



Ensuring a Good Death:

Improving Palliative Care for Patients and Caregivers

The number of people who need palliative care in Canada is rising,^{1,2} yet we have no national policy and no national regulations to ensure consistency and quality of care.

Developing national regulations is complicated. The range of sites involved is wide – hospital, hospice, long-term care facilities, and home – and these involve both formal, paid and informal, unpaid care workers. How then do we achieve consistent, high-quality palliative care across all sites and caregivers?

A promising approach may be to broaden the scope of health care performance analysis and incorporate the findings into national regulations. This means asking some essential questions:

- How are continuity of care and the same standard of care to be achieved across all sites and caregivers?
- How do we ensure equality of access to palliative care?
- When is palliative home care appropriate?
- How do we assess patient satisfaction?
- Who is providing palliative care and what impact does caregiving have on caregivers' health and well-being?

What is palliative care? Palliative care is “the active total care of patients whose diseases are not responsive to curative treatment.”³ According to Health Canada, palliative care should meet “not only physical needs but also psychological, social, cultural, emotional and spiritual needs.”⁴ It focusses on the patient, family and friends as the “unit of care”⁵ and usually begins when the disease becomes terminal, which generally means a three- to six-month life expectancy,⁶ although this may vary.

The scope of care may include pain and symptom management, use of life sustaining treatments, and assistance to patients, families, and friends with decision-making, emotional needs, and spiritual concerns that surround dying, death, and bereavement.

Palliative home care – for everyone? Palliative care is provided in many settings and a patient may move from setting to setting in their final months and days. Recent government reports propose home care as a key part of the solution to the growing need for palliative care.^{2,7} Often cited is an Angus Reid report that

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states that 84% of the Canadians who were surveyed would prefer to spend their final days at home with their families.^{2,8} But there is evidence to suggest that some Canadians do not want family or friends to take care of them in the final months and days of their lives: those who can afford to prefer to pay for such care.⁹ When Canadians with limited financial resources cannot afford to pay for drugs and equipment such as pain pumps, oxygen, and commodes, they are forced to seek admission to hospital.¹

Preferences aside, studies also show that palliative home care is frequently not available. Today 75% of all deaths in Canada occur in people over 65 and 75% of deaths take place in hospitals and long-term care facilities.¹ The National Forum on Health reports that many terminally ill seniors in Canada do not have family or friends to care for them at home.¹⁰ Gender differences are apparent in these patterns. For example, older men who are cared for by their wives are more likely to die at home as compared to older women.¹¹ Is it realistic to assume that most dying patients can be cared for at home?

Proposals that Employment Insurance (EI) benefits or “compassionate leave plans” could be made available to family members who provide palliative care in the home are welcome,^{2,7,12} and supported by 80% of Canadians,¹³ but it’s important to consider that this strategy would leave out many women caregivers who are ineligible for such benefits by virtue of not being in the labour force. This strategy would also exclude “chosen” families and friends who provide care in the home. The National Profile of Family Caregivers in Canada 2002, prepared by Health Canada, indicates that women represent 77% of those providing care in the home to a family member who is ill.¹⁴ Of these, 31% are homemakers and 19% work part-time or are self-employed, which would render them ineligible for EI benefits or compassionate leave plans.

Who receives palliative care in Canada? Women represent the majority of caregivers in home care and the majority of care recipients, possibly because they have a longer life expectancy than men.¹⁵ However, overall gendered statistics on palliative care, specifically, are not available. We do know that only about 10% of Canadian adults and children have access to palliative care and access to hospice care is limited to 5%.¹⁶ According to Senator Sharon Carstairs, health care reform has cut the number of palliative care beds in hospitals.¹⁷ Those who live in remote and rural communities and individuals with disabilities have limited access. Of those who do have access, over 90% are cancer patients.¹⁸ This overlooks many who suffer from other terminal illnesses or conditions, such as cardiovascular impairment and AIDS and other chronic, life-threatening diseases.

How do those who receive palliative care rate its quality? We don't know the answer to this fundamental question. Many studies assert the primacy of patient satisfaction in quality of care evaluations,^{16,17,18} but patient satisfaction measures are not always included in performance or evaluation indicators for health care services. Efforts to assess quality of palliative care, such as the Senate Subcommittee to Update *Of Life and Death*, found evidence of “uneven provision of services, and disruptive and ineffective care leading to substandard outcomes.”¹ The Subcommittee concluded that there is “a possible crisis in end-of-life care” in Canada.¹ One example of a specific problem that was cited was that physicians receive insufficient training in proper drug use to ease unnecessary suffering at the end of life.¹ Experts on hospice care say that children have different pain management needs than adults and specialized standards should be developed to address these.¹⁹

Recent studies from the Centres of Excellence for Women's Health also provide important information about caregivers' assessments of quality of care. For example, in a study of formal and informal caregivers of people who had suffered a stroke, caregivers expressed concerns about the quality of home care provided.²⁰ They cited unmet needs for medical equipment and therapies, a lack of training for unpaid caregivers, and “abandonment” by the health care system. In a study on palliative home care of AIDS and cancer patients in three provinces, caregivers stated that “There needs to be better training for home caregivers. Often they are not educated enough about what they are doing. Many formal caregivers don't know what to do, how to react. They haven't got a clue.”²¹ Unpaid caregivers cited a lack of information about the process of dying and death and a reluctance or inability of doctors to impart such information. “Families are afraid in the hospital, let alone at home. Provide them with information.”²¹

Who gives palliative care? Depending upon the site of care, caregivers may include health care professionals, long-term care facilities staff, home care workers, family, friends, community services workers, or combinations of these people. We also know that women represent 80% of paid health care providers^{22,23} and a similar proportion of those providing unpaid care.¹⁴ Unpaid female caregivers also perform essential services other than direct care, such as cleaning, cooking, laundry, and transportation. Women are the principal caregivers (informal and formal) to elderly and disabled relatives.¹⁵ As both recipients of care and as paid and unpaid caregivers, “women will be disproportionately and differentially affected by palliative care policy.”²⁴

Some writers have suggested that women's unpaid contribution is voluntary, others see it as part of women's social role, and others, such as the National Forum on Health, warn that women must not be “conscripted” into providing

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unpaid health care by health reform.¹⁰ A national 2002 survey on family caregivers found that 35% of unpaid caregivers in Canada indicate that they have taken on the role because there is no one else available to do so, or because of a lack of home care services (25%).¹⁴ The survey also found that “The most significant predictor (or indicator) of caregiving stress is the lack of choice in taking on the responsibility.”¹⁴

Whatever the reasons, it is certain that there are consequences in costs, meaning, and benefits for women who provide unpaid care. For example, because more women live in poverty than men do, their ability to pay for uninsured services is limited. In addition, most of the research points to “a greater negative impact” of caregiving on women’s health than men’s health.¹⁵ Yet men represent a significant minority of those providing unpaid care. Whether or not the same health and economic costs accrue to male caregivers is the subject of ongoing inquiry. That said, all of these factors indicate that effective policy on palliative care must include a gender-based analysis.

What is the impact of unpaid caregiving on the caregiver? The impact of unpaid caregiving, palliative or otherwise, is significant. As health reform shifts larger portions of the burden from institutions to the families and friends of patients, recent research has investigated the burdens and benefits of providing unpaid health care. In a study of mothers caring for children with cancer, 42% of the participants reported that they left their paying jobs to provide care, and 19% reduced their paid work hours.²⁵ One participant described the impact of caregiving, “Sometimes you don’t have much left ... because you’re emotionally drained, you’re physically drained, financially drained.”

In Canada, close to one in ten female caregivers who are looking after a family member who is ill are also caring for a second family member.¹⁴ Many studies have found that women home caregivers report significantly greater burden than do men^{23, 26} and express interference with their personal life and career goals.²⁷ Keating et al. (1999) found that almost three times as many women caregivers (27.5%) as compared to men caregivers (10.6%) reported negative health effects resulting from their caregiving role.²³ Recent US research (2003) indicates that women who care for an ill or disabled spouse more than nine hours per week are potentially twice as likely to develop cardiovascular disease as women who do not have such responsibilities.²⁸ A 2002 study from Britain found that 21% of women providing care to sick, disabled or elderly family members or friends reported mental health problems, compared to 12% of men, and caregivers who spent the most time caring had worse mental health.²⁹

Researchers in a 2002 study on the socioeconomic costs of palliative home caregiving interviewed female and male caregivers of patients with cancer or AIDS. Through a cost-identification process the study estimated that unpaid palliative caregivers contributed approximately \$6,000 of caregiving labour in the final four weeks of the patient's life.²¹ In addition, 75% of unpaid caregivers reported having to travel away from home at their own expense to give care. Caregivers described a wide range of spiritual and psychological experiences resulting from providing palliative care. Some reported acquiring greater meaning in life from supporting the patient along what they perceived to be a very difficult journey, while others reported becoming emotionally drained. Caregivers called for more public education about palliative care and an effort to remunerate unpaid caregivers.

Family caregivers tend to have household incomes below the national average.¹⁴ Nationally, two-thirds of family caregivers report spending more than \$100 per month on out-of-pocket costs related to caregiving, with 24% spending in excess of \$300 per month.¹⁴ Given that women's incomes are consistently lower than men's, a gender-based analysis should be applied to all policies designed to ameliorate the effects of providing palliative care.

How is the quality of palliative care measured? The use of national indicators to measure elements of health care provides an effective way to compare and evaluate health care delivery. Currently, however, there are no coherent and consistent national indicators for measuring and comparing palliative care, for assessing the similarities and differences in care and caregiving between women and men or diverse groups of women and men, and no national regulations for enforcing quality of care.

The Canadian Palliative Care Association (CPCA) has completed a model of "national principles and norms of practice" for hospice palliative care.⁵ The purpose of these norms is to provide hospice palliative care programs and services with consistent and comparable responses to "ensure all caregivers and staff are knowledgeable and skilled and have the support they need to fulfill their roles, to reveal gaps in care," and to relieve suffering and improve quality of life for patients and their families.⁵ The CPCA's conceptual framework for hospice palliative care programs and services is limited as a tool to measure or enforce standards of care. (The application of standards is voluntary, whereas regulations are rules that are enforceable.) However, the framework serves as a commendable model on which to build future policy. Importantly, the patient and their family constitute its core. Furthermore, the fixed characteristics of the patient and family (such as age, sex, ethnicity, race, education, and literacy) that can have a great impact on access to care are highlighted.²¹

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With respect to palliative care delivered in the home, there appears to be a great deal of variance across regions in Canada with respect to the availability, delivery, and administration of home care services in general. There are no common sets of tasks that home support workers perform and no standard training requirements across provinces and territories. Often, the indicators that are used by provinces to measure quality of care have been developed by funders to serve their needs, such as acquiring data on expenditures and utilization. These indicator sets are often not wide enough to accurately measure the health of patients and the full effect of programs of home care.

To address the issue of inconsistent collection of home care information across Canada, the Canadian Institute of Health Information (CIHI) undertook the National Home Care Indicators Project.³⁰ An extension of the larger CIHI Health Indicators Project, the objectives were to obtain agreement on priority indicators for home care, to identify the needed data, to use standardized data definitions and elements, and to test and evaluate recommended indicators.

Such efforts, while laudable, often fail to measure certain critical issues in palliative home caregiving. For example, continuity of care is important to patients and their caregivers. The seamless integration of service delivery, facility use, and health care worker interaction is integral to both home and palliative care, and consequently, it needs to be an issue that we examine and monitor. Sometimes this will mean that we must design new measures and ways of collecting data in order to supplement existing indicators and data collection systems already in place. We know that many issues pertaining to the caregiver herself are crucial to understanding and developing policy in this area, such as the level of training and education of home care providers. Finally, there is often an omission of patient satisfaction measures, and other, more general attempts to assess quality of care. Even when such indicators are developed, they often focus on more easily retrievable quantitative measures, often overlooking the importance of rich qualitative data that bear on these issues. In short, more and different types of data are important to both program and policy development for palliative home caregiving – data on both informal and formal care and the responses of the patient.

According to CIHI, the difficulty in collecting consistent data accounts for the current, narrow focus. However, the Institute does acknowledge this constraint as problematic. In their proposals for future activity, the project's home care expert working group recommends the provision of contextual information on home care services, so that the indicators can be interpreted more accurately.³⁰

The evaluation of a palliative care service at a regional and tertiary care facility in Halifax, Nova Scotia provides a noteworthy example of a more comprehensive model of assessment.³¹ The study successfully found ways to measure factors

more subjective in nature by using, for example, the symptom distress scale³² to measure quality of life, the FAMCARE scale to measure family satisfaction with care,³³ and the Maslach Burnout Inventory to measure staff morale.³⁴ This study illustrates the possibility of similar evaluations taking place on a larger scale and on a national level.

Policy Recommendations

How do we achieve consistent, high-quality palliative care across all sites and caregivers?

1. In all sites where palliative care is given – hospital, hospice, long-term care facility, or home – broaden quality and accountability indicators to include:
 - patient satisfaction
 - continuity of care (service delivery, facility use, and health care worker interaction)
 - health care system support of unpaid caregivers and family of the patient (information and support related to dying, death, and bereavement)
 - caregiver analysis (stress levels, time commitments, training levels, personal relationships, respite)
 - financial costs to unpaid caregivers
 - accessibility to care for diverse populations.
2. Develop national regulations for the delivery of palliative care across sites and caregivers, based on the information gained from a broader set of quality and accountability indicators, to facilitate the provision of consistent, high-quality care and to protect both patients and caregivers.
 - Use the Canadian Palliative Care Associations' *2001 Proposed Norms of Practice for Hospice Palliative Care*⁵ as a model to guide the development of new policy and regulations, to be applied across all sites.
 - Incorporate a gender-based analysis to identify the distinct needs of women and men as both patients and caregivers, such as the different economic, social, physical and spiritual impacts of unpaid caregiving, and disparities in respite, service delivery and compensation strategies.
 - Incorporate a diversity analysis to measure access to care, distinct needs, and disparities in service delivery and compensation measures for culturally and ethnically diverse groups of patients and caregivers.

Incorporate a gender-based analysis to identify the distinct needs of women and men as both patients and caregivers.

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3. Support research to determine if there are acceptable margins of variance in palliative care between home and other sites.
4. Support research to develop mechanisms to determine when palliative home care is appropriate. Decisions to place patients at home must be based on full evidence and standards and not only on the desire to save or shift health care costs.
5. Enlist nurse practitioners and family physicians to be Palliative Care Coordinators to ensure continuity of service delivery, facility use, health care worker interaction, and to provide leadership to teams of caregivers, with appropriate fees for service.
6. Educate physicians and other formal caregivers about palliative care and, in particular, expand training on pain control for both adults and children, through mandatory curriculum in training facilities and licensing agencies.¹
 - Educate informal caregivers and the general public about the processes of dying, death, bereavement, and palliative care. This will ensure that the responsibility to impart information about palliative care is not borne by physicians and formal caregivers alone.
 - Provide adequate training to informal caregivers to ensure that those giving palliative care do so skillfully and with confidence.
 - Increase the use of the Internet to provide plain language material about the trajectory of terminal diseases, the process of dying, death, and bereavement.
 - For those who do not have access to the Internet due to limited education, illiteracy, disability, or poverty, support the means to share information with these individuals through the health care system and community services.
7. Implement comprehensive benefits for unpaid caregivers through expanded Pharmacare for the dying for prescription and over-the-counter drugs, EI benefits for six months coverage for unpaid caregivers (family and/or friends), and tax breaks. Develop equivalent measures to compensate unpaid caregivers who are not eligible for EI benefits. Apply a gender-based analysis to all policies designed to ameliorate the financial impact of caregiving.

Current evidence indicates that we need to do more to ease the suffering and burden of patients and caregivers. To develop effective national regulations we need to expand the evidence base on their experiences to determine what type of palliative care is best, to protect the health and well-being of caregivers and, most importantly, to ensure a good death for Canadians.

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Notes

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