ability to save a life while prolonging the dying process, as reflected in abundant literature on withdrawing and withholding treatment; the economic, personal, and social costs of aggressive cure-oriented but largely futile treatment; and the need for reform in the areas of consent, decision-making control, and information-sharing by physicians. Legal, social, and health-care advances ensued. These included: a patient rights statement (Consumers' Association of Canada, 1972), informed consent guidelines (Ferguson, 1980), brain-death criteria (Ellis, 1990; Walton, 1980), hospital do-not-resuscitate policies (Wallace, 1975), and the *Joint Statement on Terminal Illness* (1984). The *Joint Statement* made it clear to health professionals that they need not provide futile treatment to dying persons.

Not surprisingly, given this contextual background, palliative care was formally introduced. In 1975–76, palliative-care units were established in two acute-care hospitals (Mount, 1976), and these became the model for palliative treatment in Canada (Heidemann, 1984; Siebold, 1992). Because it was situated in hospitals, however — with their socially accepted and culturally based mandate to diagnose and cure — palliative care became subject to competition for recognition and funding (Ajemian, 1992; Latimer, 1991; Priest, 1987).

Palliative care was also confounded by the 1970s recession. Funding cutbacks, first by the federal government and then by the provinces, led to a shift of care to the home. Concerns about informal caregiving quickly surfaced (Brown, Potter, & Foster, 1990). Whereas home care had just recently been the norm, informal caregiver burden was now considered a serious individual and social problem (Brown et al.).

Other challenges to palliative care were evident, chief among them the fact that dying in hospital was commonplace, if not standard. Another challenge was the public perception that premature death is largely preventable (Vachon, Kristjanson, & Higginson, 1995). Palliative care will understandably be resisted if a cure is considered likely. In short, although hospitals began to provide specialized palliative care in this era, death in hospital often occurred after cure-oriented hospital treatment failed to sustain life (Ajemian, 1992; Siebold, 1992). Furthermore, terminally ill persons died in hospital as this was the preferred place, if not the only possible place, for end-of-life care.

Contemporary Era (the 1990s)

The 1990s brought even more severe economic pressures and, with them, rising concern about hospital inefficiency. This concern is illustrated by numerous studies showing the widespread use of hospitals for sub-acute and non-acute care (Decoster, Roos, & Carriere, 1997; Doyle, Barrett, McDonald, McGrath, & Parfrey, 1998; Flintoff et al., 1998; Hospital Services Utilization Review Commission, 1994; Hunter, 1997; Joint Policy and Planning Committee, 1997; Kaplow, Charest, & Benaroya, 1998; Mayo, Wood-Dauphinee, Gayton, & Scott, 1997). Many of these studies report elderly persons to be high users of hospitals, a distinct issue given an ageing population.

Furthermore, and despite considerable advances in palliative care (Mount, Scott, & Cohen, 1993), concerns were raised about use of the hospital as a place of death (Ajemian, 1992; Latimer, 1991; National Forum on Health, 1997; Novak, 1997). Concerns included the issue of dying among strangers, the use of life-supporting technologies during the last days of life, and undertreated pain (Lavis & Anderson, 1996; Litwin & Lightman, 1996; National Forum on Health; Roos, Montgomery, & Roos, 1987; Stokes & Lindsay, 1996; Wilson, 1997).

Alternatives to inpatient care were now possible as a result of advances in drug therapies and diagnostic and surgical technologies (Clarkson, 1993; Dudgeon & Kristjanson, 1995; Landesman, 1996;

Macnaughton, 1992; National Forum on Health, 1997). There was a shift to day surgery and outpatient care, shorter hospital stays, and community-based programs (National Forum on Health; Tully & Saint-Pierre, 1997).

The 1990s also saw the initiation and growth of non-hospital palliative-care programs (Canadian Palliative Care Association, 1997; Health Canada Working Group, 1997). Some of these were non-government, as in the case of free-standing hospices (Davies, Eng, Arcand, Collins, & Bhanji, 1996; Feser, 1992), small and oriented to the care of persons with a particular illness such as AIDS. Most were provincial home-care programs that did not cover the full cost of home supports, medications, and nursing (Canadian Palliative Care Association). No national program emerged to ensure the availability of palliative-care services across Canada (Muzzin, Anderson, Figueredo, & Gudelis, 1994).

The 1990s shift to largely unsupported home care was viewed as problematic in that it added to existing concerns about the ability of families to provide care. Home care had also become more challenging, as informal caregivers were expected to provide many of the treatments that had previously been provided in hospital. Research was finding barriers to the provision of home-based terminal care: smaller nuclear families, the anguish of providing terminal care for loved ones, and personal financial difficulties (loss of income, career interruption, reduced pension) (Chochinov & Kristjanson, 1998; Coyle, 1997; Dudgeon & Kristjanson, 1995; Gomas, 1993; Grande, Addington-Hall, & Todd, 1998; Hagen & Gallagher, 1996; Hinton, 1994a, 1994b; Hull, 1991; McWhinney, Bass, & Orr, 1994; Myles, 1991; Pugh, 1996; Townsend et al., 1990). Many other barriers to home-based care were also evident, such as physician fee-for-service systems that did not support home visits (Latimer, 1995). The shift to home care affected mainly women, as women were now clearly recognized as the chief informal care providers (Angus, 1994; Baines, Evans, & Neysmith, 1991; McDaniel, 1992; Ross, 1991; Wuest, 1993).

The 1990s also saw increased interest in natural or technology-free death (MacDonald, 1991), perhaps in reaction to the persistence of active treatment late in the dying process (Lindsay, 1991; Wilson, 1997), infrequent referral to palliative-care specialists (Hooper, 1991), and the continued emphasis on life-saving procedures in the education of doctors and nurses (Ajemian, 1992; Bruera, Selmsler, Pereira, & Brenneis, 1997; Kristjanson & Balneaves, 1995; Marshall, Hutchison, Latimer, & Faught, 1997). As some terminally ill persons were avoiding

hospitals because of the technology housed there (Tolle, Rosenfeld, Tilden, & Park, 1999), the desire for a natural death outside of the hospital can be seen as a major new influence on location of death.

Regardless, home deaths still occurred only among those people who had come to accept a need for comfort-only care (Grande et al., 1998; McWhinney et al., 1995; Townsend et al., 1990). At the same time, research was finding that cardiopulmonary resuscitation was rarely used in Canadian hospitals and continuing-care facilities after it had been determined that nothing further could be done to preserve life (Wilson, 1997) — an indication that natural death could take place in hospital as well as elsewhere.

Public demand for information and control was another significant development of the 1990s (Calder, 1994; Davies, 1996; Fakhoury, McCarthy, & Addington-Hall, 1996; Keizer & Kozak, 1992; Sneiderman, 1993). Interest in assisted suicide (Elash, 1997), advance directives (living wills) (Singer, 1994), and alternative health care (Astin, 1998) is further evidence of changing public needs and expectations. Advance-directive laws (Singer), palliative-care guidelines for health professionals (Canadian Medical Association, 1992), and clear recognition of and strong support for palliative care (Mykitiuk & Paltiel, 1994; National Forum on Health, 1997; Senate of Canada, 1995; van Weel, 1995) are some of the key outcomes of these changing needs and expectations.

In summary, the extensive use of hospitals by dying persons throughout the 1990s indicates that many health-care and social influences continued to favour hospitals as the prime location of death. However, some major developments in non-hospital palliative-care programs and beliefs about death and dying were evident in the 1990s, and these influenced location of death in that they supported a shift of care from the hospital to other locations.

Conclusion

This multidisciplinary historical investigation identified two key influences, among many, on location of death in Canada. One key influence was health-care and health-system developments that consolidated health care in hospitals while at the same time raising and sustaining public expectations about curative or least beneficial hospital care. The rising hospital death rate throughout much of the 20th century can thus largely be considered an outcome of the shift in illness care from the home to the hospital. The other key influence on location of death was the reduced availability of home-based formal and informal caregivers.

This report has identified a number of discrete developments that limited the possibility of end-of-life caregiving in the home. Chief among these were the increased participation of women in the workforce, the shift in nursing work from private home duty to hospitals, and a shift in medical care to hospitals, clinics, and physicians' offices. Although the 1990s witnessed the development of some health and social support for caregiving in the home, this clearly did not match the health and social support for hospital-based care.

These findings indicate that location of death is an important focal point for studying and planning improvements in end-of-life care. The recent reduction in the number of hospital deaths, after a shift of death to the hospital setting during much of the 20th century, indicates that this is an opportune time for nurses and others to research and address issues in end-of-life care. On a final note, this study shows that the health system and health care both shape and are shaped by the needs and expectations of the public.

Appendix 1 *Research Plan*

Nurse: search for nursing, health policy, and law information in CINAHL, HealthSTAR, Canadian Research Index/Canadian Government Documents, CANSIM, and Index to Legal Periodicals and Books.

Palliative-care physician: search for medical, pharmacological, and health-care technology information in Medline, EMBASE, and Cancerlit.

Health-care historian: search for historical information on vulnerable/disadvantaged populations, including children, women, and immigrants, in Histline and America: History and Life (this database includes Canadian historical literature).

Nurse gerontologist/psychologist: search for psychology and gerontology/ageing information in PsychINGO and Social Studies Abstracts.

Philosopher/ethicist: search for philosophy, religious studies, and ethics information in Humanities Abstracts and Philosophers Index.

Sociologist: search for sociology, political science, and business/economics information in SocLit, EconLit, ABI Inform, and Canadian Business and Current Affairs.

All researchers began their search using the following key words: death, dying, palliative care, terminal care, end-of-life care, hospital, home care, health system, location of death, Canadian, and Canada. The search was initially limited to the distinct years of each historical era, then expanded as the researcher sought extensive and diverse sources of information.

References

- Adams, O. (1989). The hospital at home: Interest in New Brunswick's experiment is growing. *Canadian Medical Association Journal*, 141(10), 1087-1089.
- Agnew, G. H. (1974). *Canadian hospitals, 1920 to 1970*. Toronto and Buffalo, NY: University of Toronto Press.
- Agnew, H. (1947). The role of the hospital in medical economics. *Canadian Medical Association Journal*, 56, 558-562.
- Ajemian, I. (1992). Hospitals and health care facilities. *Journal of Palliative Care*, 8(1), 33-37.
- Angus, J. (1994). Women's paid/unpaid work and health: Exploring the social context of everyday life. *Canadian Journal of Nursing Research*, 26(4), 23-42.
- Astin, J. A. (1998). Why patients use alternative medicine: Results of a national study. *Journal of the American Medical Association*, 279(19), 1548-1555.
- Baines, C. T., Evans, P., & Neysmith, S. (Eds.). (1991). *Women's caring: Feminist perspectives on social welfare*. Toronto: McClelland & Stewart.
- Bell, J. (1900). The treatment of cancer of the female breast. *Montreal Medical Journal*, 29(11), 812-818.
- Blackader, A. D. (1916). Drugs and medicinal agents considered from the professional, economic and national standpoints. *Canadian Medical Association Journal*, 6(7), 557-585.
- Brown, L. J., Potter, J. F., & Foster, B. G. (1990). Caregiver burden should be evaluated during geriatric assessment. *Journal of the American Geriatrics Society*, 38, 455-460.
- Bruera, E., Selmsler, P., Pereira, J., & Brenneis, C. (1997). Bus rounds for palliative care education in the community. *Canadian Medical Association Journal*, 157(6), 729-732.
- Buckley, S. (1988). The search for the decline of maternal mortality: The place of hospital records. In W. Mitchinson & J. D. McGinnis (Eds.), *Essays in the history of Canadian medicine* (pp. 148-163). Toronto: McClelland & Stewart.
- Calder, K. (1994). Beyond informed consent. *Canadian Nurse*, 90(11), 23-26.
- Canadian Medical Association. (1992). CME policy summary: 1992. Advanced directives for resuscitation and other life saving or sustaining measures. *Canadian Medical Association Journal*, 146, 1072a.
- Canadian Nurses Association. (1980). *Putting health back into health care. Submission to Health Services Review '79*. Ottawa: Author.
- Canadian Nurses Association Research Unit. (1966). Pie charts. *Canadian Nurse*, 62(9), 40.
- Canadian Palliative Care Association. (1997). 1997. *The Canadian directory of services. Palliative care and HIV/Aids*. Ottawa: Author.
- Chisholm, A. (1944). A married nurse returns to duty. *Canadian Nurse*, 40(7), 491.
- Chochinov, H. M., & Kristjanson, L. (1998). Dying to pay: The cost of end-of-life care. *Journal of Palliative Care*, 14(4), 5-15.

- Chui, T. (1996). Canada's population: Charting into the 21st century. *Canadian Social Trends*, (Autumn), 3-7.
- Clarfield, A. M. (1983). Home care: Is it cost effective? *Canadian Medical Association Journal*, 129(11), 1191-1183, 1199.
- Clarkson, I. R. (1993). Beyond hospital walls: Restructuring for the future. *Leadership in Health Services*, 2(6), 12-15.
- Colton, D. (2000). Quality improvement in health care: Conceptual and historical foundations. *Evaluation and the Health Professions*, 23(1), 7-42.
- Consumers' Association of Canada. (1972). *Consumer rights to health care*. Ottawa: Author.
- Coyle, N. (1997). Focus on the nurse: Ethical dilemmas with highly symptomatic patients dying at home. *Hospice Journal*, 12(2), 33-41.
- Curtin, L. L. (1996). First you suffer, then you die: Findings of a major study of dying in U.S. hospitals. *Nursing Management*, 27(5), 56-60.
- Davies, B., Eng, B., Arcand, R., Collins, J., & Bhanji, N. (1996). Canuck Place: A hospice for dying children. *Canadian Nurse*, 92(4), 22-25.
- Davies, J. (1996). Patients' rights of access to their health records. *Medical Law International*, 2(3), 189-213.
- DeCoster, C., Roos, N., & Carriere, K. C. (1997). Inappropriate hospital use by patients receiving care for medical conditions: Targeting utilization review. *Canadian Medical Association Journal*, 157(7), 889.
- Donahoe, R. A. (1961). Impact of hospital insurance on patient care. *Canadian Nurse*, 47(4), 352-354.
- Doyle, M., Barrett, B. J., McDonald, J., McGrath, J., & Parfrey, P. S. (1998). The efficiency of acute care bed utilization in Newfoundland and Labrador. *Healthcare Management Forum*, 11(3), 15-19.
- Dudgeon, D. J., & Kristjanson, L. (1995). Home vs hospital death: Assessment of preferences and clinical challenges. *Canadian Medical Association Journal*, 152(3), 337-339.
- Elash, A. (1997). Legalized MD-assisted suicide needed to improve care, physician tells right to die group. *Canadian Medical Association Journal*, 157(11), 763-764.
- Ellis, J. (1990). Pronouncing and certifying death. *RNABC News*, 22(1), 22.
- Fakhoury, W., McCarthy, M., & Addington-Hall, J. (1996). Determinants of informal caregivers' satisfaction with services for dying cancer patients. *Social Sciences and Medicine*, 42(5), 721-731.
- Ferguson, D. S. (1980). Informed consent: What the law requires. A comment on *Lepp v. Hopp* (Supreme Court of Canada - May, 1980) and *Reibl v. Hughes* (Supreme Court of Canada - October, 1980). *Health Law in Canada*, 56-57.
- Feser, L. (1992). Hospice for Calgary. *AARN Newsletter*, 48(7).
- Flintoff, V. F., Williams, J. I., Williams, R. C., Basinski, A. S. H., Blackstein-Hirsch, P., & Naylor, C. D. (1998). The need for acute, subacute and non-acute care at 105 general hospital sites in Ontario. *Canadian Medical Association Journal*, 158(10), 1289-1296.

- George, A. W., & Gerber, I. (1915). The early diagnosis of gastric carcinoma. *Canadian Medical Association Journal*, 5(3), 197–200.
- Gomas, J. (1993). Palliative care at home: A reality or mission impossible? *Palliative Medicine*, 7, 45–59.
- Grande, G. E., Addington-Hall, J. M., & Todd, C. J. (1998). Place of death and access to home care services: Are certain patient groups at a disadvantage? *Social Science and Medicine*, 47(5), 565–579.
- Groncin, P., Lepage, G., & Castonguay, Y. (1964). Aortic valvular replacement: Clinical experience with 13 cases. *Canadian Medical Association Journal*, 91(9), 405–410.
- Guest, D. (1985). *The emergence of social security in Canada* (2nd Ed.). Vancouver: University of British Columbia Press.
- Hagen, B., & Gallagher, E. (1996). Looking out for family caregivers. *Canadian Nurse*, 92(3), 27–31.
- Hale, J. (1989). After rocky start, plans for international AIDS conference move ahead. *Canadian Medical Association Journal*, 140(2), 204–208.
- Hamilton, D. B. (1993). The idea of history and the history of ideas. *Image: Journal of Nursing Scholarship*, 25(1), 45–48.
- Harding le Riche, W. (1979). Seventy years of public health in Canada. *Canadian Journal of Public Health*, 70(3), 155–163.
- Health Canada. (1996). *National health expenditures in Canada, 1975–1994*. Ottawa: Minister of Supply and Services.
- Health Canada Working Group on Continuing Care in Consultation with Provincial and Territorial Government Officials and Others Involved in Palliative Care Services. (1997, March 23–24). *Overview of provincial and territorial palliative care services. A working paper prepared for the Invitational Symposium on Palliative Care: Provincial and Territorial Trends and Issues in Community-Based Programming*. Ottawa: Author.
- Heidemann, E. G. (1984). Palliative care: Planning a regional system. *Dimensions in Health Services*, November, 16–39.
- Heyland, D. K., Lavery, J. V., Tranmer, J. E., Shortt, S. E. D., & Taylor, S. J. (2000). Dying in Canada: Is it an institutionalized, technologically supported experience? *Journal of Palliative Care*, 16(Suppl.), S10–S16.
- Hinton, J. (1994a). Can home care maintain an acceptable quality of life for patients with terminal cancer and their relatives? *Palliative Medicine*, 8(3), 183–196.
- Hinton, J. (1994b). Which patients with terminal cancer are admitted from home care? *Palliative Medicine*, 8(3), 197–210.
- Hooper, G. (1991). The ethics of palliative care. *Dimensions in Health Services*, 68(5), 10–11.
- Hospital Services Utilization Review Commission. (1994). *Barriers to community care: Summary report*. Saskatoon, SK: Author.
- Hull, M. M. (1991). Hospice nurses: Caring support for care giving families. *Cancer Nursing*, 14(2), 63–70.

Twentieth-Century Influences on Location of Death in Canada

- Hunter, D. (1997). Measuring the appropriateness of hospital use. *Canadian Medical Association Journal*, 157(7), 901.
- Joint Policy and Planning Committee. (1997). *Non-acute hospitalization project (adult): Final report*. Toronto: Ontario Ministry of Health and Ontario Hospital Association.
- Joint Statement on Terminal Illness*. (1984). A protocol for health professionals regarding resuscitation intervention. *Canadian Nurse*, 80(6), 24.
- Kaplow, M., Charest, S., & Benaroya, S. (1998). Managing patient length of stay better using an appropriateness tool. *Healthcare Management Forum*, 11(2), 13-16.
- Keizer, M. C., & Kozak, J. F. (1992). Primary care providers' perceptions of care. *Journal of Palliative Care*, 8(4), 8-12.
- Kristjanson, L. J., & Balneaves, L. (1995). Directions for palliative care nursing in Canada: Report of a national survey. *Journal of Palliative Care*, 11(3), 5-8.
- Kubler-Ross, E. (1969). *On death and dying*. New York: Macmillan.
- LaLonde, M. (1974). *A new perspective on the health of Canadians: A working document*. Ottawa: Minister of Supply and Services Canada.
- Landesman, A. (1996). Restructuring hospitals, restructuring nursing: Dealing positively with downsizing. *Canadian Nurse*, 92(2), 27-30.
- Latimer, E. (1991). Auditing the hospital care of dying patients. *Journal of Palliative Care*, 5(4), 43-58.
- Latimer, E. J. (1995). Caring for the dying in Canada. *Canadian Family Physician*, 41, 362-365.
- Lavis, J. N., & Anderson, G. M. (1996). Appropriateness of health care delivery: Definitions, measurement and policy implications. *Canadian Medical Association Journal*, 154(3), 321-328.
- Lindabury, V. A. (1969). Student observations at postpartum examinations. *Canadian Nurse*, 65(2), 57-58.
- Lindsay, E. (1991). Life at all costs. *Canadian Nurse*, 87(3), 16-18.
- Litwin, H., & Lightman, E. (1996). The development of community care policy for the elderly: A comparative perspective. *International Journal of Health Services*, 26(4), 691-708.
- MacDonald, B. (1991). Death with dignity: How can we ensure this? *Canadian Nurse*, 86(11), 119-20.
- MacDougall, H. (1994). Sexually transmitted diseases in Canada, 1800-1992. *Genitourinary Medicine*, 70(1), 56-63.
- Macnaughton, E. (1992). Canadian mental health policy: The emergent picture. *Canada's Mental Health*, 30, 3-10.
- MacPhail, A. (1904). The Hospital for Contagious Diseases. *Montreal Medical Journal*, 13(10), 712-717.
- Mair, M. (1967). The fight against cancer. *Canadian Nurse*, 63(4), 44-46.
- Marshall, D., Hutchison, B. G., Latimer, E. J., & Faught, J. W. (1997). Surveys of palliative care in family medicine. *Canadian Journal of CME*, 9, 81-99.

- Mayo, N. E., Wood-Dauphinee, S., Gayton, D., & Scott, S. C. (1997). Nonmedical bed-days for stroke patients admitted to acute-care hospitals in Montreal, Canada. *Stroke*, 28, 543–549.
- McDaniel, S. A. (1992). Women and family in the later years: Findings from the 1990 General Social Survey. *Canadian Woman Studies*, 12(2), 62–64.
- McGinnis, D. D. (1988). From salvarsan to penicillin: Medical science and VD control in Canada. In W. Mitchinson & J. D. McGinnis (Eds.), *Essays in the history of Canadian medicine* (pp. 126–147). Toronto: McClelland & Stewart.
- McIlveen, K. H., & Morse, J. M. (1995). The role of comfort in nursing care: 1900–1980. *Clinical Nursing Research*, 4(2), 127–148.
- McPherson, K. (1996). *Bedside matters: The transformation of Canadian nursing, 1900–1990*. Toronto: Oxford University Press.
- McVey, W. W. Jr., & Kalbach, W. E. (1995). *Canadian population*. Toronto: Nelson.
- McWhinney, I. R., Bass, M. J., & Orr, V. (1995). Factors associated with location of death (home or hospital) of patients referred to a palliative care team. *Canadian Medical Association Journal*, 152(3), 361–367.
- Middleton, F. C. (1919). The nursing, medical, and hospital problem in the rural west. *Public Health Journal*, 10(7), 297–307.
- Miller, L. F. (1960). Geriatric nursing in the home. *Canadian Nurse*, 56(7), 606–609.
- Minuck, M., & Perkins, R. (1969). Long-term study of patients successfully resuscitated following cardiac arrest. *Canadian Medical Association Journal*, 100(24), 1126–1128.
- Mount, B. M. (1976). The problem of caring for the dying in a general hospital: The palliative care unit as a possible solution. *Canadian Medical Association Journal*, 115(2), 119–121.
- Mount, B. M., Scott, J., & Cohen, S. R. (1993). Canada: Status of cancer pain and palliative care. *Journal of Pain and Symptom Management*, 8(6), 395–398.
- Munroe, A. R., Hoare, E. S., & Cristall, E. (1939). The mortality of appendicitis. *Canadian Medical Association Journal*, 40(5), 463–470.
- Muzzin, L. J., Anderson, N. J., Figueredo, A. T., & Gudelis, S. O. (1994). The experience of cancer. *Social Science and Medicine*, 38(9), 1201–1208.
- Mykitiuk, R., & Paltiel, J. T. (1994). Terminal care, terminal justice: The Supreme Court of Canada and Sue Rodriguez. *Constitutional Forum*, 5(2), 38–42.
- Myles, J. (1991). Women, the welfare state and care-giving. *Canadian Journal on Aging*, 10(2), 82–85.
- National Forum on Health. (1997). *Canada health action: Building on the legacy. Final report of the National Forum on Health*. Ottawa: Minister of Public Works and Government Services.
- Nicholls, E. S., Jung, J., & Davies, J. W. (1981). Cardiovascular disease mortality in Canada. *Canadian Medical Association Journal*, 125(9), 981–992.
- Novak, M. (1997). *Aging and society: A Canadian perspective* (3rd Ed.). Toronto: ITP Nelson.

Twentieth-Century Influences on Location of Death in Canada

- Ostic, R. (1940). Nursing care of the chronically ill. *Canadian Nurse*, 62(1), 97–99.
- Ostry, A. (1994). Public health and the Canadian state: The formative years, 1880–1920. *Canadian Journal of Public Health*, 22(3), 293–294.
- Postman, N. (1993). *Technopoly: The surrender of culture to technology*. New York: Vintage.
- Priest, A. (1987). Care for the dying. *RNABC News*, 19(5), 11–13.
- Pugh, E. M. G. (1996). An investigation of general practitioner referrals to a palliative care service. *Palliative Medicine*, 10, 251–257.
- Quint, J. C. (1967). When patients die: Some nursing problems. *Canadian Nurse*, 63(12), 33–36.
- Roland, C. (1985). History of medicine. In *The Canadian encyclopaedia* (pp. 1112–1114). Edmonton: Hurtig.
- Roos, N. P., Montgomery, P., & Roos, L. L. (1987). Health care utilization in the years prior to death. *Milbank Quarterly*, 65(2), 231–254.
- Ross, M. M. (1991). Spousal care giving in later life: An objective and subjective career. *Health Care for Women International*, 12(1), 123–135.
- Roy, D. J. (1999). Palliative care Canada: 1999 – A question period. *Journal of Palliative Care*, 15(1), 3–5.
- Rozovsky, L. E. (1974). *Canadian hospital law*. Ottawa: Canadian Hospital Association.
- Sarnecky, M. T. (1990). Historiography: A legitimate research method for nursing. *Advances in Nursing Science*, 12(4), 1–10.
- Sellers, A. H. (1951). Public health and medical aspects of an aging population. *Canadian Nurse*, 47(2), 116–120.
- Senate of Canada. (1995). *Of life and death: Report of the Special Senate Committee on Euthanasia and Assisted Suicide. Final report*. Ottawa: Author.
- Shapiro, E. (1983). Impending death and the use of hospitals by the elderly. *Journal of the American Geriatrics Society*, 31(6), 348–351.
- Siebold, C. (1992). *The hospice movement: Easing death's pain*. New York: Twayne.
- Singer, P. A. (1994). Advance directives in palliative care. *Journal of Palliative Care*, 10(3), 111–116.
- Sneiderman, B. (1993). The case of Nancy B: A criminal law and social policy perspective. *Health Law Journal*, 1, 25–38.
- Soderstrom, L. (1978). *The Canadian health system*. London: Croom Helm.
- Special Report. (1970). Task force on the cost of health services in Canada. *Canadian Nurse*, 62(2), 23–24.
- Statistics Canada. (2000). *Canada yearbook, 2001*. Ottawa: Author.
- Stevenson, C. L. (1963). *Facts and values: Studies in ethical analysis*. New Haven, CT: Yale University Press.
- Stingl, M. (1997). Ethics 1900–1945: Philosophy of meaning, knowledge and value in the twentieth century. In J. V. Canfield (Ed.), *Routledge history of philosophy* (Vol. 10). London: Routledge.

- Stokes, J., & Lindsay, J. (1996). Major causes of death and hospitalization in Canadian seniors. *Chronic Diseases in Canada*, 17(2), 63–73.
- The SUPPORT Principal Investigators. (1995). A controlled trial to improve care for seriously ill hospitalized patients: The Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment. *Journal of the American Medical Association*, 274(20), 1591–1598.
- Tolle, S. W., Rosenfeld, A. G., Tilden, V. P., & Park, Y. (1999). Oregon's low in-hospital death rates: What determines where people die and satisfaction with decisions on place of death? *Annals of Internal Medicine*, 130(8), 681–685.
- Townsend, J., Frank, A., Fermont, D., Dyer, S., Karran, O., Walgrove, A., & Piper, M. (1990). Terminal cancer care and patients' preference for place of death: A prospective study. *British Medical Journal*, 301, 415–417.
- Tully, P., & Saint-Pierre, E. (1997). Downsizing Canada's hospitals, 1986–87 to 1993–94. *Health Reports*, 8(4), 33–39.
- Vachon, M. L. S., Kristjanson, L., & Higginson, I. (1995). Psychosocial issues in palliative care: The patient, the family, and the process and outcome of care. *Journal of Pain and Symptom Management*, 10(2), 142–150.
- Van Weel, H. (1995). Euthanasia: Mercy, morals and medicine. If Sue Rodriguez had been your client, could you have dealt with it? *Canadian Nurse*, 91(8), 35–40.
- Vayda, E., & Deber, R. B. (1984). The Canadian health care system: An overview. *Social Science and Medicine*, 18(3), 191–197.
- Wallace, J. A. (1951). Care of the sick aged in the home. *Canadian Nurse*, 47(2), 116–120.
- Wallace, J. D. (1975). The "no resuscitation" order has grave legal as well as ethical, moral connotations. *Canadian Medical Association Journal*, 112(5), 620.
- Walton, D. (1980). *Brain death*. West Lafayette, IN: Purdue University Press.
- Weir, G. (1932). *Survey of nursing education in Canada*. Toronto: Author.
- What is the V.O.N.? (1943). *Canadian Hospital*, 23–25(September), 52.
- Wilkins, K., & Park, E. (1998). Home care in Canada. *Health Reports*, 7(3), 23–26.
- Wilson, D. (1997). A report of an investigation of end-of-life patient care practices in health care facilities, and the influences for those practices. *Journal of Palliative Care*, 13(4), 34–40.
- Wilson, D. M., Northcott, H., Truman, C., Smith, S., Anderson, M., Fainsinger, R., & Stingl, M. (2001). Location of death in Canada: A comparison of 20th-century hospital and nonhospital location of death and corresponding population trends. *Evaluation and the Health Professions*, 24(4), 385–403.
- Wilson, D. M., & Truman, C. D. (2001). Does the availability of hospital beds affect utilization patterns? The case of end-of-life care. *Health Services Management Research*, 14, 1–12.

- Wuest, J. (1993). Institutionalizing women's oppression: The inherent risk in health policy that fosters community participation. *Health Care for Women International, 14*(5), 407-417.
- Zilm, G., & Warbinek, E. (1995). Early tuberculosis nursing in British Columbia. *Canadian Journal of Nursing Research, 27*(3), 65-81.

Authors' Note

This investigation was supported by a National Health and Research Development Program (NHRDP) grant (#6609-2096-96), and by a Social Sciences Research grant and an EFF Support for the Advancement of Scholarship grant from the University of Alberta.