



CONTINUING CARE

CANADIAN FEDERATION OF NURSES UNIONS BACKGROUND

Introduction

Continuing care – the suite of services comprising long-term care, home care, respite care and palliative care is in need of serious reform across Canada. Insufficient funding, lack of access, lack of planning, including lack of discharge planning, poor quality, unsafe staffing and a patchwork of care regulations and standards across the country have led to a crisis for Canadians in need of continuing care. The implications impinge on the acute care system, creating backlogs and inappropriate care settings, thereby compromising the quality of care for patients and the efficiency of the system as a whole.

The good news is that improvements in the public funding and delivery of continuing care will have a positive impact on the health and social condition of Canadians and increase the sustainability of the overall health care system. It is time we move beyond acute care.

The time to act is now. Frail elderly and those with multiple chronic conditions are the demographics most in need of a continuing care system and constitute a growing portion of the population. By making collective, concerted efforts to improve continuing care in terms of access and quality, we will improve patient, client and resident experiences and health outcomes across the full continuum of care.

Continuing Care

Continuing care is an integrated mix of health, social and support services offered on a prolonged basis, either intermittently or continuously, to individuals whose functional capacities are at risk of impairment, temporarily impaired or chronically impaired. Continuing care is provided by formal and informal caregivers at home, in the community or within facilities. The objective of continuing care is to maintain, and when possible, improve the functional independence and quality of life of these individuals.¹

A more holistic vision of health care is emerging wherein primary health care services, hospital services and continuing care services are

intended to work seamlessly with each other to deliver the best and most efficient health care possible. A view of the entire continuum of care allows for patient-centred care with each need being managed by the most appropriate system. Recognition of the continuum of care has been described as the “antidote to fragmented and uncoordinated health and social service systems in which continuity of care is often the victim.”²

Continuing Care Services

Long-term care (LTC), also known as “residential care” or “facility-based long-term care,” refers to care in a facility dedicated to people with complex health needs, who are unable to remain at home or in another supportive living environment. People requiring long-term care are often seniors with moderate to extensive functional deficits and/or chronic conditions, although younger Canadians with extensive health challenges also require long-term care. Long-term care facilities differ from assisted or supported living, retirement or group homes in that nursing care is available 24-hours a day.³

Home care involves a wide range of caregivers providing a wide range of services to recipients in their homes. Caregivers may be paid trained and regulated professionals, paid unregulated care providers, volunteers working for service organizations, or family members, friends, neighbours or members of the community. Home care services include medical services and a wide range of necessary support services. Care recipients include persons recently discharged from hospital, those who are dying, persons with a mental illness, persons with physical or mental disabilities, the elderly who are able to remain in their home rather than a long-term care facility, children with special needs, and people with chronic illnesses.⁴

Respite care is provided on a temporary basis to relieve informal home care providers and care recipients. It is not meant to be a replacement or change in the direction of care but rather a necessary support to informal caregivers and recipients who need a break to be able to continue the existing care arrangement.⁵

Palliative care helps patients and families dealing with a life-threatening illness, and can be delivered in a specialized facility, a hospital setting, a long-term care facility or at home. It aims to relieve suffering, to improve the quality of living and dying, and to promote “meaningful and valuable experiences, personal and spiritual growth, and self-actualization.”⁶ It involves medical care as well as psychological and spiritual care, often including some support for loved ones.⁷

Situation in Canada

Although continuing care is often medically necessary, it is not covered along with physicians and hospital services in the *Canada Health Act*. As a result, continuing care programs form a patchwork, with variations between and within provinces in the availability of services, level of public funding, eligibility criteria and out-of-pocket costs borne by residents. The lack of access to quality continuing care is an important factor of overuse and misuse of the acute care sector.

Long-term Care

In 2010, there were 4,633 residential care facilities in Canada, serving 242,270 residents.⁸

Spending on ‘other institutions,’ including nursing homes and residential care facilities, was over \$18 billion in 2011, accounting for a forecasted 10.1% of total health expenditures. Hospital care, the largest component of health spending, comprised a forecasted 29.1%.⁹

In 2010, there were 24,891 RNs (registered nurses), 29,295 LPNs (licensed practical nurses) and 909 RPNs (registered psychiatric nurses – western provinces and Yukon only) working in long-term care across the country.¹⁰

Home Care

In Canada there are over 900,000 recipients of home care, 70% of whom are aged 65 and older.¹¹

Home care accounted for 3.7 % of total public health care spending in Canada in 2007.¹²

In 2005, 3-4 % of Canadians aged 65 and older said they needed home care services that they did not receive.¹³

Home Care: Informal Caregivers

In 2009, 2.1 million caregivers were doing the equivalent of 275,509 full-time employees’ work.¹⁴

The value of informal caregiving in Canada (care provided by family and friends) is estimated to be between \$5 billion and \$26 billion. Another study reports that over one in four Canadians (including more than one in three Canadians between 45 and 65) cares for a close friend or family member with a serious health problem.¹⁵

Women are more likely than men to be caregivers for children, dependant adults, aging parents and intimate partners.¹⁶

Nurses’ training makes them particularly likely to be involved in the care of elderly relatives. A recent survey of Canadian RNs found that 38.5% cared for elderly relatives apart from their regular work hours.¹⁷

Over 40% of caregivers rely on personal savings to survive during the time they provide care, and 22% of caregivers take one or more months off work per year for caregiving.¹⁸

The Victorian Order of Nurses (VON Canada) has prepared a web source page for informal caregivers called caregiver-connect.ca. The site provides detailed information for caregivers in Canada, including resources, connections and tools.¹⁹

Palliative Care

75% of deaths today take place in hospitals and long-term care facilities.²⁰

Hospice palliative care programs are still at least 50% funded by charitable donations, and families must bear part of the cost of dying at home, or almost anywhere else outside of a hospital.²¹

Challenges

Pan-Canadian inconsistencies

The cost of long-term care varies widely across Canada, from as low as \$918 per month in Manitoba to as high as \$2,800 in Newfoundland and Labrador. These figures do not include potential additional costs such as medical supplies, housekeeping and transportation.²²

Average costs in for-profit facilities are higher than their publicly funded counterparts. In British Columbia, for example, the average monthly rent is estimated at \$4,718 in for-profit facilities.²³

As the Premiers of British Columbia and Nova Scotia have recently pointed out,²⁴ the population is aging at different rates across the country and this creates challenges for provinces to provide a comparable range of services.²⁵ Continuing care is not an insured health service under the *Canada Health Act*, and as such, provinces and territories vary widely in their provision of support services, medical supplies, equipment and drugs to individuals and families needing care.

The lack of an integrated continuum of care is also problematic. A disjointed system is very difficult to navigate, and this burden is placed on seniors and others requiring continuing care. As the Senate Committee on Aging put it, “Ensuring that these services are integrated is not an administrative or financial requirement, but rather a necessity...”²⁶

Demographics

The number of Canadians over 65, currently at 4.2 million, will reach 9.8 million by 2038.²⁷ According to the Conference Board of Canada, 5.9% of Canadian seniors live below the poverty line.²⁸

As the number of seniors rises, it is estimated that as many as 560,000 to 740,000 seniors could need LTC by 2031.²⁹

Only 25% of Canadians in the private sector have a pension (compared to 80% in the public sector), and thus many Canadians are left with only Old Age Security and potentially Canada/Québec Pension Plan or Guaranteed Income Supplement benefits to pay for long-term care once they are retired.³⁰

It is estimated that the number of seniors with chronic conditions requiring home care services will rise 33% by 2017 to 840,000. The sector had already experienced an over 51% increase in the previous 12 years (1996-2008).³¹

20% of seniors receiving long-term home care had a diagnosis of Alzheimer’s or other form of dementia, with more than one in six suffering

from moderate to severe impairment.³² 44% of seniors in residential care live with depression³³ or symptoms of depression, and 88% report having two or more chronic conditions.³⁴

Access to Home Care

The home care sector is facing a crisis in health human resources with a shortage of both professional and unpaid family caregivers. A pan-Canadian nursing shortage coupled with under-investment in health human resources has severely impacted community and home care services.

Family caregivers often experience extreme financial, emotional, physical and mental burden due to caregiving responsibilities.³⁵ The CIHI Report, *Supporting Informal Caregivers – The Heart of Homecare*, evaluated factors that increase caregiver distress, and which can lead to the interruption of care. While the highest odds ratio associated with caregiver distress was moderate to severe cognitive impairment, other factors include the lack of nursing care, home health, homemaking, meals, respite and other services.³⁶

Under-investment in home care jeopardizes the sustainability of the entire health care system.³⁷ Inadequate access to home care needlessly sends people to, or keeps people in, acute care or long-term care, resulting in fewer beds for those who need them most. This phenomenon leads to over-expenditure in acute care and over-crowding in hospitals, exacerbating wait times.

The Romanow report called home care the “next essential service” and recognized that investment in home care could save money and improve the quality of life for care recipients. Unfortunately, no progress at the federal level has been made in the years since the report was released despite an increased recognition by provincial governments of the growing importance of this area of health care.

Commission on the Future of Health Care in Canada. (2002). *Building on Values: The Future of Health Care in Canada. Final Report.* Ottawa.

Access to Long-Term Care

The ratio of LTC beds to population has been declining across the country even though demand is up. The exception is Ontario where the expansion of beds has been almost entirely in the for-profit sector. This risks a decrease in quality, as for-profit facilities are known to reduce staffing and other services in favour of the bottom line,³⁸ or a decrease in access as higher-end facilities will be out of reach for average Canadian seniors and other clients.

An aging population is one factor driving demand for long-term care facilities. The number and proportion of seniors 80 and over is projected to increase substantially. By 2056, about one in ten Canadians will be over 80 compared to about one in 30 in 2005. Demand for long-term care beds is expected to triple by 2031.³⁹

Long waiting lists are forcing seniors to make difficult choices. Some must accept the first available bed, often at a facility they would not choose, or distant from a partner or family. In some provinces, a person who refuses an offered space is moved to the bottom of the list, waiting months, possibly years, for another opening.⁴⁰ For some there is no choice as the only care available is unaffordable.

Lack of access to long-term care facilities has a ripple effect on the health system. Daily, approximately 7,550 beds in acute care hospitals are occupied by patients who have been medically discharged but cannot get placement in an alternate level of care, such as a long-term care facility.⁴¹

For-Profit Long-Term Care

For-profit LTCs are on the rise. They currently make up 35% of LTC beds; the number is 53% in Ontario.⁴²

Many studies document the dangers of for-profit LTC: higher risk of hospitalization for dehydration, pneumonia, anaemia, falls and fractures.⁴³

Research published in the *British Medical Journal* estimates that across-the-board non-profit ownership would give Canadian LTC residents 42,000 more nursing care hours every day.⁴⁴

Research in Canada and abroad indicates that for-profit facilities, even if publicly funded, are

more likely to produce inferior quality care.⁴⁵ A 2006 report by the Manitoba Nurses Union found that 84% of nurses working in a non-profit facility would recommend their facility to a family member compared to 67% in for-profit facilities.⁴⁶ The same study found that by every measure (hip fractures, non-hip fractures, accidental falls, skin ulcers, respiratory infections and fluid/electrolyte imbalances) for-profit facilities reported higher rates of negative events than non-profit facilities.

Inadequate Staffing in Long-Term Care

The main reason for the pattern of lower quality of care at for-profit facilities is lower staffing levels. The skills mix and ratio of staff to patients are key factors affecting quality of care and health outcomes. When nurses are removed from the care mix, morbidity and mortality rise. For example, urinary tract infections and pressure ulcers rise exponentially.⁴⁷

Although generally worse in for-profit facilities, understaffing is a chronic problem in the long-term care sector. Understaffing affects negatively the quality of care of residents, the quality of life of residents and workers, and staff retention and recruitment. A recent survey of nurses working in LTC in Newfoundland and Labrador found that 74% believe current staffing levels are inadequate.⁴⁸

A Manitoba study revealed that nearly 20% of nurses reported resident-to-nurse ratios of greater than 80:1 on night shifts.⁴⁹

Residents in higher-staffed facilities spent less time in bed, experienced more social engagement and consumed more food and fluids.⁵⁰

In 2008, the Health Council of Canada found that home care, one of the foundations of the Canadian health care system, is so stretched that it is often not as comprehensive or coordinated as it should be, leaving patients to fall through the cracks.

Health Council of Canada. (2008). *Fixing the foundation: An update on primary health care and home care renewal in Canada*. Toronto, Ontario: Health Council.

No province effectively ensures appropriate staffing levels. In Saskatchewan, the only province with a legislated minimum staffing standard, the standard is two hours per resident day of personal and nursing care, less than half, for example, of what is recommended by the US Center for Medicare and Medicaid Services to not risk the health and safety of residents.⁵¹

Long-term care workers are generally compensated less than their counterparts in the hospital sector. Part-time, casual and temporary work is also more common than in other sectors requiring workers to patch together jobs at different facilities to get enough hours.⁵² Lower rates of unionization in long-term care also result in less compensation and benefits for workers there.

Long-term care facilities can also be a dangerous place to work, with understaffing being the main reason.⁵³ One study of worker injury data from 1,076 LTC facilities in three states in the US found that each additional hour of direct nursing decreased the injury rate by nearly 16%.⁵⁴

A recent study revealed that LTC workers in Canada experienced violence over six times the rate of their counterparts in Nordic countries, in part due to differences in staffing levels.⁵⁵

Few jurisdictions regulate care hours per resident, and no jurisdiction in Canada requires the number of care hours considered safe for patients, residents and clients. Yet, instead of strengthening legislation, governments are increasingly paying for beds in new categories of housing to which the regulations do not apply.⁵⁶

Choice in Palliative Care

It is estimated that 95% of deaths would benefit from palliative care, yet as many as 70% of Canadians lack access because hospice and palliative care programmes are unevenly distributed across Canada.⁵⁷

Research suggests that most Canadians wish to die at home, though only a minority manage to do so.⁵⁸

Moving Forward

In the 2004 10-year *Plan to Strengthen Health Care*, the First Ministers committed to renew

home care services in Canada. They agreed to first-dollar coverage for a few specific home care services including: short-term acute home care, short-term community mental health home care, and end-of-life care.⁵⁹ This represented an important first step.

78% of Canadians support the development of more home and community care programs as a means to improve the health care system.⁶⁰ Support for the full continuum of care beyond doctors and hospital services will help reduce strain and will allow Canadians to receive the care they need in the appropriate setting.

Reject for-profit funding and delivery

First-dollar coverage of physician and hospital services was not meant to be the sum of Medicare. The critical second stage, which has yet to materialize, would effectively address illness prevention and health promotion, and extend coverage beyond hospitals and doctors.

Equal access to quality health care is a core Canadian value, and most home care and long-term care are medically necessary. Following the rationale behind Medicare, the *Canada Health Act* should apply to all medically necessary services no matter where they are received. This is especially critical as services that used to be publicly funded are increasingly being moved out of hospitals requiring Canadians to pay privately.

Private health insurance is costly to the buyer, does not provide universal access, is problematic even for the policy-holder and overall is costly to Canadians.

Public funding to for-profit long-term care facilities should be phased out as for-profit facilities cost more overall and deliver less.

National Standards

Because most continuing care services fall outside of the *Canada Health Act* and are not covered by national programs, there are considerable differences between and within provinces on how they are organized, funded and delivered. Governments need to agree on comparable classification systems to facilitate the collection of data that can be compared between and within jurisdictions.

National standards are required, including agreed upon and mandated standards for minimum care hours. The Canadian Healthcare Association, for example, has called for data standards on staffing ratios, staffing qualifications, levels of care, admissions, discharges and deaths.⁶¹

Leadership

Public administration, funding and delivery across the full continuum of care will ensure that Canadians receive the right kind of care in the right place from the right health care professional.

Federal and provincial/territorial government intervention is needed to expand coverage and access to services through legislation, making the full spectrum of continuing care a focal point of health care renewal strategies.^{62,63}

Governments should provide leadership and coordination through initiatives such as a National Caregiver Strategy that recognize the value of family caregiving by providing financial support to caregivers and facilitating flexible work environments.^{64,65} Similarly, they should create and support an Expert Advisory Panel on family caregiving to develop a multi-sectoral strategy to better support caregivers and citizens across Canada.⁶⁶

The Secretariat on Palliative and End-of-Life Care should be restored to increase equitable access to palliative care service and to help more Canadians die in the setting of their choice.

As part of a national health human resource strategy, governments should help build a stable continuing care workforce, guided by pan-Canadian standards, and comprised of caregivers that are skilled, dedicated and who have experience suited to long-term care, home care and palliative care.

Promising Initiatives

An Edmonton program, Comprehensive Home Option of Integrated Care of the Elderly (CHOICE), helps keep older people healthy and living at home. CHOICE relies on timely recognition and intervention responding to changes in medical status and support from informal family caregivers. It resulted in a 67% decrease in in-patient episodes, 70% decrease in in-patient days, 84.7% decrease in sub-acute use,

62.9% decrease in emergency room visits and a 51.5% decrease in ambulance trips.⁶⁷

Because of a lack of effective community home care, 15-20% of older Canadians are readmitted to hospital within one month of discharge. A nurse-led community home care initiative in Sault Ste. Marie has reduced readmission for heart failure by nearly 50%.⁶⁸

Home First, an initiative of the Mississauga Halton health region, instituted a series of programs to facilitate the transition of hospital patients requiring alternate levels of care into other appropriate care settings, be it home care, long-term care or community clinics for the elderly. The program has resulted in excellent health outcomes.⁶⁹ It also contributed to considerable savings. The Ontario Association of Community Care Access Centres reports that for patients requiring alternate levels of care, every 10% shift from acute care to home care results in \$35 million in savings for the province.⁷⁰

There are many other current initiatives that show the potential and promise of reform in continuing care. Implemented on a larger scale, such initiatives could readily translate into improved health outcomes and increased efficiency.

Conclusion

The CFNU applauds the increased recognition that continuing care is receiving. However, it is important to recognize that modest measures such as tax credits and the proposed Employment Insurance provisions do not go far enough to address the serious shortfalls, inequities, lack of access and lack of national standards within the system. Comprehensive, multi-jurisdictional solutions are required.

The CFNU calls on governments to support a comprehensive national strategy on aging and health human resources to support a continuum of accessible, timely and appropriate care. This strategy must include income support so that seniors and others have access to the quality care they require. An effective continuing care system can reduce costs in acute and primary care, and improve the efficiency of the entire health system.

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