VOICE in Health Policy

Transforming Policy:
Strategic Policy Directions on the Role of Informal Caregivers in Palliative and End-of-Life Care

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Introduction

Informal caregivers, family members, friends, neighbours and loved ones of people who are dying, play a key role in hospice palliative and end-of-life care. That role continues to evolve. The ability of Canadians to choose the setting where they want to die often depends on the ability and availability of informal caregivers to provide care. The tasks that informal caregivers are expected to do and the tasks that they are able to do are shaped and influenced by a number of factors, including changes in larger social and economic trends, legal, ethical and moral considerations, advancements in technology, and changes in health and social policy and health service delivery.

People die in a number of settings including residential hospices, long-term care facilities, acute-care hospitals, and at home. With the exception of residential hospices, the role of the informal caregiver has changed in all of these settings, with caregivers being asked to take on a larger share of the care required as well as assuming significant responsibilities. Generally people have indicated that they want to share the responsibility of care for their family or friends; however, in many cases they do so without an awareness of the physical, emotional and financial commitment the care and increased responsibility will require.

Background

The Voluntary Sector Initiative (VSI) was announced in June 2000 as a joint venture between the Government of Canada and the voluntary sector with the objective of strengthening the sector’s capacity to meet the challenges of the future, and enhancing the relationship between the sector and the federal government. Part of the VSI’s mandate is to enhance policy development in federal departments – by creating opportunities for input by voluntary sector organizations: VOICE (Voluntary Organizations Involved in Collaborative Engagement) is one such initiative. VOICE provides a unique opportunity for voluntary organizations working in health and Health Canada to collaborate on a health policy issue within the federal government’s policy development process. VOICE in health policy is a national initiative, funded by Health Canada, and administered by the Canadian Public Health Association (CPHA).
The VOICE Project objectives are to:

- increase the policy capacity of voluntary organizations working in health and Health Canada; and
- to enhance individual and collective collaboration by voluntary organizations working in Health Canada’s policy development process.

Recent policy initiatives and trends in health services delivery are having a significant impact on end-of-life and hospice palliative care. In order to review the current context of informal caregiving, the Canadian Hospice Palliative Care Association (CHPCA) first commissioned a discussion paper entitled *The Role of Informal Caregivers in Palliative and End-of-Life Care in Canada: A Discussion of the Legal, Ethical and Moral Challenges*. The discussion paper is based on information gathered through a literature review, informal case studies, and key informant interviews with informal caregivers, and health care professionals (e.g., nurses, physicians, spiritual advisors and social workers) who work with informal caregivers, and experts in law and ethics. The discussion paper then formed the basis for a national roundtable discussion with key stakeholders held in Ottawa on May 10, 2004. The national roundtable was attended by 32 participants representing a broad range of sectors/interests including: health care professionals, ethicists, lawyers, government policy advisors (federal & provincial), informal caregivers, first nations representatives, seniors groups, researchers, mental health professionals and representatives from disability groups.

A broad range of policy issues related to the role of informal caregivers in hospice palliative and end-of-life care were identified through the literature review and roundtable discussion. For the purpose of this paper, these issues were grouped into five key strategic policy directions. Under each direction is a brief description of the issue, the key collaborators that need to be involved in its development, and strategic activities required to achieve the desired outcome. Estimated timelines for development are also identified, while acknowledging that changes in public policy can take a significant amount of time and require sustained efforts on the part of all collaborators.

Underlying the approach to each of the following strategic policy directions, is the fundamental belief of the Canadian Hospice Palliative Care Association and its members, that *every Canadian has the right to die with dignity, free of pain, surrounded by their loved ones, in a setting of their choice*. It is this belief, and the desire to ensure it is met in every Canadian jurisdiction, that will drive efforts to succeed in each of these policy areas.

It is also important to recognize that these five policy areas, while addressing a range of the issues raised in the discussion paper and the subsequent key stakeholder meeting, are not meant to be definitive of all the legal, ethical and moral issues facing informal caregivers in providing end-of-life care. However, achieving the goals set out in each of these five areas will help address the challenges and will go a long way to ensuring that informal caregivers receive the support and guidance they require if they choose to care for a dying loved one.
Five Strategic Policy Directions

1. Supporting the Informal Caregiver

In recent years, government officials, policy-makers, and the media have begun to focus on the growing number of Canadians struggling to care for ill family members and relatives. It is estimated that 2.1 million Canadians provide care to such persons and that two thirds of these caregivers are members of the workforce. Many of these dependent persons have long-term health problems and require assistance with daily activities.

Economic and social changes are the catalysts for the growing conflict between work and family. Women, who have traditionally performed the family caregiver role, have entered the workforce at increasing rates in the past few decades. An equally important factor is the rising number of elderly persons in the Canadian population, in large part attributable to technological and medical advances. In 1998, 12.3% of the population in this country were 65 years or older; one million more people than a decade earlier. Another factor that contributes to the tension between work and family is the rise in the number of single parent households. The high costs of providing institutional care to ill family members as well as the view that institutionalization may have adverse effects on the physical and mental well-being of a family member are further exacerbating factors.

Few employers in Canada have instituted measures to protect the jobs of employees who strive to provide care for family members who are chronically ill. According to some economists, “Canada lags behind other G-7 countries in family-friendly policies such as family leave and flexible employment opportunities.” It is asserted that the federal and provincial/territorial governments ought to focus on this societal problem so that employees who seek to provide care for chronically ill family members can do so without threats to employment stability or the termination of the employer/employee relationship. Legislation should be enacted, it is argued, to foster the twin objectives of care and stability in the family as well as productivity in the workplace.

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4 Carey, “Caregivers Struggle To Look After Ailing Relatives”, ibid.


7 Ward, supra., note 3, at 417.

8 See comment by Carey, supra., note 2.


10 Excerpted from Job Protection to Family Caregivers, Ronda Bessner, April 25, 2000 – available on request from the CHPCA
On January 4\textsuperscript{th} 2004, the government of Canada addressed this important issue by implementing the Compassionate Leave Benefit which is administered through the Employment Insurance Program at Human Resources and Skills Development Canada. This benefit provides for up to six weeks of paid leave for someone who is caring for a terminally ill child, parent or spouse. At the same time, many provincial governments introduced similar legislation protecting a person’s employment status while on leave to care for a terminally ill child parent or spouse.

While this is an important step forward toward financially supporting employed informal caregivers who take time away from work to care for a dying loved one, it has been identified that the relatively short duration of the benefit, given the uncertainty that often accompanies the length of time individuals require hospice palliative or end-of-life care, does not always meet the needs of Canadians. Private sector companies, such as GlaxoSmithKline, have offered extended employee benefits of up to 13 weeks (renewable every two years) of compassionate leave to care for a dying loved one.

Currently, the federal Compassionate Leave Benefit is only available to the parent, spouse or child of a dying loved one. Other family members or friends are excluded from accessing the benefit. It is important that the Compassionate Leave Benefit be expanded to more accurately reflect the range of informal caregivers who care for dying loved ones and the length of time that is sometimes required for hospice palliative and end-of-life care.

**Key Collaborators**

- National Stakeholders including the Canadian Hospice Palliative Care Association, Canadian Caregiver Coalition, Canadian Home Care Association, Canadian Health Care Association, CARP: Canada’s Association for the Fifty Plus, National Advisory Council on Aging, and the National Council of Women of Canada
- Health Canada
- Human Resources and Skills Development Canada
- Employers – private sector, public sector, NGO sector and unions and employers at the national, regional and local level
- Informal caregiver representatives

**Strategic Initiatives**

Work with various key collaborators (where appropriate) on the following initiatives:

- Mail-outs to federal Members of Parliament and Senators to raise awareness about the financial pressures faced by informal caregivers when deciding whether or not to care for their loved one in the current policy context
- Meetings with federal Members of Parliament and Senators to follow up on the mail-outs and further raise awareness and work with them to implement changes in current federal government policy
Meetings with Human Resources and Skills Development Canada Staff regarding key issues

Collaboration with other federal government departments that are impacted by this issue

Outcomes

- The eligibility of the Compassionate Care Benefit is expanded to include other family members and friends instead of just the child, parent or spouse of a dying loved one
- The duration of the Compassionate Care Benefit is extended to a period of up to six months

Timeline

- Effective date that changes to the Compassionate Care Benefit are implemented: January 2006

2. Federal Home Care Initiative

Home care is a key component of health care renewal and sustainability in Canada. Governments are increasingly utilizing home care services to reduce, delay and prevent hospital and other health institutional stays to reduce costs. Given this trend, the increased demand on home care services by Canadians will likely continue to grow as the Canadian population ages.

In February of 2003, the former Prime Minister Jean Chrétien and the provincial Premiers agreed on the Accord on Health Care Renewal. In particular, the federal, provincial and territorial governments agreed to provide first dollar coverage for a set of minimum services for short-term acute home care, including acute community mental health and end-of-life care.

It is vital that end-of-life and hospice palliative care issues, including strengthening supports for informal caregivers in this arena, be included as an integral part of future work in this area. Without adequate support, informal caregivers will be expected to provide care to their family members without appropriate training and be ill prepared to provide much needed care. Furthermore, the moral, legal and ethical risks that informal caregivers face may deter them from providing care for their loved one. For example, caregivers may be asked to administer treatments to the patient without the appropriate training putting them at risk of legal action if something was to go wrong and placing them in morally uncertain situations. Given the recent commitment of the federal government to re-double its efforts and increase funding for health care, this is an opportune time to advance the educational interests and legal and ethical responsibilities of informal caregivers in this policy area.

Key Collaborators

- Canadian Hospice Palliative Care Association
Strategic Initiatives

- Work with federal, provincial and territorial government representatives to ensure that issues related to the role of informal caregivers are broadly addressed in federal/provincial/territorial policy and program discussions on home and community care health services delivery.
- Work with federal, provincial and territorial representatives to ensure the role of informal caregivers is addressed through the work of the Federal/Provincial/Territorial (FPT) Advisory Committee on Health Services as well as any other federal/provincial/territorial health mechanisms such as the Division of Aging and Seniors, the FPT Ministers Responsible for Seniors, and the FPT Ministers Responsible for the Status of Women.

Outcomes

- Work on having the home care policy agenda renewed with consideration given to the impact on informal caregivers.
- Policy and program issues related to supports for informal caregivers who provide home care are addressed in provincial and territorial delivery of hospice palliative and end-of-life health services.

Timeline

- Policy and programs initiated by 2006.
- Evaluation of the policy and resulting programs to be completed by 2008.

3. Guidelines for Informal Caregivers in Hospice Palliative and End-of-Life Care Situations

As was noted in the discussion paper and by participants of the May 10th roundtable meeting, informal caregivers are faced with an increasing number of caregiving tasks in both institutional and home settings, including the provision of care previously delivered by nurses, personal attendants or even physicians. Informal caregivers are being asked, and are expected, to provide not only emotional and personal support, but to deliver medical care, such as the administration of medications for pain management. In some cases, they may be pressured into assuming a role they feel unprepared for, and in other cases they are being asked to make critical decisions about the care of their loved one as substitute decision-makers.

Informal caregivers could be helped immeasurably by having access to a comprehensive framework of guidelines that would address the many legal, ethical and moral issues they
face, provide assistance in making informed decisions about whether to become an at-home caregiver for a dying loved one, and how to ensure access to the best care possible. The guidelines should include a formal caregiver assessment tool that would assist in determining the capacity of the informal caregiver to deliver appropriate care and/or their capacity to identify and secure the appropriate services for their loved one. It is important to note that the guidelines will need to ensure flexibility based on the personal values and wishes of the dying individual and the capacity of the informal caregiver(s).

Key Collaborators
- Canadian Hospice Palliative Care Association
- Health Canada
- Quality End-of-Life Care Coalition
- Informal caregiver representatives
- Bioethicists
- Legal Experts
- Clinical Representatives
- Spiritual Community
- Researchers

Strategic Activities
- Two national meetings with national, provincial and local collaborators and stakeholders to develop draft guidelines, and provide additional input during its development
- Committee made up of key participants from national meeting(s) to provide additional input
- Testing of the guidelines with informal caregivers in hospice palliative and end-of-life care situations

Outcomes
- Development of implementation/Guidelines for Informal Caregivers in Hospice Palliative and End-of-Life Care addressing the following issues:
  - Choice/capacity of informal caregiver to provide care
  - Identification of potential legal/liability considerations
  - Ethical decision-making and substitute decision-making
  - Pain/symptom management
  - Financial and psychosocial supports/considerations for informal caregivers
  - Confidentiality issues
  - Grief/bereavement
  - Moral/ethical considerations for informal caregivers
  - Parameters of informal care provision in hospitals and home settings

Timeline
- Best practice guidelines completed by the end of March 2006
4. Provincial/Territorial Inequities in Informal Caregiver Supports

The Quality End-of-Life Care Coalition recently issued a status report on end-of-life and hospice palliative care services available in Canada. The report, *Dying for Care: Quality End-of-Life Care Coalition Status Report (July 2004)*, indicated significant differences between provinces and territories in how hospice palliative and end-of-life care services are accessed and delivered. Although the report included some survey results on service options that can provide respite for informal caregivers, its focus was on issues specific to informal caregivers such as access to hospice palliative care professionals and volunteers 24 hours a day/ 7 days a week; home care services including home support and compassionate leave for caregivers. A more detailed review of significant differences between access and service delivery between the provinces and territories may be essential in the future.

With informal caregivers taking on expanding roles, inconsistencies in accessibility of services between provincial or territorial jurisdictions will become increasingly critical to determining the capacity of informal caregivers to be part of the care for loved ones who are dying. Alignment and consistency among jurisdictions regarding supports and services for informal caregivers is a policy imperative.

Key Collaborators
- Provincial and territorial government representatives
- Regional health authorities
- Canadian Hospice Palliative Care Association
- Provincial Hospice Palliative Care Associations
- Quality End-of-Life Care Coalition
- Informal caregiver representatives

Strategic Activities
- A comprehensive review of supports (i.e. respite) for informal caregivers in the basket of end-of-life and hospice palliative care services available in provinces and territories and the identification of gaps in available services and supports
- Stakeholder meetings to discuss the results of the review and to identify approaches and priorities in ensuring equitable access to services (not equal services) across provinces and territories to informal caregiver supports
- Provincial hospice palliative care associations are provided with background information to equip them to meet with provincial government representatives and regional health authorities

Outcomes
- Report on informal caregiver supports available in provinces and territories
- Provincial/territorial agreement on a common basket of informal caregiver supports
Timelines
- Review of supports for informal caregivers: December 2005
- Provincial/territorial agreement on a common basket of informal caregiver supports: December 2006

5. Research on Informal Caregivers in End-of-Life and Hospice Palliative Care

The discussion paper on legal, ethical and moral challenges faced by informal caregivers references several studies, primarily from the United States, which address specific components of the impact on informal caregivers providing care in hospice palliative and end-of-life care situations. [Stajduhar, 1998; Glajchen, 1997; Cannuscio et al, 2002; Glajchen & Fraidin, 2000] A survey was also commissioned by Health Canada and published in 2002. The survey is a profile of family caregivers and provides important information on the demographics, impact of and desired supports required by family caregivers. The survey is limited to situations of caring for family members with a physical or mental disability or with a chronic illness. It did not address the unique needs of end-of-life and hospice palliative care and did not provide data on informal caregivers outside the family, such as friends and neighbours.

Additional research is required about the impact on informal caregivers of providing hospice palliative and end-of-life care to their loved ones and on the supports required by individuals caring for a dying loved one. Given the increasing extent to which health services are being “downloaded” from institutions to home and community care, it will also be important for research on home and community-based health services delivery. Both the financial savings to the health care system and additional economic and psychosocial pressures on informal caregivers need to be calculated as an increasing number of Canadian jurisdictions follow through on this aspect of health system restructuring.

Key Collaborators
- Canadian Hospice Palliative Care Association
- Canadian Caregiver Coalition
- Health Canada
- Canadian Institutes of Health Research (CIHR)
- Local and provincial hospice palliative care organizations

Strategic Activities
- Work with Canadian Institutes for Health Research (CIHR) to develop a Request For Proposal(s) on the role of informal caregivers in hospice palliative and end-of-life care, focusing on:
  - Socioeconomic impacts on informal caregivers who provide end-of-life and hospice palliative care
  - Health system impacts of informal caregiving in end-of-life and hospice palliative care
Outcomes
- Research findings on the informal caregiving

Timeline
- RFP issued by March 2005
- Research completed by September 2006

Conclusion
Informal caregivers, family members, friends, neighbours and loved ones of people who are dying, play a key role in hospice palliative and end-of-life care. As that role continues to evolve, the Canadian health care system must be prepared to address the legal, moral and ethical issues raised as a result of new challenges faced by informal caregivers. The tasks that informal caregivers are expected to do and the tasks that they are able to do will continue to be influenced by a social and economic trends, legal, moral and ethical considerations, advancements in technology, and changes in health and social policy and health service delivery.

The five policy areas discussed in this paper (Supporting the Informal Caregiver; Federal Home Care Initiative; Guidelines for Informal Caregivers in Hospice Palliative and End-of-Life Care Situations; Provincial/Territorial Inequities in Informal Caregiver Supports; and Research on Informal Caregivers in End-of-Life and Hospice Palliative Care) are not meant to be definitive of all the legal, ethical and moral issues facing informal caregivers in providing end-of-life care. However, achieving the goals set out in each of these five areas will help address the challenges and will go a long way to ensuring that informal caregivers receive the support and guidance they require if they choose to care for a dying loved one.

Every Canadian has the right to die with dignity, free of pain, surrounded by their loved ones, in a setting of their choice. It is this belief, and the desire to ensure it is met in every Canadian jurisdiction, that will drive efforts to succeed in each of the five identified policy areas.