



Canadian Healthcare Association
Association canadienne des soins de santé

Continuing Care: A Pan-Canadian Approach

**A Policy Synthesis by
The Canadian Healthcare Association**

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Introduction

Canadians expect their healthcare system to be effective, sustainable, accountable, and, above all, to deliver high-quality health services across the country. As demographics shift and the demand for services across the continuum of care increases, sustainable solutions for evolving health needs must be identified. Within the continuum of care, home, long term, palliative and respite care have progressively taken on an importance that was not anticipated when medicare began; that is, when healthcare only included care provided in hospitals or by physicians.

The Canadian Healthcare Association (CHA) has an 80-year history of advocating for an appropriately funded, effectively organized, and integrated health system. CHA's interests cross the full continuum of care from health promotion and disease/illness prevention to continuing care, which includes home, facility-based long term, respite and palliative care. Since 2009, CHA has released several significant policy briefs on aspects of continuing care. (For detailed reports, please visit: www.cha.ca). This paper is intended to provide a synthesis of the common themes that have emerged across CHA's continuing care policy briefs and identifies priority recommendations for action.

Background and Context

When the first hospital insurance program was introduced in Canada in the 1950s, the Canadian population was generally younger, life expectancy was shorter, and people did not live as long once they became ill. The picture is very different today. The population has generally aged, people are now living longer and often with multiple chronic and/or complex conditions (Canadian Healthcare Association, 2009).¹

The health system is responding to these changes in many ways. Care is shifting from the acute care sector to the community. People often prefer to be cared for at home rather than in a hospital or long term care facility, and technological developments have contributed to making care in the home or community increasingly possible. In some cases downsizing, or reorganization within the system, has influenced this shift to the community (Canadian Healthcare Association, 2009).² As a result, continuing care services are playing an increasingly important role in health care delivery. In some respects, however, the required concurrent shift in attention and resources from acute to community and continuing care is not happening fast enough. This is evident in Canada by the number of people in acute care settings who are awaiting care in another setting such as home care or long term care for example.^a This situation is widely known to put additional pressure on the acute care system. It also contributes to the demand for a range of continuing care services and provides a supporting argument for its importance.

^a These are also referred to as alternate level of care or ALC patients. ALC patients are medically discharged acute care hospital patients who are occupying beds while awaiting placement within the continuing care system, for example, in facility-based long term care (Canadian Healthcare Association, 2009).

CHA's Perspective on the Pillars of Continuing Care

Home Care

Home care is “an array of services, provided in the home and community setting, that encompass health promotion and teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration, and support for the informal (family) caregiver” (Canadian Healthcare Association, 2009).³ Canadians 65 and over are more likely to use government-funded home care services, yet between 3 and 4 percent (125,000 and 170,000 people) (Statistics Canada, 2005⁴) report needing home care services that they did not receive (Health Council of Canada, 2008).⁵ As identified in 2002, the elderly are not the only users of home care. In Ontario for example, 45 percent of home care recipients were under 65 years of age and 15 percent were children (Standing Senate Committee on Social Affairs, Science and Technology, 2002).⁶

The provinces and territories are largely responsible for public expenditures in home care, with support from the federal government provided through transfer payments. In 2006, home care expenditures ranged from 1.56 percent to 6.8 percent of provincial and territorial health budgets and 3.7 percent or \$3.9 Billion of total public health care spending in Canada (Canadian Home Care Association, 2008).⁷

Facility-Based Long Term Care

Facility-based long term care is both a home for residents and a workplace for providers. Accommodation, hospitality services and health services are provided, typically over an extended period of time, to people with complex health needs who are unable to remain at home or in a supportive living environment because of moderate to extensive functional deficits and/or chronic conditions (Canadian Healthcare Association, 2009).⁸

Residents of long term care facilities are generally the very frail and very old. However, younger adults with severe disabilities also make long term care facilities their home; in 2008, 6.3 percent of residents in residential care were younger than 65 (Canadian Institute for Health Information, 2008).⁹ The difference in life expectancy between Canadian women and men is expected to decrease in the future (Statistics Canada, 2006).¹⁰ But today's longer life expectancy of women (86.4 years) as compared to men (83.2 years) (Statistics Canada, 2009)¹¹ is reflected in the long term care resident population, where the vast majority of residents are female (Armstrong, 2008).¹²

Although the Canadian population is aging, there has actually been a downward trend in the number of people living in long term care facilities. From 1986 to 1996 the percent of Canadians over age 75 who lived in long term care homes decreased from 16 to 14 percent (Statistics Canada, 2006).¹³ Better overall health from developments in technology, pharmaceuticals and surgical treatment, the availability of community support and home care services, and progressive social and economic policies have helped more seniors live independently for longer (Canadian Healthcare Association, 2009).¹⁴ This trend, however, means that when people do enter long term care facilities, they are older and have more complex care needs.

Respite Care

Respite care is the provision of short-term and/or temporary relief to those who are caring for family members or loved ones who might otherwise require permanent placement in a facility outside the home. It provides a much-needed temporary break from the challenges faced by the informal caregiver. Respite care can take many forms, for example, day programs, in-home visits, camps for chronically ill children and beds in residential facilities set aside for short-term stays. A broader view of respite care, as both a service and an outcome, is emerging that takes into consideration the needs of the care recipient as well as other family members (Canadian Healthcare Association, 2011).¹⁵

Palliative Care

Palliative care integrates medical, psychological and spiritual care at the end-of-life and is an increasingly important aspect of continuing care. In Canada, approximately 60 percent of deaths take place in hospitals when, in many cases, patients and their families would prefer a different setting for the end of life (Quality End-of-Life Care Coalition of Canada, 2008).¹⁶ Training for palliative care providers and caregivers is limited in Canada (Kortes-Miller et al, 2007).¹⁷ The Quality End-of-Life Care Coalition of Canada (2008) also notes that “no more than 37% of Canadians dying in all settings receive the kind of comprehensive, coordinated palliative care that improves quality of life at the end of life.” As noted by Canadian Hospice Palliative Care Association (2010) Executive Director Sharon Baxter, “there is still much more to be done to ensure that every Canadian has access to quality hospice palliative and end-of-life care regardless of where they live.”¹⁸

Continuing Care Issues

There are four inter-related issues or themes that are common to home, facility-based long term, respite and palliative care, and which CHA feels must be addressed as highest priorities: dignity and respect, support for caregivers, funding and health human resources, and quality of care.

Dignity and Respect

Dignity and respect are basic human rights which apply equally to those who receive continuing care services and/or reside in a long term care facility. The maintenance of dignity and quality of life are often more important to many seniors than extended life. However, there is a mainstream perception that one’s dignity (i.e. through lack of privacy and loss of autonomy) is lost in the long term care setting. Whether this sentiment is real or perceived, there are several factors that have an impact on the culture of caring that is required in the continuing care setting to maintain a resident’s dignity.

Variations in the funding of services across jurisdictions may undermine a resident’s dignity. For instance, funding impacts staffing and inadequate staffing and training impacts not only the quality of care residents receive, but also their dignity and quality of life. The need for dignity and respect must also extend to the resident’s informal caregivers, family and friends. By allowing caregivers to become part of the dynamic interdisciplinary team that is providing the continuing care services, it not

only demonstrates respect, but also positively impacts on the person receiving care and contributes to creating a culture of caring.

Personal income may also affect dignity. If no personal money - either through a jurisdiction's personal allowance and/or personal funds - is left over for simple pleasures after services are paid for, one's personal dignity is diminished. Senior women are particularly vulnerable since they are at least twice as likely as men to be living on low incomes or in poverty with no additional pensions or private means to access higher levels of care (Canadian Healthcare Association, 2009).¹⁹

Organizational values, culture and standards that acknowledge and entrench a culture of caring through dignity and respect are critical across all aspects of continuing care. A culture of caring must become an expected and accepted environment in which the dignity and respect of those receiving continuing care services and of their informal caregivers, family and friends is honoured and upheld. Leadership at all levels must play a key role in achieving and sustaining this culture.

Recommendation # 1:

Create a culture of dignity and caring where continuing care services and long term care facilities:

- Reflect a home, rather than institutional, environment;
- Address the needs of non-senior residents and clients by providing opportunities and/or environments which are appropriate to their needs;
- Support end-of-life care through adequate funding of palliative care services and ensuring that people can die in the environment of their choice;
- Ensure the appropriate human resources and physical environment in which to support those with mental health needs.

Support for Caregivers

Informal caregivers play a significant role in the provision of continuing care. The continuing care system could not exist without the volunteer work of friends and family who help take care of loved ones. The value of their contribution is enormous and has been estimated at between \$5 Billion²⁰ to \$26 Billion²¹ (Hollander, 2001; Hollander, Lui and Chappell, 2009). The ongoing University of Alberta research study, *Hidden Costs/ Invisible Contributions*, estimates that the work some 2.1 million informal caregivers do for seniors is the equivalent of 275,509 full-time employees (Canadian Healthcare Association, 2009).²²

Informal caregiving can pose significant financial, emotional, mental and physical demands on the caregiver. Often, family caregivers give up paid employment to care for their loved one; 11 percent of respondents to the 10th anniversary *Health Care in Canada* survey reported quitting their job to care for a family member or friend (Pollara, 2007).²³ The experience of observing their loved one face ill and/or declining health may cause emotional strain and it may take great physical effort to provide care as well. Overall, the situation can lead to significant stress and poor health for the caregiver. The value of the significant contribution and sacrifice that informal caregivers make needs to be formally acknowledged.

The June 2011 Family Caregiver Tax Credit announced by the Government of Canada is a welcome first step toward supporting caregivers. This tax credit aims to provide tax relief to caregivers of all types of infirm dependants and relatives by providing a 15-percent non-refundable tax credit on an amount of up to \$2,000 (Government of Canada, 2011).²⁴ However, the use of tax credits or targeted tax cuts as instruments of social policy marginalizes those Canadians who do not have the financial ability to make use of those credits. In these cases, caregivers would be better served through targeted programs such as adjustments in CPP/QPP pension calculations and expanded compassionate care benefits (Canadian Healthcare Association, 2010).²⁵

Recommendation # 2:

Increase support for informal caregivers in the form of an adjustment in CPP/QPP pension calculations and the provision of an expanded compassionate care benefit.

Funding and Health Human Resources

In 1984, when the *Canada Health Act* came into effect, home care and long term care facilities were defined as “extended health services” (Government of Canada, 2011, p. 2).²⁶ This is still the case today and means that it is up to individual provinces and territories to decide if these services are provided and, if so, how (or if) they are funded. The result is variation in the programs and services that are funded across jurisdictions. Not only is funding not standardized across jurisdictions, it is not portable. Thus, a person requiring continuing care services who moves between jurisdictions will find that what was funded in one jurisdiction may not be in the other.

Health human resources are also impacted by the funding situation in continuing care. Specifically, paid home care workers tend to earn less than their institution-based counterparts. This results in high turnover in home care, which subsequently affects quality of care. Funding also affects the level of staffing and the amount of training that staff has, which can affect the quality of services and may impede achieving a culture of caring.

Recommendation # 3:

Ensure appropriate and dedicated funding for continuing care.

Recommendation # 4:

Allow funding to follow the client from one jurisdiction to another.

Recommendation # 5:

Invest in health human resources, including standardized education and skills training for continuing care providers.

Quality of Care

There is no national strategy or set of principles upon which continuing care services are based across Canada. The availability and provision of home, long term, respite and palliative care varies across (and even within) provincial and territorial

jurisdictions and there are no common standards either for the services themselves or for the education and skills training for many providers of continuing care. Canadians in different jurisdictions are assessed and admitted to care according to different criteria, and experience variations in access to services and the nature and quality of the care they receive. Further, the exclusion of continuing care services from insured health services compromises quality by enabling the creation of a patchwork of services across the country.

Accreditation, a process that is synonymous with quality, is generally voluntary. CHA believes, however, that accreditation systems such as Accreditation Canada's *Qmentum*[™] program could ensure improved care for residents and worklife for staff in facility-based long term care. In the area of long term care, specific accreditation rates are difficult to determine due to differing definitions of long term care and variations in regional and organizational structures and service delivery. The following description makes evident the complexity of the system and the potential variation in quality of care across the country.

In Western Canada most publicly funded long term care facilities are accredited through the accreditation process of their regional health authority and an estimated 50 percent of private long term care facilities are accredited. In Ontario, funding for long term care facilities is tied to accreditation and approximately 50 percent are accredited. Accreditation is mandatory in Quebec. Thus, all long term care facilities in that province are accredited. Similar to Western Canada, in Atlantic Canada, most publicly funded long term care facilities are accredited through the accreditation process of their regional health authority. Funding is not tied to accreditation in the Atlantic region and, as such, a much smaller proportion of private facilities are accredited. In Northern Canada, there are significantly fewer long term care facilities; publicly funded long term care facilities that are part of health authorities receive accreditation as part of the accreditation process of their health authority and those that fall outside of the public system are generally not accredited.²⁷

Recommendation # 6:

Encourage a quality-driven approach to continuing care through a national continuing care strategy for home, long-term, respite and palliative care.

Recommendation # 7:

Develop standards, conduct research, and identify and share best practices to ensure the provision of quality continuing care services to Canadians.

Recommendation # 8:

Ensure that funding is available to support the engagement of facility-based long term care homes in mandatory accreditation processes, expanding across continuing care services as accreditation programs become available.

Conclusion

Home, facility-based long term, palliative and respite care have the potential to affect all Canadians, as, at some point in their lives, most Canadians will find themselves providing or receiving one or more of these types of care. Canadian demographics are shifting and governments must act today in order to meet the continuing care needs of the future; a future characterized by increasingly complex health, financial and social needs. In concert with the acute care system, continuing care plays a key role in delivering timely, quality and effective care to Canadians in appropriate settings. A national strategy that fully and appropriately integrates home, facility-based long term, respite and palliative care services with other parts of the system would contribute significantly to the efficacy, effectiveness and sustainability of the Canadian health system, and must become a priority.

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