

Seniors in need, caregivers in distress:

What are the home care
priorities for seniors
in Canada?



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About the Health Council of Canada

Created by the 2003 *First Ministers' Accord on Health Care Renewal*, the Health Council of Canada is an independent national agency that reports on the progress of health care renewal. The Council provides a system-wide perspective on health care reform in Canada, and disseminates information on leading practices and innovation across the country. The Councillors are appointed by the participating provincial and territorial governments and the Government of Canada.

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Foreword

In the last decade, the number of people receiving home care in Canada has grown considerably. Many home care recipients are seniors with chronic conditions and physical or cognitive limitations who want to stay in their homes as long as possible. Home care services help them to manage their health conditions at home and provide assistance with daily activities.

The Health Council of Canada set out to examine the characteristics of older Canadians who are receiving home care and to highlight some of the challenges facing these seniors, their family caregivers, and the home care sector. We also reviewed strategies and innovative approaches that are underway in some provinces and other countries to provide comprehensive home care to seniors, and to support their caregivers.

One of the key findings is that seniors with complex health needs receive, at most, a few more hours of home care a week than what is offered to seniors with moderate needs. A key consequence is that many family caregivers of these high-needs seniors are stretched beyond their capacity, reporting high levels of stress, depression, and difficulties in continuing to provide care.

Canadian governments are recognizing that an aging population, coupled with the need to control health care costs, requires a greater focus on home care for seniors. Home care has historically been considered a patchwork of services that are provided off-side in the community, disconnected from hospitals and family doctors. But that's outdated thinking. Home care is an

integral part of the health care we provide to Canadians and needs to be recognized as such. Canadians would benefit from expanded efforts to integrate home care with other services in the health care system, particularly hospitals and primary care, and to ensure that family caregivers continue to receive support as needs change. In this report we highlight some examples, both in Canada and internationally, that could be adapted across the country.

Finally, any thoughtful discussion about home care for seniors needs to include conversations about aging and our values, responsibilities, and expectations, both as a society and as individuals. There were many such discussions during the development of this report, derived from both the findings and the real-world experiences of report contributors who are caring for older family members and interacting with health care professionals, hospitals, and home care agencies on their behalf. No doubt many of the readers of this report will view the information through a similar personal lens. Aging well is an issue that matters to all of us.

Sincerely,

Dr. Jack Kitts
Chair, Health Council of Canada

Introduction

Most seniors in Canada live at home and would like to remain there as long as possible. Although many seniors are able to stay in their homes without support, a growing number need help from home care services and family caregivers in order to manage daily activities and care for their health conditions.¹⁻³ In this report, we focus on the issues and challenges related to home care for seniors and their caregivers in Canada.



We begin by looking at the types of clients who are receiving home care, the services they are receiving, and the intensity of their needs. We then look at the characteristics of family caregivers, including the number of hours they spend on care and their level of distress. In particular, our analyses show that many seniors with complex and multiple health needs are receiving limited hours of home care, and as a consequence their family caregivers—many of whom are seniors themselves—are stretched beyond their capacity and reporting high levels of distress.

We also examine system issues such as the importance of integrating home care with hospitals and primary care, and the challenges facing the home care sector, such as the recruitment and retention of personal support workers. We also discuss the cost-effectiveness of home care compared to hospital care and long-term care facilities, noting that public spending on long-term care facilities in Canada is much higher than spending on home and community care. We look at the experiences of other countries that spend proportionally more on home care and have implemented strategies to ensure that seniors can remain at home longer with a better quality of life.

Throughout the report, we profile innovative practices that are examples of effective home care policy and programs, and that illustrate how home care can be integrated with other health services and sectors. These practices offer tools and ideas that can be adapted by governments and health systems across Canada.

The home care landscape

Home care has many faces. It is used to provide care after hospitalization or when someone is dying, to help vulnerable seniors stay in their homes independently, and to manage chronic conditions, disabilities, and mental illness.⁴ Home care programs are also linked with community support services such as food delivery, house cleaning, and transportation, which are often provided to the client at additional cost.

The Canadian Home Care Association defines home care as “an array of services for people of all ages, provided in the home and community setting, that encompasses 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.”⁵ Although provinces and territories are increasingly moving towards capturing many aspects of this definition in their policies, existing home care programs in Canada still have a long way to go to fully achieve this vision.

Home care, defined as an “extended health service,” is not an insured health service under the Canada Health Act.⁶ Each province and territory administers its own publicly funded home care programs and services, but these vary in terms of levels of coverage, eligibility criteria, and funding schemes. Many provinces and territories contract out a portion of their home care services to private agencies.

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programming in the last decade

Terminology in this report

One of the challenges in discussing home care is the lack of consistency in the way terminology is used. We have chosen to use the following definitions for this report:

Home care - publicly funded and administered services received in the home.

Senior - age 65 and older.

Client or care recipient - the person who is receiving home care services.

Caregiver - family members, friends, or others who are providing unpaid care.

Provider - any paid professional or worker who provides home care services.

Personal support worker (PSW) - an unregulated worker who provides support for personal care, such as bathing, toileting, and homemaking functions. Personal support workers are employed in home care, long-term care, and hospital settings. This role is known by different names, such as home support worker or health care aide.

Long-term care - care received in an institution such as a nursing home.

Continuing care - a general term used to encompass home care, assisted living, and institutional long-term care where the sectors are not clearly separated, but seen as part of a continuum (as in Europe).

Assisted living - a type of residential living that provides supportive services, such as housekeeping, communal dining, and in some cases personal care assistance to seniors who require some help with daily living.

Community supports (or community support services) services provided in or through the community, such as transportation, shopping, house cleaning, and yard maintenance.

Vulnerable senior - someone who has some challenges with independent living due to health limitations and who may be at risk for further disability or complications. The word “frail senior” is often used to describe this population, but frailty is considered a pre-disability state.¹⁹ As many seniors receiving home care services already have disabilities, in our report we will refer to this group as “vulnerable.”

Alternate Level of Care (ALC) patients - people who no longer need intensive medical care, but who still require a lower level of care as they cannot manage independently. These patients must remain in the hospital while waiting for space to become available in another facility (such as a rehabilitation hospital or long-term care facility), or for home care supports to be put in place.

IADL - instrumental activities of daily living such as cleaning, cooking, grocery shopping, and home maintenance

ADL - activities of daily living such as bathing, eating, and toileting



Canadian governments have significantly expanded their home care programming in the last decade, and as a result the number of home care recipients in Canada has grown by 51%.⁵ This greater emphasis on home care is a result of various factors, many of which stem from governments' focus on cost-effectiveness and more efficient use of health care resources. Some research shows that home care can be less expensive than long-term care facilities if clients do not have high needs.⁷

One important factor driving the increased demand and use of publicly funded home care is the large number of hospital beds that are occupied by patients who no longer need intensive medical care, but who still require a lower level of care and cannot manage independently. This affects not only hospitals' budgets, but also the ability to admit other patients who need care. These patients, described as Alternate Level of Care (ALC), must remain in the hospital while waiting for a more appropriate place of care (such as a rehabilitation hospital or long-term care facility), or for supports to be put in place for them to return home, if possible. Many ALC patients in hospitals waiting for long-term care facility placement can be cared for at home instead if they have appropriate supports.⁷ Hospitals are working with their community partners to arrange home care services to support these patients.

In addition, as part of their health accord commitments, provinces and territories have been making specific efforts to increase short-term acute home care after discharge from hospital, short-term acute home care for mental health, and home care for people at the end of life (see

What governments promised in the health accords on page 9). These efforts are discussed in the Health Council of Canada's 2012 progress report (release date June 2012).

Despite these considerable efforts, our analyses show that many seniors with complex health conditions are not receiving the home care services they need. Our data reflects those who are already receiving home care; there is no data available on people who need home care but are not receiving it. We have tried to identify some of this invisible population by analyzing data on seniors who had experienced a fall but were not receiving home care services.

A focus on seniors

Although we recognize that home care is provided to people of all ages (see *Who else needs home care?* on page 7), more than 75% of the home care clients in the five regions we examined were seniors.

Most seniors (93%) in Canada live at home and want to stay there as long as possible.¹ One definition of successful aging is the ability to adapt well to the changes that come with growing older.⁸ Although many seniors can do this without support, an increasing number need help from both family caregivers and home care services to stay in their homes.

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What governments promised in the health accords

In the 2003 First Ministers' Accord on Health Care Renewal and the 2004 10-Year Plan to Strengthen Health Care, Canada's First Ministers agreed to provide first-dollar coverage for specific types of home care services:

- short-term acute home care after discharge from hospital consisting of two weeks of case management, intravenous medications related to the discharge diagnosis, and nursing and personal care;
- short-term acute community mental health home care consisting of two weeks of case management and crisis response services; and
- end-of-life (palliative) care consisting of case management, nursing, palliative-specific drugs, and personal care.

The Health Council of Canada has said previously that the provision of two weeks of acute home care services is not enough.¹ In addition, the accord focus on short-term acute home care alone falls short of addressing the challenges currently facing the longer-term home care of seniors.

Please see the Health Council's *Progress Report 2012* (release date June 2012) for a detailed discussion and evaluation of jurisdictional progress on these commitments.

¹ Health Council of Canada, *Health Care Renewal in Canada: Clearing the Road to Quality*. 2006, Health Council of Canada: Toronto.



The proportion of seniors in Canada, particularly those who are 85 years of age and older, is growing. A large percentage (41%) of Canadian seniors are dealing with two or more select chronic conditions,^a such as diabetes, respiratory issues, heart disease, and depression,⁹ and many are experiencing a decline in physical and/or cognitive functioning.¹ Deteriorating health can lead to disability and make it difficult to carry out essential daily activities. Seniors may also be socially isolated, which can contribute to declining health and well-being. Seniors may need assistance from home care services to help them manage their daily lives at home and to avoid or delay entrance into long-term care facilities.

Assisted living is another option for seniors who require some help with daily living activities, but not the full-time care provided in long-term care facilities. Assisted living facilities typically provide accommodation in a residential-style setting, as well as services such as housekeeping, communal dining, recreational programs, a 24-hour emergency response system, and in some cases, personal care assistance to seniors who are able to live relatively independently but require some help with daily living.¹⁰

One size does not fit all; whether vulnerable seniors and their families choose home care, assisted living, or long-term institutional care depends not only on health issues, but also on their finances, cultural values, and the family's ability to contribute to care. Family caregivers are crucial, as home care is intended to be a complement to their support.⁵

In a 2007 health care survey, nearly 80% of Canadians said they would support developing more home and community care programs.¹¹ This public interest is reflected in emerging “aging at home” strategies, in the political platforms for recent federal and provincial elections, and in the growing number of media stories about seniors and home care.

Even as the importance of home care is acknowledged, there is no shared understanding of what home care should look like for Canadian seniors—no shared vision, common principles, or collective standards—and in the absence of this, there is significant variation in what is happening across the country, such as the types and hours of publicly funded home care services that people can receive.

A growing body of research suggests that when home care is appropriately managed and properly integrated into the health care system, it can improve the health and well-being of many seniors and their families, and reduce the costs of care in hospitals and long-term care facilities.^{12, 13}

We look more closely at examples of integration and other system issues in later sections of this report. But first, we present our analysis of recent data that puts a human face on seniors receiving home care: who they are, why they need care, how many hours of publicly funded support they are receiving, and the impact on their family caregivers, many of whom are seniors themselves.

a. Health Council of Canada reports typically focus on seven high impact and high prevalence chronic conditions, which include arthritis, cancer, chronic obstructive pulmonary disease, heart disease, high blood pressure, and mood disorders including depression.

Who else needs home care?

Not just seniors need home care services. Many other Canadians under the age of 65 also face challenges in accessing high-quality home care services, including children, youth, Aboriginal peoples, and people with disabilities, severe chronic illnesses, or mental illness.

Sources for information on these populations include the following:

- *Home Care for Children with Special Needs: An Environmental Scan across Canadian Provinces and Territories*¹ by the Canadian Home Care Association;
- *Health Canada's Final Report—Health Transition Fund Project NAIOS: First Nations and Inuit Home Care*,² and
- *Mind, Body, Spirit: Promising Practices in First Nations and Inuit Home and Community care* by the Canadian Home Care Association.³

There are also differences in access to home care services between urban and rural communities. The Canadian Home Care Association discusses the delivery of home care in rural and remote regions and innovative practices in two reports, *The Delivery of Home Care Services in Rural or Remote Communities in Canada* and *A Scan of Options for Delivering Home Care in Rural, Remote, and Northern Regions of Canada*.^{4,5}

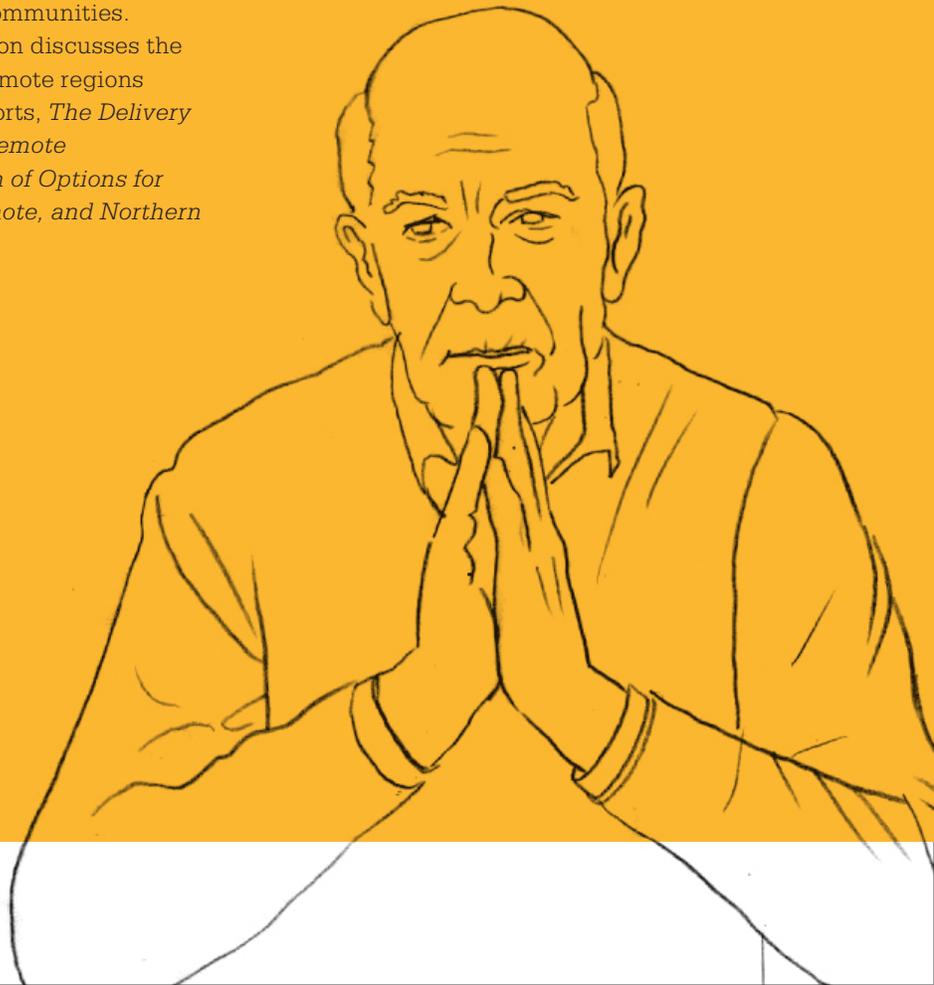
¹ Canadian Home Care Association, *Home Care for Children with Special Needs: An Environmental Scan across Canadian Provinces and Territories*. 2006, Canadian Home Care Association: Mississauga.

² Wentworth, J., *Final Report. Health Transition Fund Project NAIOS: First Nations and Inuit Home Care*. 2000, Health Canada: Ottawa.

³ Canadian Home Care Association, *Mind, body, spirit: Promising practices in First Nations and Inuit home and community care*. 2010.

⁴ Canadian Home Care Association, *The Delivery of Home Care Services in Rural or Remote Communities in Canada*. 2006, Canadian Home Care Association: Mississauga.

⁵ Canadian Home Care Association, *A Scan of Options for Delivering Home Care in Rural, Remote and Northern Regions of Canada*. 2008, Canadian Home Care Association: Mississauga.



Home care and seniors: A Canadian snapshot



We commissioned analyses of data on seniors (65+) who are receiving publicly funded home care in Canada and who have been assessed using the Resident Assessment Instrument – Home Care (RAI-HC). This assessment is used by home care professionals to evaluate the strengths, preferences, and needs of home care clients in order to develop a care plan and allocate services.

The analyses in this report are based on available RAI-HC data from five selected regions that have implemented RAI-HC as part of their home care programs: the Yukon; the Northern Health Authority in British Columbia; the Winnipeg Regional Health Authority in Manitoba; Ontario; and Nova Scotia. Data from 2010 were used for the Yukon, the Northern Health Authority in British Columbia, and Ontario; 2007 data were used for the Winnipeg Regional Health Authority and Nova Scotia, as this was the most recent valid data available at the time of writing (see *Data sources* on page 58).

All of the seniors receiving the RAI-HC assessment are considered ongoing longer-term clients, which means that they have been receiving services (or are expected to receive them) for at least 60 days.

The data in this report are not intended to be representative of all of Canada. However, they do provide a snapshot of the ways in which home care varies in different parts of Canada, as well as information on similar trends across all regions we examined.

Demographics: Who is using home care?

In all five regions we examined, the majority of home care clients are women. Approximately 40% of home care clients are over the age of 85, although in the Yukon a slightly younger population of seniors uses home care services; about 20% over the age of 85 (see Figure 1).

Roughly one-third of home care clients in our sample are married. However, there are substantial gender disparities in marital status: approximately half of the men (44–62%) are married, compared to fewer than one-quarter of the women. Married seniors may have an advantage as the primary caregiver is most commonly a spouse, although they may be vulnerable as well. Those who are unmarried or widowed typically rely on other family caregivers, usually an adult child. If vulnerable seniors have insufficient support from family caregivers, or if none are available, it can be difficult to avoid or delay moving to a long-term care facility.⁷ Across the four provinces examined, only

FIGURE 1

Profile of seniors receiving home care

Across the five regions in our sample, more than 60% of seniors receiving home care are women and more than 70% are over 75. In most regions, 20% or more have a diagnosis of Alzheimer's or other dementia.

Note: BC NHA: Northern Health Authority in British Columbia; WRHA: Winnipeg Regional Health Authority.

Characteristic (%)	Yukon (n=145)	BC NHA (n=1,356)	Winnipeg RHA (n=8,344)	Ontario (n=125,724)	Nova Scotia (n=10,493)
Female	62.8	63.1	70.2	66.9	71.3
65–74 years of age	27.6	16.6	16.5	18	19.6
75–84 years of age	50.3	44.8	43	41.4	41
85+ years of age	22.1	38.6	40.5	40.6	39.4
Male (Married)	44.4	46.1	55.3	62.4	50.5
Female (Married)	22	17.9	20.9	25.9	21.7
Overall (Married)	30.3	28.3	31.2	38	29.9
Aboriginal	12.4	8.9	1.8	0.7	0.4
Alz / Other Dementia	12.4	32.7	19.4	22.7	24.2
Heart Failure	14.5	21.2	16	12.9	14.9
Emphysema / COPD	22.1	20.5	18.2	17.2	21
Diabetes	31.7	27.2	20.9	26.4	27.3
Cancer	15.2	9.1	12.3	13.7	14.7
Stroke	16.6	21.7	18.2	18.4	17.8
Any psychiatric diagnosis	9	18.4	12.9	12.7	10.5

Source: RAI-HC 2.0 (2010 data for the Yukon, the Northern Health Authority in British Columbia, and Ontario; 2007 data for Nova Scotia and the Winnipeg Regional Health Authority.)

What MAPLe scores mean

Low Clients are generally independent, without physical disabilities, and with only minor cognitive loss. There are no problems with behaviour, the home environment, medication, or skin ulcers. Some limited home care support may be needed because of early losses of function in limited areas.

Mild Clients need only a light level of care due to some problems with instrumental activities of daily living (e.g., housework, transportation) or loss of physical stamina.

Moderate Clients are beginning to show impairments in individual functioning that may be a threat to their independence, such as problems in the home environment, difficulty managing medications, or physical disability combined with mild cognitive impairment.

High Clients are experiencing more complex problems, including challenging behaviour or physical disability combined with cognitive impairment. These people have elevated risks of nursing home placement and caregiver distress.

Very high Clients have impairments in multiple areas of function that have a pronounced impact on their ability to remain independent in the community. These include factors such as physical disability, cognitive impairment, falls, challenging behaviour, and wandering. Rates of nursing home placement and caregiver distress are highest in this group.

2–3% of seniors in our sample who receive home care are without a family caregiver. In the Yukon, nearly 10% of home care clients do not have a caregiver.

A small proportion (approximately 1–4%) of home care clients across all regions in our sample indicated that they are making economic tradeoffs between food, heat, medication, and out-of-pocket medical and home care costs.

Many seniors receiving home care have chronic conditions

Many of the seniors in our sample have been diagnosed with one or more of the following conditions: diabetes, Alzheimer’s or other dementia, stroke, heart failure, emphysema or chronic obstructive pulmonary disease (COPD), cancer, or a psychiatric condition. Although the RAI-HC includes more diagnoses, the ones noted here have a high prevalence and a substantial impact on quality of life, independence, health expenditures, and life expectancy.

It is important to note that at least 20% of seniors receiving home care in four of the regions we examined have dementia (the percentage is lower in the Yukon, likely due to a younger population of seniors, as noted earlier). People with dementia often require more intensive care because of problems with memory and decision-making. These cognitive deficits have been shown to be associated

with aggressive behaviours.¹⁴ In our analyses, we also found that cognitive impairment was associated with behavioural problems; between 6–5% of seniors in our sample of home care recipients exhibited aggressive behaviour. It can be difficult for both family caregivers and home care workers to provide care, particularly if they have not been trained to deal with aggressive behaviour.

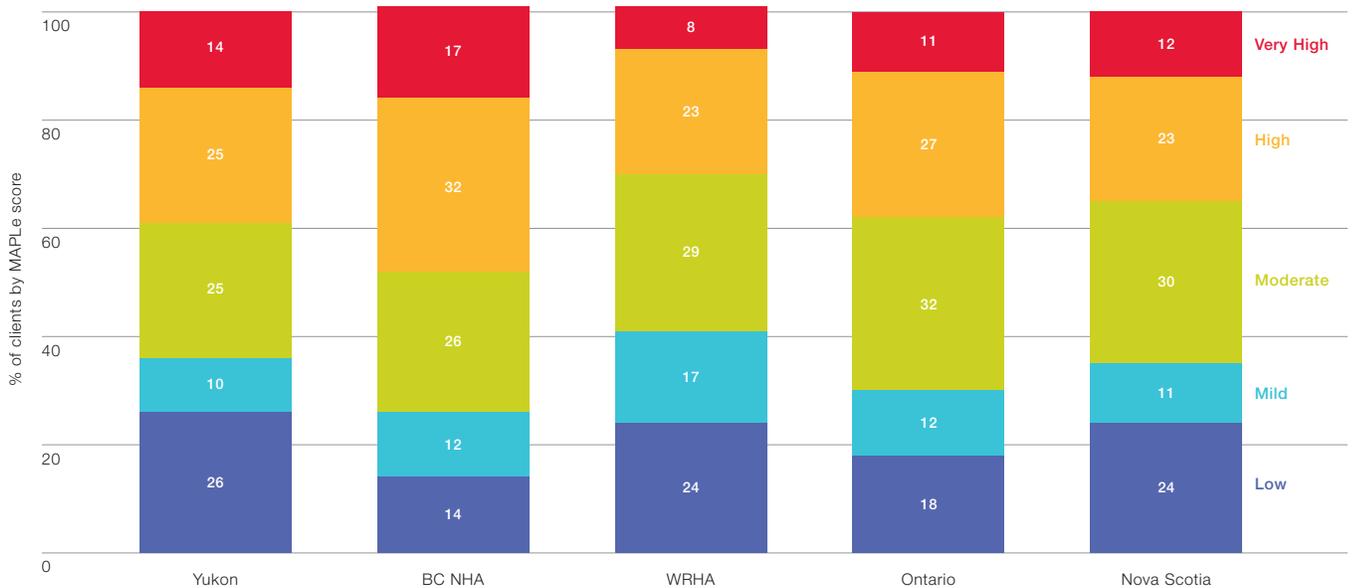
Nearly one-third of home care clients have high needs

The RAI-HC data also provide information on the level of clients’ needs through the MAPLe scoring system. (MAPLe stands for Method for Assigning Priority Levels; see *What MAPLe scores mean* on page 12.) This tool evaluates factors such as the degree of physical limitations, cognitive impairment, and behavioural problems. The MAPLe is used to help health care professionals prioritize clients’ needs and to appropriately allocate home care resources and placement in long-term care facilities.¹⁵

More than 30% of clients in each of the regions examined have a MAPLe score of high or very high (see Figure 2). Seniors with these scores have complex health problems, such as challenging behaviour or physical disability combined with cognitive impairment. Their family caregivers have the highest risk of burnout, and the seniors have a

FIGURE 2
Home care clients’ level of needs
About one-third of seniors receiving home care have high or very high needs.

Note: MAPLe scores indicate the level of care need and complexity (see sidebar for description of MAPLe levels). Regional differences are significant at $p < .0001$. Columns may not sum up to 100% due to rounding. BC NHA: Northern Health Authority in British Columbia; WRHA: Winnipeg Regional Health Authority.



Source: RAI-HC 2.0 (2010 data for the Yukon, the Northern Health Authority in British Columbia, and Ontario; 2007 data for Nova Scotia and the Winnipeg Regional Health Authority.)

high risk of placement in long-term care facilities if they and their families do not receive the support services they need.

Our analyses show that increasing levels of need are not necessarily matched by increasing levels of home care services. High-needs seniors receive, at most, a few more hours of care per week than those with moderate needs. In some regions, the hours of care do not increase at all. Due to limited funding, some provinces and territories cap the number of hours or spending on home care clients to the equivalent cost of a bed in a long-term care facility.⁵ As we will discuss in the next section of the report, this is causing significant stress for many of their caregivers.

Pain, depression, and falls are common problems

The RAI-HC analyses also showed that:

- More than half of all clients in each region experience pain, with about 15% suffering from severe pain.
- At least 30% of clients in each region require a care plan for depression. Many seniors are taking antidepressants (17–30%) and 8–19% are taking sleeping pills (hypnotics), which can increase the risk of falls.
- Approximately 16–19% of clients had experienced one fall in the 90 days prior to their evaluation, and 9–24% had suffered two or more falls.
- In the 90 days prior to their assessment, 10–20% of home care clients had visited a hospital emergency department, and at least one-quarter or more of clients in all five regions had been hospitalized.

Challenges with daily living

Analyses of RAI-HC assessments show that 95–98% of home care clients have some level of difficulty with activities such as cleaning, cooking, grocery shopping, and home maintenance (called *instrumental activities of daily living*, or IADLs). A considerable number (23–41%) need help with fundamental activities such as bathing, eating, and toileting (called *activities of daily living*, or ADLs).

What home care provides—and doesn't

When someone is referred to home care, a case manager typically meets with the client and often the family caregiver to conduct an assessment. Once someone is assessed as needing home care, the case manager coordinates care and authorizes all other home care services a client may need. The case manager continues to monitor levels of need and may make changes in the care plan as required.

All provinces and territories can provide a personal support worker and/or nurse, depending upon need. A personal support worker helps with basic daily living needs (such as bathing and toileting), and may help with a limited number of broader activities (such as the client's laundry). A nurse may provide clinical care such as changing the dressing on a wound or monitoring the client's condition. Depending on the jurisdiction and client needs, home care teams can also include occupational therapists, physiotherapists, pharmacists, nurse practitioners, social workers, dietitians and physicians.⁵

**In some regions,
the hours of care do not increase at all.**

Whether clients are provided with the equipment, supplies, and medications they need varies by jurisdiction, as does public funding of community support services such as general house cleaning, meal preparation or delivery, or help with errands.⁵

In all five regions, the RAI-HC data show that the majority of home care services (50–69%) for this population of longer-term home care clients are being provided by personal support workers (see Figure 3), although their duties vary and the services they provide may be limited by legislation, their employers’ policies, or their training and abilities.¹⁶

Although 15–24% of seniors in our sample are receiving nurse monitoring services, fewer clients are receiving other types of medical care. For example, wound care is received by fewer than 15% of clients across all five regions, while oxygen therapy is received by fewer than 12%. The remaining medical therapies (chemotherapy, dialysis, and respirator) are each received by fewer than 2% of clients.

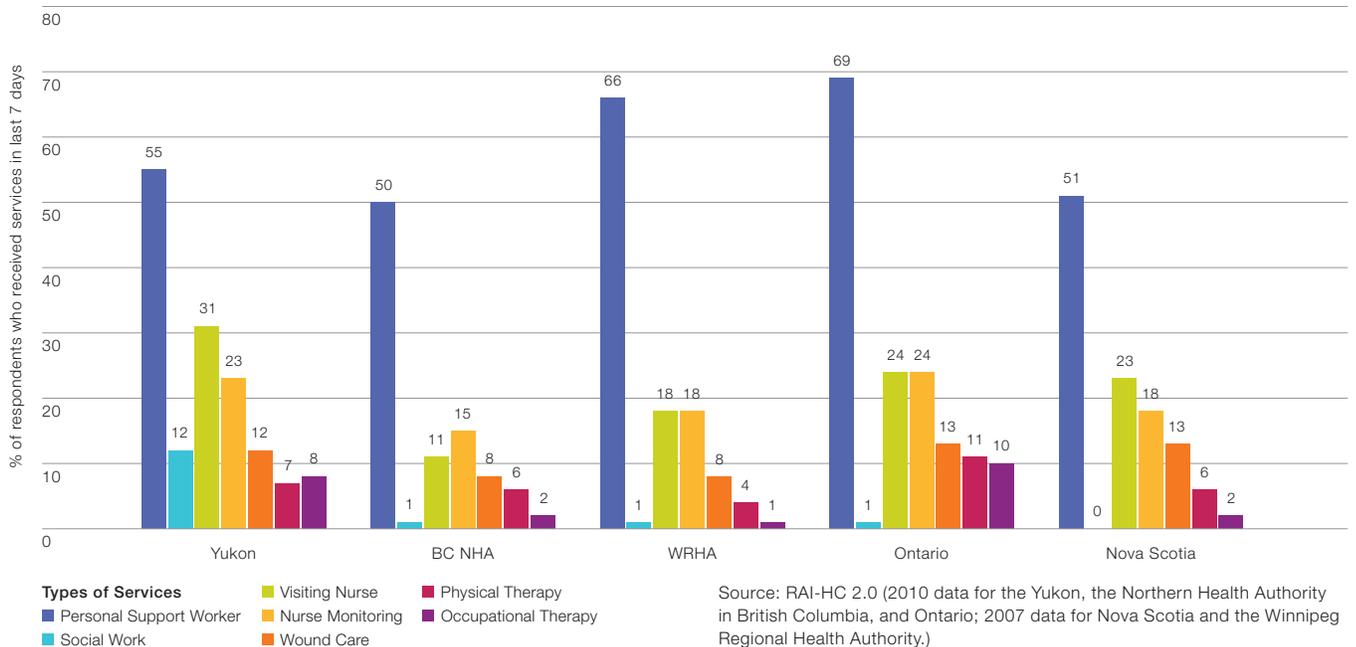
Rehabilitation services are provided to only a small proportion of home care clients in our sample, about 10% in Ontario and much less in the other regions we

examined. Although there are substantial regional differences in the availability of physiotherapists and occupational therapists, the low involvement of these professionals across all five regions is a concern given the prevalence of falls and difficulties that seniors are having with both basic and broader activities of daily living (ADLs and IADLs). The Canadian Home Care Association recently reviewed the research on the positive impacts of rehabilitation and emphasized the importance of rehabilitation services in home care.¹⁷

Other services are even more limited. Very few clients anywhere receive speech language pathology services (for stroke recovery, for example), or social work visits (with the exception of the Yukon). Data are not available on the services of professionals such as pharmacists, who help with medication management, or dietitians, who advise on disease-specific diets.

FIGURE 3
Types of services provided through home care
 Personal support workers provide at least half of all home care services to the seniors in our sample

Note: In the RAI-HC assessment, support services are divided into home health aides and homemaking services. Because most regions indicate that personal support workers provide both of these services, they have been combined to form the personal support worker category. Regional differences are generally significant at $p < .0001$. BC NHA: Northern Health Authority in British Columbia; WRHA: Winnipeg Regional Health Authority.



Quality and safety

Safe care at home When a senior is sent home from the hospital, families and providers may have concerns about whether he or she can be cared for safely at home. Home care safety involves looking at not only issues that could affect the client, but those that could affect the family, caregiver, and home care provider.

The Canadian Patient Safety Institute (CPSI) has taken the lead in exploring safety in home care by publishing a toolkit for medications management in home care settings¹ and a report on safety issues encountered in home care,² including those that are affected by the client and family's physical, emotional, social, and functional circumstances. Common safety concerns include the difficulty of following health care regulations in people's homes, and the human resources safety issues that can arise from problems with communication, transitions, and competence.² CPSI has commissioned a more detailed study of safety in home care, to be released in 2013.
patientsafetyinstitute.ca

Accreditation for home care organizations

Accreditation Canada provides external peer review of the quality of services in health service organizations based on evidence-informed standards that they develop. There are published standards for home care and home support services, as well as more general standards for medications management, for infection prevention and control, and for governance, organization, and recognition.^{3, 4} Eight provinces and territories have achieved or are working towards accreditation through the Canadian Council on Health Services; it is mandatory in Manitoba, Quebec, Newfoundland and Labrador, and the Northwest Territories. Home care programs can pursue accreditation on their own or through regional health authorities.⁵
accreditation.ca

Indicators for home care quality in Ontario

Health Quality Ontario has been mandated through the Excellent Care for All Act to develop quality improvement initiatives for community care providers. The organization is publicly reporting on some specified indicators, based on RAI-HC assessment data, that have been implemented across Community Care Access Centres in Ontario⁶
ohqc.ca

¹ ISMP Canada, VON Canada, and Canadian Patient Safety Institute, *Medication Reconciliation in Home Care: Getting Started Kit*. 2011.

² Lang, A. and N. Edwards, *Safety in Home Care: Broadening the Patient Safety Agenda to include Home Care Services*. 2006, University of Ottawa: Ottawa.

³ Accreditation Canada. *Accreditation Canada: About Us*. no date; Available from: <http://www.accreditation.ca/about-us/>

⁴ Accreditation Canada, *Qmentum Program: Standards*, in Home Care Services. 2010, Accreditation Canada: Ottawa.

⁵ Canadian Home Care Association, *Portraits of home care in Canada*. 2008, Canadian Home Care Association: Mississauga.

⁶ Health Quality Ontario. *Public reporting*. 2011; Available from: <http://www.ohqc.ca/en/index.html>.

Hospitals are the most common source of home care referrals

One-third to one-half (36–52%) of seniors across all regions examined were referred to home care by a hospital, indicating that publicly funded home care likely began after a health challenge. A detailed breakdown of the ways in which people are referred to home care is available using Ontario data (see Figure 4).

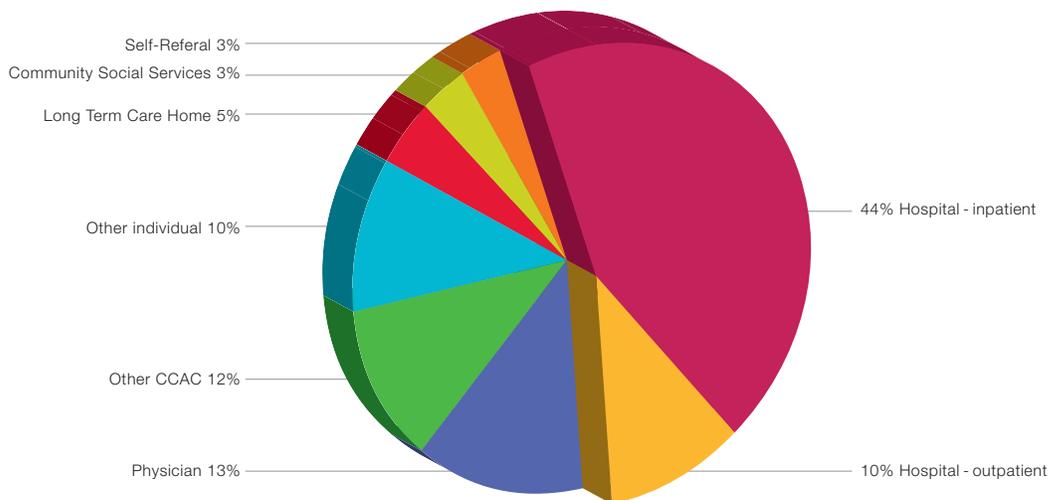
One factor in hospital referrals to home care is the Alternate Level of Care (ALC) issue, which is a significant challenge for many Canadian hospitals. An average of 5,200 hospital beds each day are occupied by patients who no longer require intensive medical care, but who still require some level of care as they are not able to manage independently.¹⁸ The majority (85%) of these ALC patients are seniors; more than one-third (35%) are 85 years or older.¹ These patients remain in hospital, sometimes for weeks or months, while waiting for space to become available in another facility (such as a rehabilitation hospital or long-term care institution) or for home care supports to be put in place.¹⁹ Remaining in hospital can have

detrimental effects on seniors, leading to further deterioration.²⁰ Transitional restorative programs can help patients to regain some mobility and functionality, enabling them to return home with supports, rather than be placed in a long-term care home (see *Transitional Restorative Care Program* on page x).

Hospitals are under pressure to reduce the number of beds being used by ALC patients to bring down costs, increase efficiencies, and improve patient outcomes. A hospital with ALC patients has fewer beds available for incoming patients with higher needs, which can lead to long waits in emergency rooms and cancelled elective surgeries.¹⁹ The experience of being stuck in an ALC bed can be both emotionally and physically detrimental to patients; it can lead to a decline in their mobility and ability to carry out daily functions independently. This is a particular concern for seniors.^{20, 21}

FIGURE 4
Sources of home care referrals in Ontario
 In Ontario, more than half of home care clients are referred through hospitals.

Note: Referral source for persons admitted for home care service, Ontario CCAC intakes only (n = 153,152 persons and 176,083 referrals) (2007). Among the five jurisdictions in our data sample, only Ontario has information available about referral sources.



Source: RAI-HC 2.0 (2007 data).

Cross-Canada data from 2007–08 shows that ALC patients stayed in hospital beds anywhere from a few days up to as long as 100 days, with a median of 10 days.¹⁸ Between 2009 and 2010, 47% of ALC patients were discharged to long-term care homes, 11% were discharged to rehabilitation facilities, 14% were discharged home with support services, and 12% went home without support. Nearly a quarter of all seniors who were ALC patients had dementia, and these seniors remained in hospital about twice as long (an average of 20 days) as those who did not have the condition.¹

Home care support is important for ALC patients who are discharged home, as many of them are still vulnerable and require varying levels of assistance. If appropriate supports for patients and caregivers are not available once patients are discharged home, then patients may be at higher risk for readmission to hospital²² or for more extensive care in long-term facilities at an earlier stage than necessary. Their family caregivers may also become overburdened and require health services themselves. This may increase the burden on the health care system and the costs of care, as well as decrease the quality of life for seniors who may no longer be able to remain at home if their caregivers cannot manage.

An Ontario study comparing home care clients to ALC patients waiting for admission to long-term care homes found that the ALC patients had higher levels of functional disability and more complex conditions. More than one-third of the ALC patients had moderate to severe cognitive impairment. The researchers of this study suggested that many of these patients could be supported at home if they had intensive home care supports. However, the findings also revealed that these ALC patients were less likely to have a caregiver living with them, or more likely to have a caregiver who was burned out and could not continue in a caregiving role. This factor alone may determine whether a patient is able to return home.²³

Initiatives such as the Home First philosophy implemented in Ontario and Nova Scotia are helping patients to return home with added supports, while they and their families make decisions about longer-term options.

The Home
Again program
is currently
expanding within
the health
region.

PROMISING PRACTICE**The Home First Philosophy**

Canadian provinces and territories are looking for ways to manage the issue of Alternate Level of Care (ALC) patients. In Ontario, the problem has been particularly acute due to large waiting lists—and long waits—for beds in long-term care facilities. In the last few years, Ontario has developed a Home First program that sends patients back to their communities and homes with intensive case management. Clients receive several weeks of enhanced home care support, allowing seniors to see how well they manage at home before they make decisions about where they wish to live long-term. Home First allows seniors to make this potentially life-altering decision over time and in a familiar setting, rather than in a stressful and disorienting hospital environment.^{24, 25}

Home First is as much a health care management philosophy as a program. Under Home First, transferring a patient from a hospital to a long-term care home is considered as a last resort only after other community options have been explored. This is better for patients and helps to reduce the demand and wait list for long-term care facilities.²⁵

Home First was first introduced in Ontario by the Mississauga-Halton Local Health Integration Network (LHIN) in 2008. The LHIN has invested significantly in expanding community support services for vulnerable seniors who were referred to long-term care after a hospitalization, but who could be cared for appropriately and safely in their own homes with enhanced home care services.²⁶

These types of improvements can lead to cost savings, improved flow through the system, and improved quality of life for many seniors. Over a two-year period, Home First programs for seniors in the Mississauga-Halton region have enabled 2,500 people to go home with support instead of staying longer in the hospital or being moved into long-term care.²⁶

All LHINs across Ontario are currently implementing Home First, although each is at a different stage of development. Each LHIN and CCAC determines the types of services and hours allotted to Home First clients, based on availability of resources and services within the region.²⁶ A *Home First Implementation Guide and Toolkit* was produced in February 2011 by the advisory body for the LHINs (*lhincollaborative.ca*).

Home Again in Nova Scotia

Capital Health, Nova Scotia's largest District Health Authority, has adopted Ontario's Home First philosophy to guide its ALC strategy and programs. In 2009, Capital Health launched the Home Again Continuing Care program, providing enhanced home care services that include:

- intensive case management;
- home support services up to 56 hours per week, to a maximum of 60 days;
- home support services through five established agencies;
- consistency in providers and assurance of a replacement when a regular provider is unavailable;
- nursing and personal services as required; and
- assessment and follow up by a rehabilitation team (occupational/physiotherapist).

A six-month pilot with 30 clients showed some encouraging results. When the program ended, the majority of clients were able to remain at home with reduced home care supports. The Home Again program is currently expanding within the health region.^{27, 28}

The Home First philosophy is quickly becoming an important layer in the health care system of the provinces where it is applied. However, it is important to evaluate whether seniors can continue to manage well at home, and for how long, once the time-limited period of intensive home care support comes to an end.

The tendency to move patients back home “quicker and sicker” to relieve mounting pressures on hospitals may lead to allocating a greater amount of resources towards short-term home care, leaving longer-term chronic needs unmet.²⁹ These short-term initiatives may also put a greater burden on caregivers, especially in the long term, if intensive supports come to an end before arrangements for ongoing home care have been made.

Do falls indicate unmet needs?

The RAI-HC provides information about seniors who are receiving home care, but there is no information in Canada to tell us how many seniors may be falling through the cracks— people who don't have home care support, but probably should.

To find out about this invisible population, we reviewed data on falls from the 2008-2009 Canadian Community Health Survey (CCHS). Falls, which can cause serious injury and disability, are an important indicator that a senior may need home care services to prevent further problems. People with a history of falls have a significantly increased risk of falling again; about 40% of home care clients who have fallen once, will fall again over a 90-day period, and about two-thirds of clients who have fallen multiple times will fall again during the same time period.¹

We looked at data on seniors who said they are not receiving any services (either publicly funded or paid from their own pockets) to help with activities such as personal care, medical care, or homemaking, which are typically included as part of home care services. Only a small proportion (15%) of these seniors had some support from family caregivers.

Of the seniors who said they are not receiving any services at home (see Figure 5):

- Nearly one in five (18%) had fallen at least once in the last 12 months.
- Two-thirds (63%) had suffered an injury due to their fall, and 39% of these seniors received medical attention.
- Almost one in five (18%) seniors who received medical attention had been hospitalized, and 43% of these people were continuing to receive follow-up medical care—but they were not receiving home care services to help them recuperate and prevent future falls.

Home care services could also play a part in preventing these falls from occurring in the first place if seniors at risk are identified. Following a fall, home care services can help seniors to recuperate and prevent future falls.

While these data are just one potential indicator of unmet needs, they do raise questions about gaps in assessment to identify seniors at risk. For example, Denmark offers all seniors aged 75 and over a twice-yearly assessment (see *Integrated Home Service, Denmark* on page x).

¹ Morris, J.N., et al., *interRAI Clinical Assessment Protocols (CAPs). For use with community and long-term care assessment instruments*. 2008, Ottawa: interRAI Corporation.

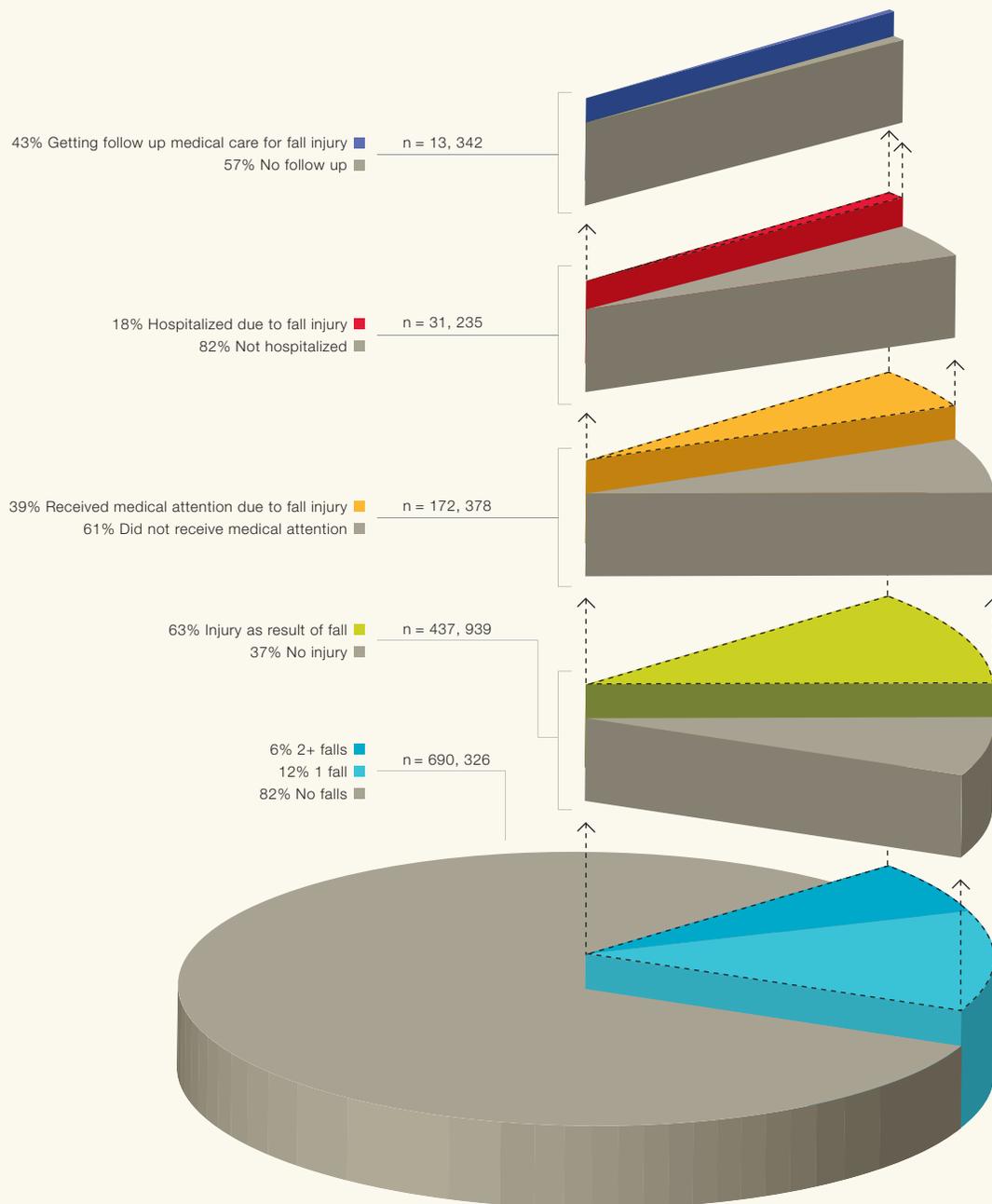
FIGURE 5
Falls in seniors not receiving home care

Sample: This sample is based on respondents aged 65 and older who responded that they did not receive professional assistance at home due to a health condition or limitation.

Source: Statistics Canada, CCHS: Healthy Aging Component, 2008–2009.

Question asked: During the past 12 months, did you receive short-term or long-term professional assistance at home, because of a health condition or limitation that affects your daily life, for any of the following activities? Include any services provided by professionals. Exclude assistance from family, friends, or neighbours.

1. Personal care such as assistance with eating, dressing, bathing, or toileting
2. Medical care such as help taking medicine or help with nursing care (for example dressing changes or foot care)
3. Managing care such as making appointments
4. Help with activities such as housework, home maintenance, or outdoor work
5. Transportation, including trips to the doctor or shopping
6. Meal preparation or delivery
7. None – if answered “YES”, then they are not receiving professional services (n = 3,864, 716)
8. Other



Home care varies widely across Canada

There is significant variation in home care across Canada, as well as within provinces and territories. There are differences in eligibility, the types and amounts of services that are provided, and whether clients need to pay for a portion of their services. This variability may lead to inequities in both access to and quality of home care services.⁵

Publicly funded home care programs are planned and delivered either directly by the provincial or territorial government, or by regional health authorities. All provinces and territories provide publicly funded needs assessments and coordination of home care services through case managers. In some regions, home care providers are public employees; others use a mix of public employees and contracts with agencies. These agencies could be not-for-profit (which may be receiving public funding) or for-profit (which are not receiving public funding unless they are awarded a contract to provide home care services).⁵

Do clients pay?

- In Ontario, Manitoba, Quebec, Prince Edward Island, the three territories, and in federal programs,^b there are no income tests or direct fees for home care services.
- In the remaining six provinces (British Columbia, Alberta, Saskatchewan, New Brunswick, Nova Scotia, and Newfoundland and Labrador), professional and often personal care services are covered by provincial plans, while direct fees based on income are generally attached to personal and community support.
- There are subsidized fees for community support services such as respite, adult day programs, homemaking, and meal delivery services in most provinces and territories where they are available.⁵

The role of community support services

Helping someone to live and age successfully at home requires programming beyond physical and medical care needs. Home care case managers often provide clients with referrals to organizations that provide other support services, such as adult day programs, respite care, housework, transportation, and food preparation/delivery. These services promote independence and are necessary to maintain a person's physical and psycho-social well-being, as well as that of their caregiver. In addition to practical support, these services also provide people with connections to their community, reducing their social isolation.³⁰

RAI-HC data on community support services are limited, but they do indicate that 9–18% of seniors in our sample are receiving food delivery (such as Meals on Wheels), while only 1% or fewer are visited by a volunteer.

In many regions across Canada, community support services are provided through some form of government subsidy, with most requiring an additional out-of-pocket co-payment by the recipient.⁵ Although a case manager refers clients to these community services or provides options from which to choose, it is often up to the client—or more often the caregiver—to seek out these services and make arrangements themselves. This may not happen if caregivers are already overburdened by other duties.

b. Federal programs are the First Nations and Inuit Health Branch, Veterans Affairs Canada, Canadian Forces Health Services, and the Royal Canadian Mounted Police.

Coordination by a single point of contact can make it easier to access these services. As one example, the Waterloo-Wellington Community Care Access Centre (CCAC) in Ontario offers a referral form with a description of the community services offered. Once the form is filled in by the client or caregiver, the CCAC coordinates the receipt of services.³¹

Community services such as grocery shopping, meal delivery services, and basic house cleaning can help with the transition from hospital to home.³² One such example is the Veterans Independence Program of Veterans Affairs Canada, which offers various community support services such as housekeeping, grounds maintenance, and transportation, in addition to personal care and nursing services, to eligible veterans.³³ When surveyed, clients of this program said they believed that services such as housekeeping and meal preparation were helping them remain at home and out of long-term care facilities.³⁴

Apart from this study, community support services have not been given much attention in the home care research or literature. More research on their impact is needed to determine the role of such supports in home care. As we will discuss later in this report, it has been suggested that the inability to carry out activities such as house cleaning, shopping, and meal preparation is a tipping point for admission to long-term care facilities, particularly for those without family caregivers to support them at home^{7, 35, 36} or without the option of moving to an assisted-living facility.

Early assessments would help to identify seniors at risk. The RAI suite of assessments is one way of doing this; it includes an instrument for community health assessment (RAI-CHA) that is designed to assess generally healthy

seniors and identify those who may be in need of further assessment or services to stabilize early decline.³⁷ This assessment is currently being implemented in Ontario among clients of community support services. When linked to hospital data, it may also lead to research that connects community support services to health resource utilization.

IN SUMMARY

In this section we discussed the profile of seniors who are receiving home care, the types of services they are receiving, and the intensity of their needs. The number of home care clients who have a MAPLe rating of high or very high is a concern, as these ratings are associated with a higher risk of caregiver burnout and placement in a long-term care facility.

In order for these clients to remain at home—either longer-term or while waiting for placement in a long-term care facility—more resources would need to be allocated to ensure that both clients and family caregivers receive the care and support they require. This is not always the case. Due to limited resources and funding, many provinces and territories cap the number of hours of home care that are provided, even as clients' needs increase.⁵ The result is that their family caregivers—many of whom are also seniors—end up carrying the brunt of the burden and are becoming more and more distressed, as we will see in the next section.

Early assessments would help to identify seniors at risk.

Palliative Care

According to 2008 data from Statistics Canada, two-thirds (67%) of deaths in Canada occur in hospitals,¹ even though many people would prefer to die at home.²

Although this report does not focus specifically on palliative (end-of-life) home care, it is an important part of any discussion about home care and seniors. The RAI-HC analyses show that home care costs and resources for seniors who have less than six months to live are roughly double what are required for home care recipients who are not dying (see Figure 6).

In 2004, provinces and territories agreed to provide first-dollar coverage for case management, nursing, personal support, and palliative-specific medications as part of their palliative home care programs (see *What governments promised in the health accords* on page x). The federal government further committed to supporting the Employment Insurance Compassionate Care Benefit, which provides up to six weeks of financial support and job security to qualifying caregivers who provide care and support to their dying loved ones at home. Most provincial and territorial governments subsequently amended their labour laws to align with the federal program and to provide employment protection for leaves of absences.

In 2006, the Canadian Hospice Palliative Care Association,² in collaboration with the Canadian Home Care Association, published recommendations for gold standards in palliative home care to help guide provinces and territories as they enhance their existing home care programs. The recommendations stress the importance of partnerships and collaboration between team members, intensive case management, a philosophy of providing services based on needs, and continued monitoring and evaluation of quality. Standards included:

- adopting strategies that will give people 24/7 access to hospice palliative home care—including appropriate pharmaceuticals and equipment—allowing them to feel confident that they can choose to die at home;

- establishing interdisciplinary palliative care teams;
- supporting ongoing hospice palliative care education for members of the health care team and family caregivers;
- investing in home care case management and information systems that support the interdisciplinary teams and facilitate evaluation; and
- supporting ongoing research into innovative practices for hospice palliative care at home, including the cultural, ethical, and spiritual aspects of care.

In a 2010 report to the Senate on the status of palliative care in Canada, the Honourable Sharon Carstairs noted that a “good system” would provide comprehensive supports to the person dying and to their caregivers and reduce the financial and psycho-social impacts, allowing them to continue living their own lives.³

In 2011, the Parliamentary Committee on Palliative and Compassionate Care also made a number of key recommendations, including that Canadians should have the right to home care, long-term care, and palliative care, that the Compassionate Care Benefit should be expanded and made more flexible, and that a refundable tax credit and a Canada Pension credit should be established for family caregivers to protect against the high costs of caregiving.⁴

¹ Statistics Canada, *CANSIM Table 102-0509: Deaths in hospital and elsewhere, Canada, provinces and territories, annual*, S. Canada, Editor. 2008: Ottawa.

² Canadian Hospice Palliative Care Association, *The Pan-Canadian Gold Standard for Palliative Home Care*. 2006: Ottawa.

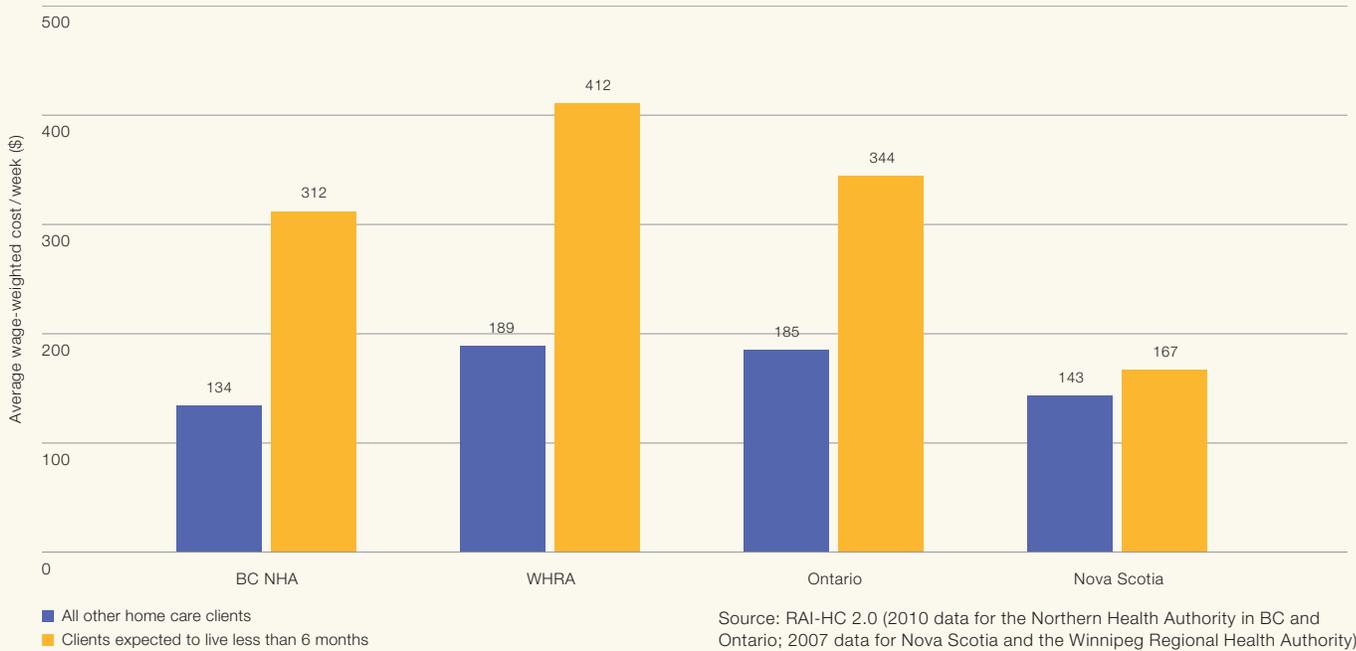
³ Carstairs, S., *Raising the bar: A roadmap for the future of palliative care in Canada*. A report to the Senate of Canada. 2010.

⁴ Parliamentary Committee on Palliative and Compassionate Care, *Not to be Forgotten: Care of Vulnerable Canadians*. 2011.

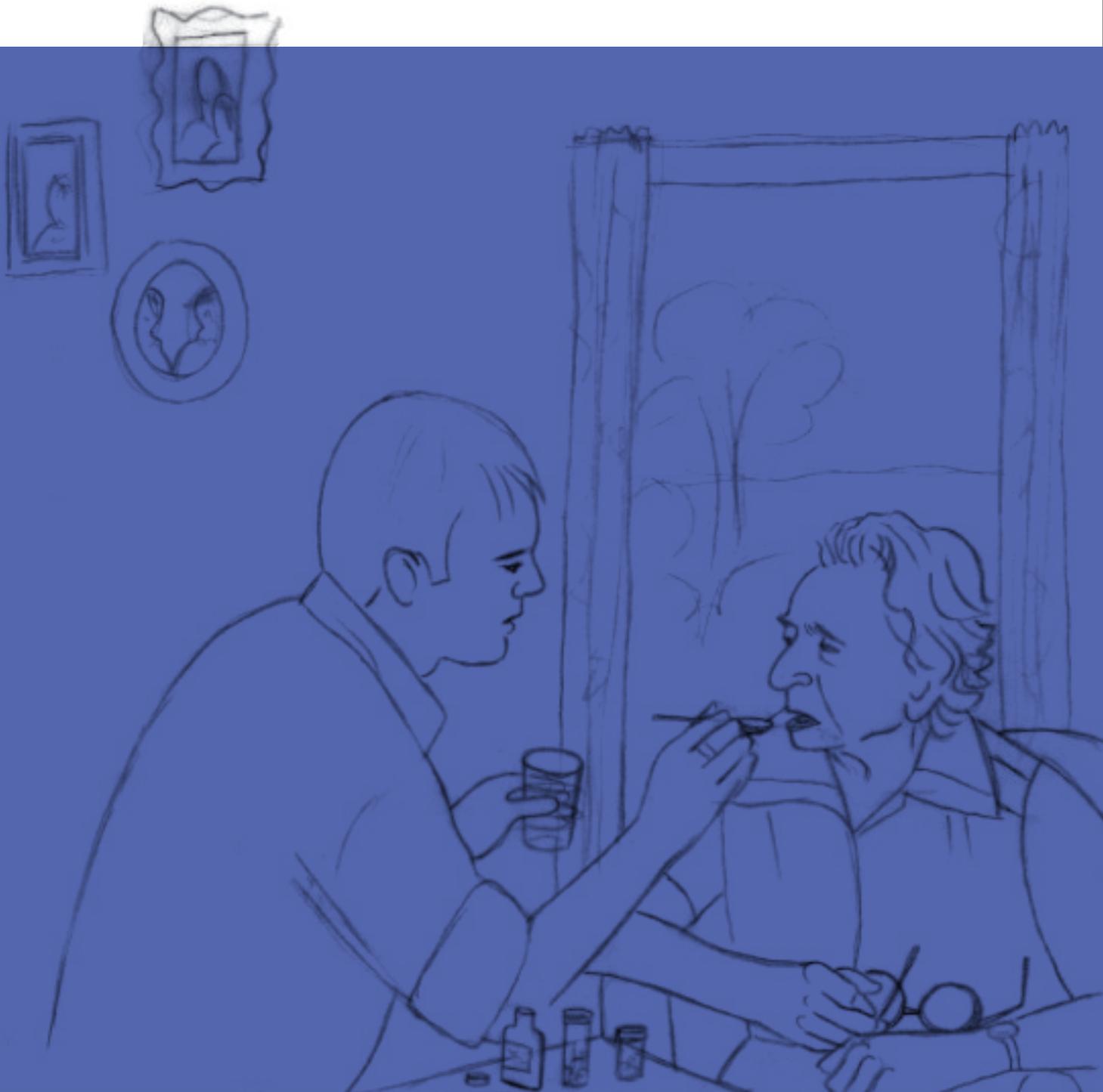
FIGURE 6

Average costs per week of home care services for seniors
Home care expenditures are highest when seniors are near the end of their lives.

Note: Regional differences are significant at $p < .0001$. BC NHA: Northern Health Authority in British Columbia; WRHA: Winnipeg Regional Health Authority. Those expected to live less than 6 months are not in a designated palliative care program. For example, cancer patients receiving palliative care are not included in this sample.



Family caregivers



Family caregivers are often described as the backbone of the health care system as they are vital to health care, yet invisible and often vulnerable themselves. The role of a caregiver can begin suddenly due to a health crisis, and typically without training or experience.³⁸

Home care services are designed to complement the care provided by caregivers, not to replace them.⁵ Home care providers help caregivers provide health and personal care (such as transfers, bathing, toileting, and administering injections), provide care when the caregiver is unavailable, and provide a break from caregiving duties, which families typically use to complete tasks such as grocery shopping and other essential errands.

Being able to stay in one’s home with their loved ones can contribute to maintaining quality of life for a vulnerable senior, and contribute to the family’s peace of mind. However, if a caregiver experiences physical and emotional stress or becomes physically injured, and is unable to continue his/her duties as a caregiver, then the quality of care and life for the senior and the caregiver can be jeopardized.

There is also a financial strain which accompanies becoming a caregiver—it may mean loss of income, additional costs for equipment, supplies, and medications, or paying for additional help.

Who is providing the care?

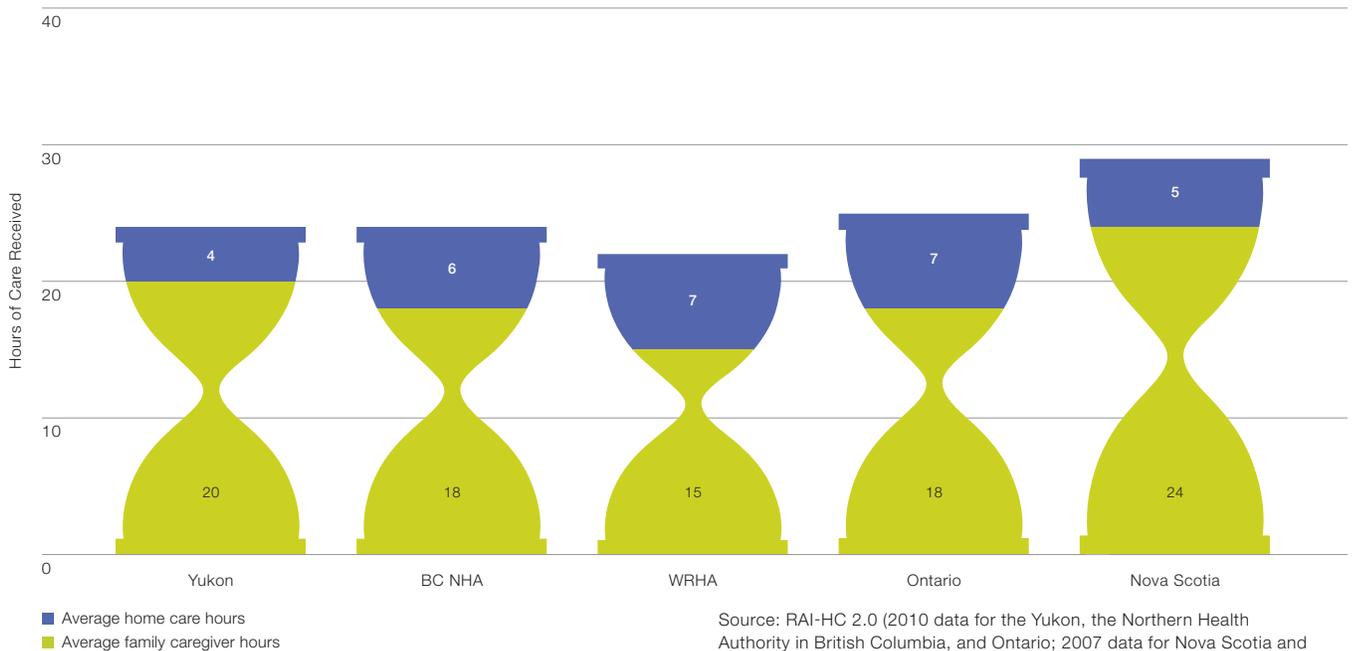
In 2007, 2.7 million Canadian family caregivers over the age of 45 were helping seniors with long-term health conditions. Three-quarters of caregivers were aged 45–64, while one-quarter were seniors themselves. Nearly 60% of these family caregivers were women, and 57% of caregivers were employed.³⁹

According to CIHI, 98% of home care recipients have a caregiver, most often a family member.⁴⁰ The bulk of care is being provided by family caregivers, about 70–75% in our sample (see Figure 7). Nearly half of caregivers in the Canadian Community Health Survey reported that they provided care to two or more care recipients.

FIGURE 7
Average hours of care in a week provided by family caregivers and home care services

Family caregivers provide roughly three-quarters of the care to seniors, while home care services provide approximately one-quarter.

Note: Regional differences in mean formal hours and mean informal hours are significant $p < .0001$. Hours of care capture the previous 7 days prior to the assessment. BC NHA: Northern Health Authority in British Columbia; WRHA: Winnipeg Regional Health Authority.



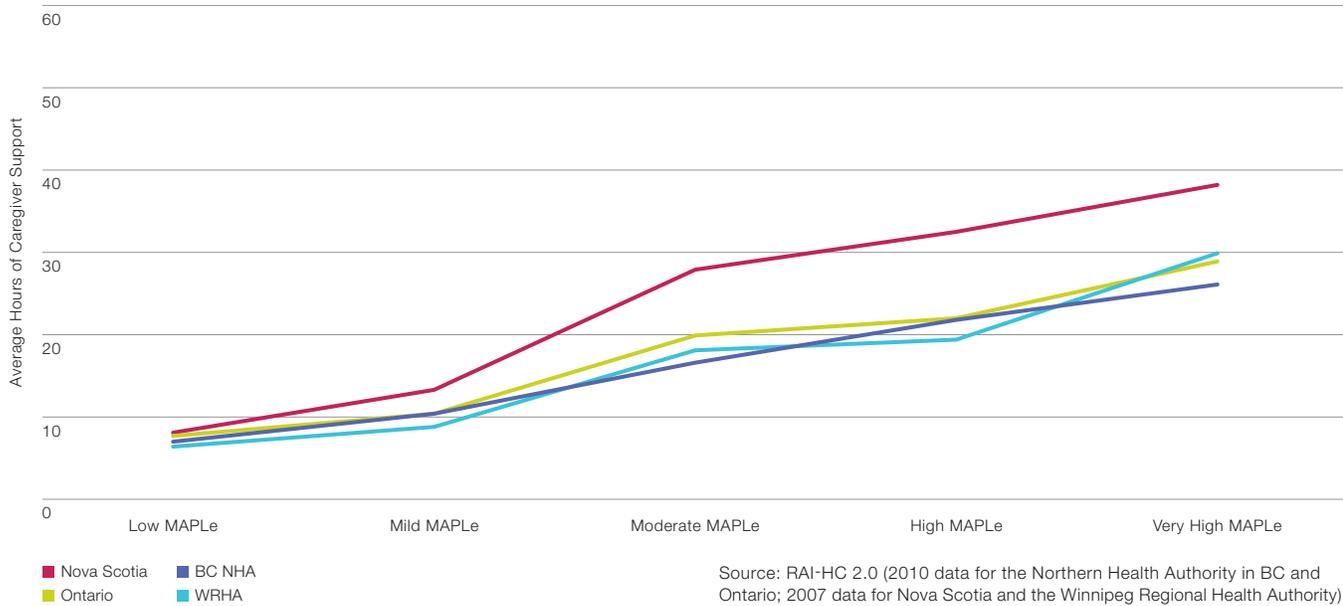
Source: RAI-HC 2.0 (2010 data for the Yukon, the Northern Health Authority in British Columbia, and Ontario; 2007 data for Nova Scotia and the Winnipeg Regional Health Authority.)

FIGURE 8A

Average hours of family caregiver support in a week, related to seniors' level of needs

As seniors' needs increase, so do their caregivers' hours of support.

Note: MAPLe level is strongly associated with mean hours of informal support in each region ($p < .0001$). Hours of care capture the previous seven days prior to the assessment. BC NHA: Northern Health Authority in British Columbia; WRHA: Winnipeg Regional Health Authority.



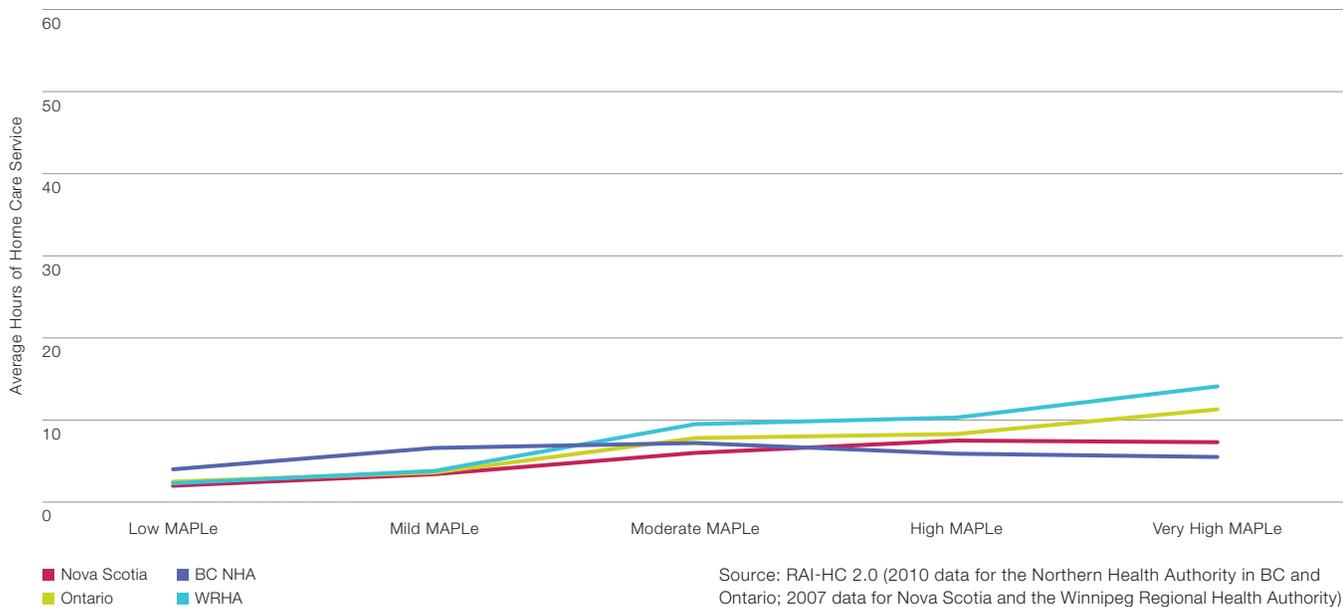
Source: RAI-HC 2.0 (2010 data for the Northern Health Authority in BC and Ontario; 2007 data for Nova Scotia and the Winnipeg Regional Health Authority).

FIGURE 8B

Average hours of home care services in a week, according to seniors' level of needs

As seniors' needs increase, hours of home care increase very little, if at all.

Note: Hours of care capture the previous seven days prior to the assessment. BC NHA: Northern Health Authority in British Columbia; WRHA: Winnipeg Regional Health Authority.



Source: RAI-HC 2.0 (2010 data for the Northern Health Authority in BC and Ontario; 2007 data for Nova Scotia and the Winnipeg Regional Health Authority).

FIGURE 8C
Percentage of seniors with distressed family caregivers, related to seniors' level of needs

The proportion of distressed caregivers increases steadily as seniors move from low to high levels of need, and spikes when seniors have very high needs.

Note: MAPLe level is strongly associated with the rates of caregiver distress in each region ($p < .0001$). BC NHA: Northern Health Authority in British Columbia; WRHA: Winnipeg Regional Health Authority.

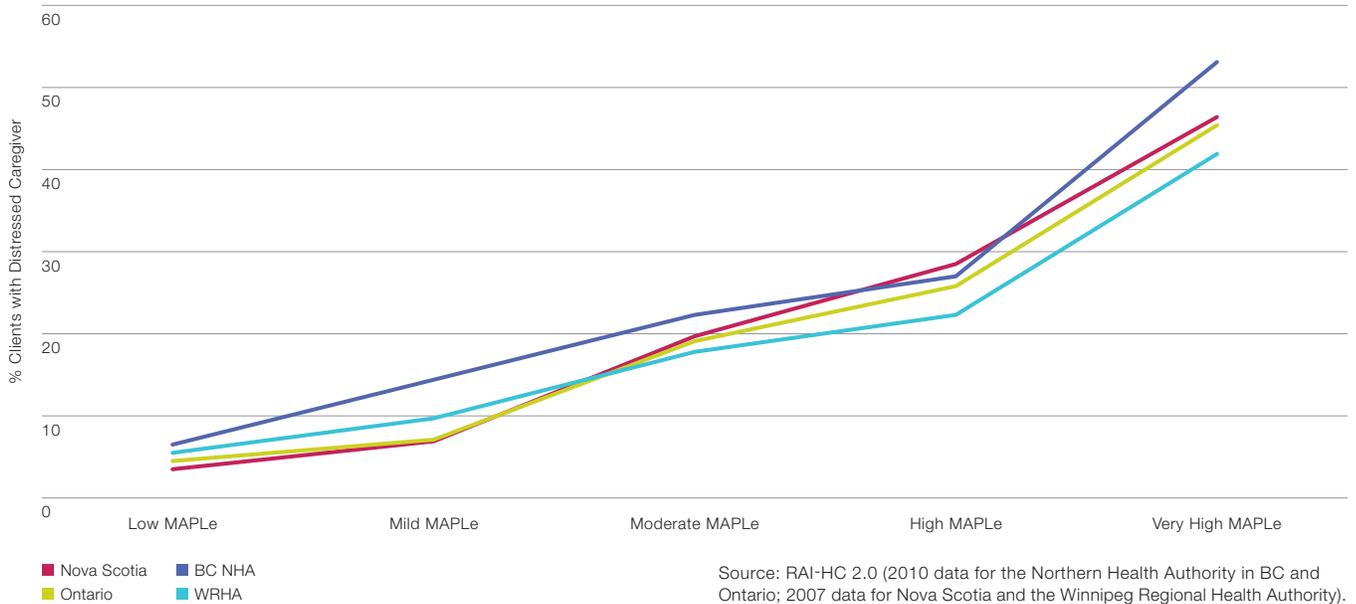
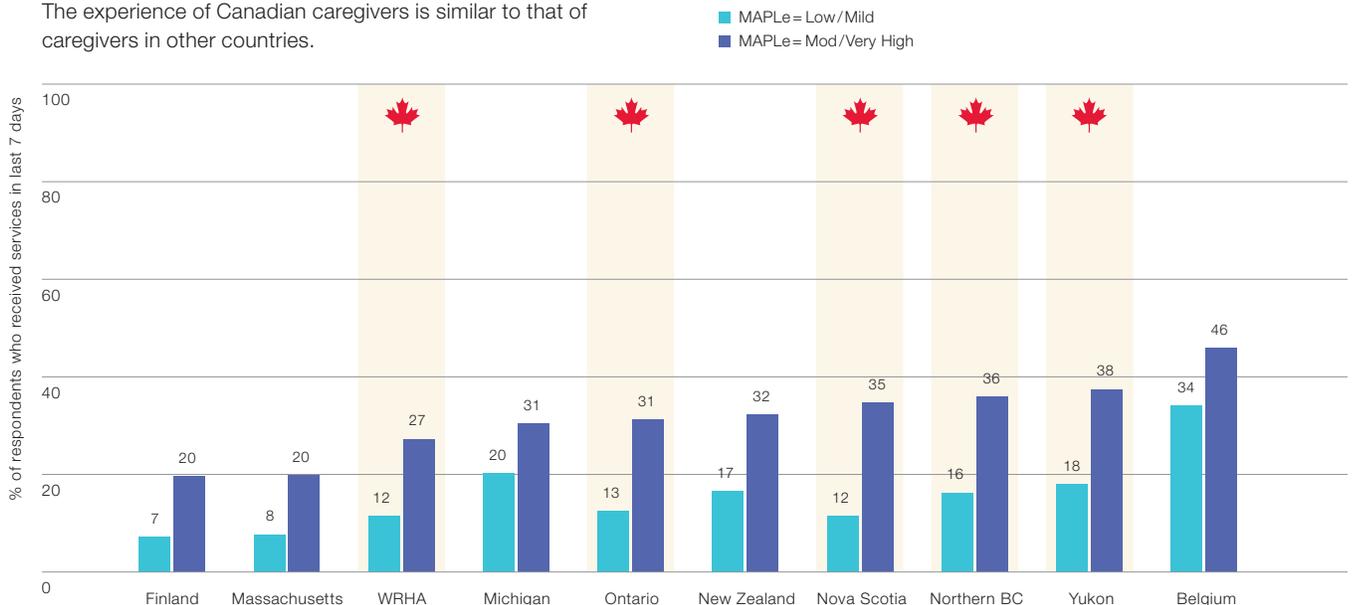


FIGURE 9
Rates of caregiver distress in Canadian and international jurisdictions

The experience of Canadian caregivers is similar to that of caregivers in other countries.

Note: WRHA: Winnipeg Regional Health Authority.



Sources: Canadian data - RAI-HC 2.0 (2010 data for Northern BC and Ontario; 2007 data for NS and WRHA). International data were provided courtesy of interRAI members in Finland, New Zealand, Belgium, and the United States to allow for a comparison of caregiver distress rates within MAPLe levels. The New Zealand (n = 820) and Belgium (n = 2,300) results are both obtained from pilot implementations

conducted in 2009. The Michigan (n = 3608) and Massachusetts (n = 2101) samples are from RAI-HC assessments among Medicaid clients in 2008. The Finland (n = 3601) sample is based on RAI-HC assessments done by home care agencies collaborating with the Finnish Institute for Health and Welfare in 2009.

The impact of caregiving

In the 2008–2009 Canadian Community Health survey, respondents over the age of 45 were asked what types of support they provided to other people. Those who said they helped people with a health condition or limitation primarily offered transportation or help with house activities. Respondents said they provided assistance for the following activities:

- 71% helped with transportation
- 51% helped with house activities
- 39% helped with meals
- 35% helped with managing care
- 32% helped with personal care
- 27% helped with medical care

These respondents were then asked about the impact of caregiving on their lives (see Figures 10A-10D).

FIGURE 10A

Benefits of caregiving

Most caregivers said that caregiving offered rewards such as personal satisfaction and a closer relationship with the senior in their care.

Note: Numbers may not sum to 100% due to rounding.

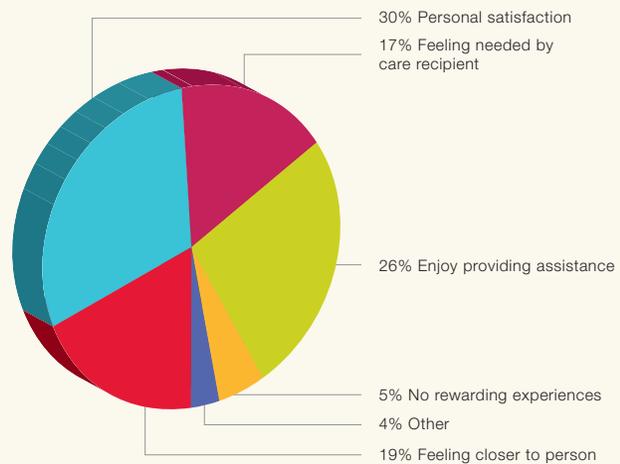


FIGURE 10B

Challenges of caregiving

More than half of caregivers report experiencing difficulties in caregiving. For many it is emotionally demanding, creates stress, and takes away time from other activities.

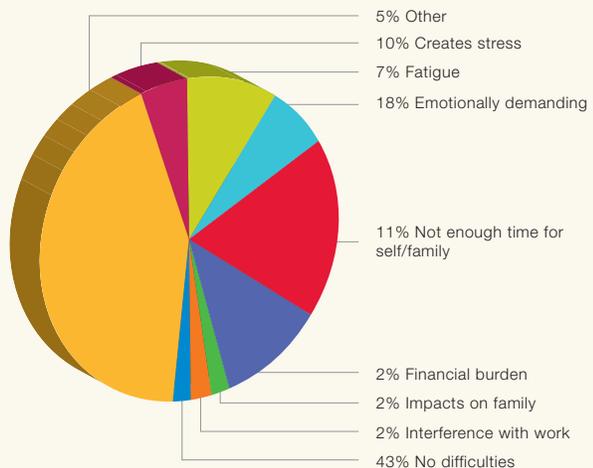


FIGURE 10C

Impact of caregiving on caregivers' work situations

A total of 13% of caregivers reported that their work situations were impacted by caregiving. More than 50% of caregivers whose work was impacted reported they needed to reduce or modify their work hours in order to accommodate caregiving, and nearly one-third used their sick days and vacation days to do this.

Note: n = 727,055. This is a weighted sample size based on the Canadian population who stated they provided assistance to those in need and said their work was impacted by care giving activities (13.2% of caregiver sample).

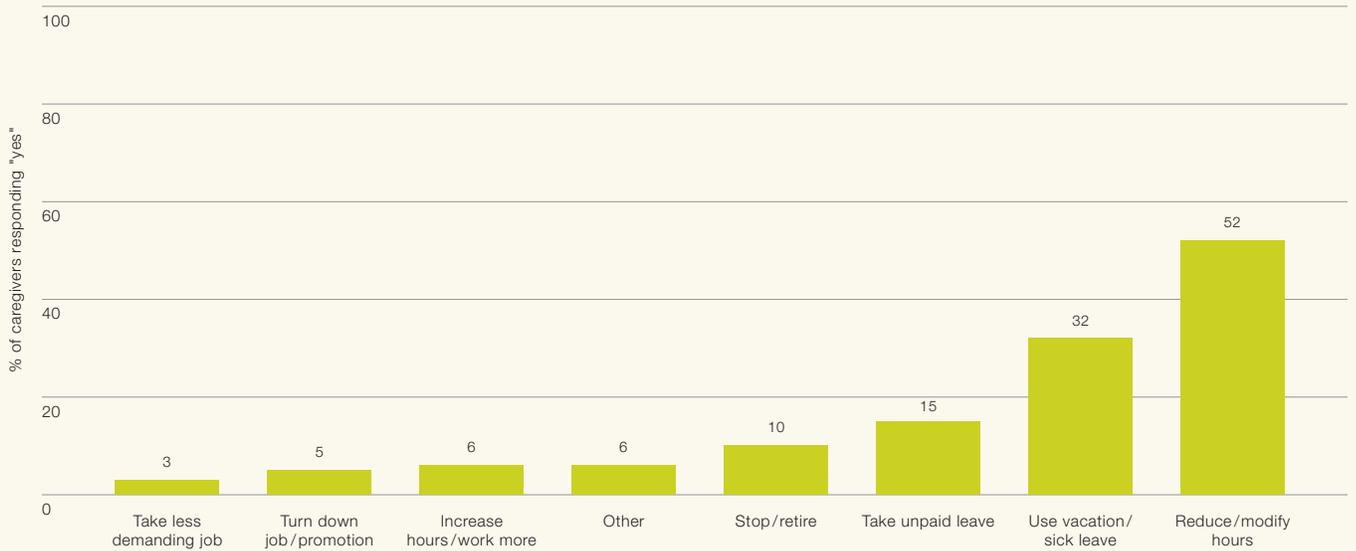
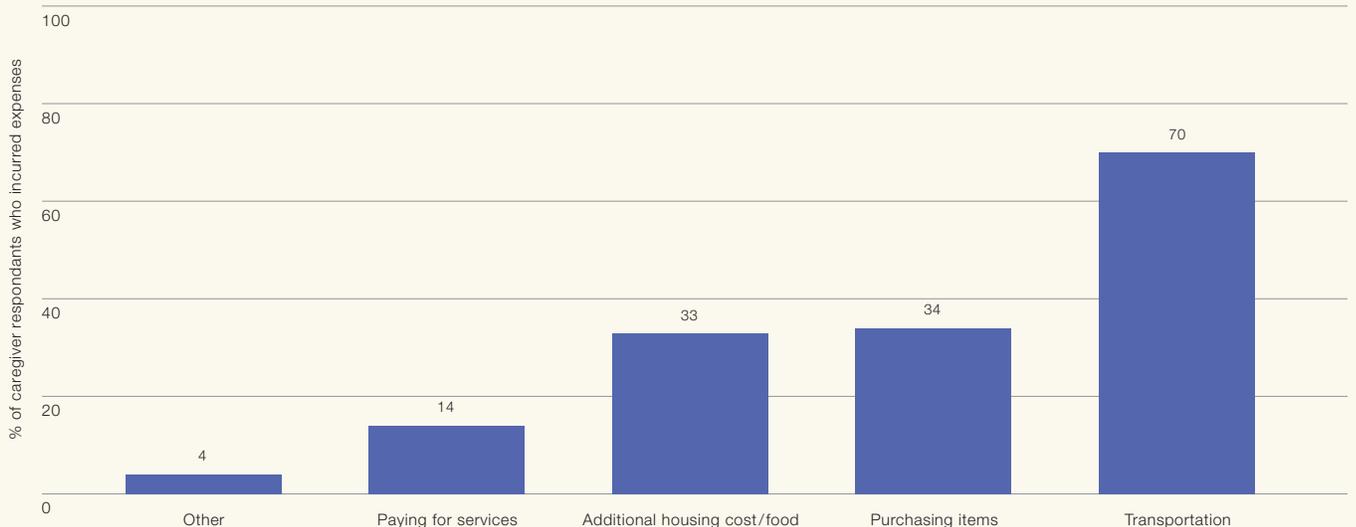


FIGURE 10D

Financial impact of caregiving

More than two-thirds (70%) of caregivers who incurred out-of-pocket expenses did so for transportation.

Note: n = 2,428,202. This is a weighted sample size based on the Canadian population who stated they provided assistance to those in need and said they incurred out-of-pocket expenses due to caregiving activities (41.7% of the caregiver sample).



Caregivers are most often women.⁴¹ Our RAI-HC analyses showed that if a home care client is married, spouses are most likely to be the primary caregiver (74%), while nearly one-quarter (23%) of married home care clients are primarily cared for by an adult child. If home care clients are not married (single, divorced, or widowed), they are most likely to be cared for by their adult children (74%); other relatives are the primary caregivers for 13%^c of home care clients. Between 39% and 50% of clients in our sample live with their primary caregivers. Friends and neighbours are much less likely to be primary caregivers.

Family caregivers provide a variety of kinds of support. They report helping most with transportation and household activities (see *Impact of caregiving on page 32*). Caregivers also help home care providers. For example, every time a new home care provider enters the home, a caregiver needs to explain the care recipient's routine and preferences, and help orient the provider. In addition, a caregiver may help a home care provider by organizing medications to be given to the client, or with tasks such as lifting or moving the client from a bed to a wheelchair (which can place the caregiver at risk for injury). Caregivers also monitor the care that is provided to ensure that home care meets their needs and preferences—both the client's and caregiver's—and that tasks are completed effectively.⁴²

Family caregivers, particularly spouses, are often seniors themselves and may have their own health problems. One-third of caregivers in the Canadian Community Health Survey reported having at least one selected chronic condition and about one-quarter reported having two or more.

A review of caregiver literature suggests that older caregivers who experience chronic stress are at a greater risk for injury or for aggravating pre-existing health issues, and their activities are limited as a result of their caregiving responsibilities. One recognized factor that can put

caregivers at risk is the lack of access to resources and services. Recommendations resulting from this review included the screening and monitoring of caregivers, developing support and health promotion services, and recognizing their contributions.⁴³

One issue that needs to be considered is the relationship between the caregiver and the person in need of care. It has been suggested that in a limited number of cases, perhaps due to the multiple stresses involved in providing care, a caregiver may become abusive.⁴⁴ Elder abuse can include abandonment, financial exploitation, neglect, and physical abuse. In Canada, of the nearly 7,900 reports of violence against seniors in 2009, about one-third were committed by a family member, although there is no information on whether family members were caregivers.⁴⁵ Systematic reviews of elder abuse have identified various interventions that can be undertaken to recognize abuse as well as educate and help seniors in abusive relationships.^{46, 47}

The Special Senate Committee on Aging recommended that the federal government increase research support for issues of neglect and abuse, and include these issues as part of government staff training.⁴⁴ In October 2011, the Government of Canada announced that it will fund pan-Canadian projects that target elder abuse.⁴⁸

c. This analysis of percentage of caregivers for married and unmarried clients is based on pooled data across the five regions, but should not be interpreted as representative of Canada, since the majority of the sample comes from Ontario. The remaining analyses of RAI data are not pooled.

A CAREGIVER'S STORY

Sandra Miller*

Sandra Miller's* husband Tom was diagnosed with Parkinson's disease in 1997, after several months of headaches and confused behaviour at his work. He took early retirement two years later, and managed on his own during the day for several years while his wife continued to work. In 2004, Tom's condition worsened and Sandra decided to retire. They sold their urban home and moved to a smaller community.

For a few years, Sandra was able to continue as her husband's caregiver, without home care support. But as Tom's Parkinson's symptoms became more severe—particularly dementia and incontinence issues—she struggled to manage on her own. Her husband began to have paranoid hallucinations, and would wander outside the house when she was sleeping. After several exhausting and stressful months, which had clearly taken a toll on Sandra's own health, their family doctor organized home care support services. Without this help, he told Sandra, he would soon have two seriously ill patients on his hands.

In 2009, Sandra was initially approved for two hours of home care support every day. But this was not enough time for her to leave the house for doctors' appointments or grocery shopping, particularly since she was also providing care for her mother, who has cancer. The agency and personal support worker agreed to adjust the hours to weekdays only, while family and friends helped out when they could on weekends. Sandra says she was lucky to have received the same personal support worker each time, a man her husband liked and trusted, which made a difference to her peace of mind. The personal support worker helped her 220-pound husband to bathe and shave, and provided the support he needed, from meals to toileting, while Sandra was out.

Sandra says she is grateful for the 14 hours a week of home care that she received, but says it was simply not enough. Earlier this year, after a few months in which Tom's dementia-related paranoia and aggression became worse, the family doctor suggested it was time to move him into a nursing home. Between Tom's medication schedule (more than 60 pills a day), frequent toileting habits, and dementia, Sandra says she never slept for more than three hours at a time. For a time, she paid for private support services at night in order to get a good night's sleep, but that was hard on their finances. Sandra's home care case manager recommended using residential respite services for Tom to give her a break, but nothing was available in their region.

Sandra believes that Tom could have stayed at home with her if they had received additional night care and respite care. She continues to serve as the primary caregiver for her mother.

* Names have been changed

Many Canadian caregivers are highly stressed

As described earlier, MAPLe scores indicate the level of physical and cognitive limitations of existing or potential home care clients, as well as their need for support. According to our RAI-HC analyses, as MAPLe scores increase, the average hours of care provided by a family caregiver increases significantly (see Figure 8A). In contrast, the hours of publicly funded home care increase very little (see Figure 8B), stopping at a maximum of 7–14 hours per week.

The RAI-HC also measures caregiver distress as someone's inability to continue providing care, and their feelings of stress, depression, and anger. Not surprisingly, the level of family caregivers' distress begins to spike once their loved one reaches high and very high MAPLe levels. In our sample, about 40–50% of people with very high MAPLe scores have distressed caregivers (see Figure 8C).

When Canadian data is compared to RAI-HC data from other countries, it is clear that caregiver distress is a common experience internationally (see Figure 9).

In other research, CIHI found that levels of distress were higher for those who provided more than 21 hours per week of care, and for those who were caring for people with depression, cognitive deficits, or behavioural problems.⁴⁰ Our analyses confirmed this. RAI-HC analyses tell us that as cognitive performance declines, behavioural problems increase. Caregivers of clients with higher MAPLe scores are often dealing with cognitive deficits such as dementia and related behavioural problems. The higher the MAPLe scores, the more time spent by caregivers giving care, and the higher the level of caregiver distress.

In our sample, at least 20% (except in the Yukon) of home care clients have Alzheimer's or another dementia.

Caregivers of patients with dementia provide 75% more care than other caregivers and experience nearly 20% higher levels of stress. The demands on the caregiver tend to increase as the disease progresses.⁴⁹

Support for caregivers

Caregivers have various needs, including a need for information, a need to be involved in decision making, a need for breaks (respite) from caregiving duties, and help with navigating the health system. However, assessments of potential home care clients usually do not include comprehensive caregiver assessments, which means that their needs go unnoticed.

Caregivers also frequently need more relief than the short breaks they receive when home care providers come to visit. *Respite* is defined as a break or relief from caregiving duties,⁵⁰ but anything that contributes to the caregiver's emotional, spiritual, physical, or social rejuvenation and allows them to continue in their caregiving role can be considered respite.⁵¹ Typically, services that provide respite include day centres, short-term stay beds in long-term care facilities, and night care, which provides temporary full-time care for clients to give caregivers a break.

When Canadian data
**is compared to RAI-HC data from other countries,
 it's clear that caregiver distress is a common
 experience internationally.**

All provinces and territories in Canada provide respite services for family caregivers, although access to these services varies widely. Some regions charge user fees, while others determine fees and eligibility according to income and assets.⁵ When considering the costs and benefits of supporting caregivers, the consequences of failing to support them should also be considered.²⁹

A study of caregivers of people who are dying found that most caregivers want information about issues such as pain management, how to navigate the system, respite, practical details about giving care, expectations of disease progression, how to deal with the care team, and legal/financial information. These information needs could be applied to family caregivers in general. Some of the barriers to receiving appropriate and timely information include a lack of coordinated and consistent providers, an absence of 24/7 services, poor communication skills, lack of emotional/spiritual support, and lack of knowledge of dealing with cultural diversity.⁵²

Caregivers often believe it is crucial for them to be involved in making decisions about their loved ones, but they don't feel entitled to ask questions or don't know the appropriate questions to ask. Families who are better informed have been shown to experience less anxiety. It is also important

to acknowledge that needs for information are not constant and are continually changing.⁵² Recently, New Brunswick released a new guide for family caregivers that provides tools for caregiving as well as practical advice for adapting lifestyles to ensure better quality of life for both care recipients and caregivers. More information is available at gnb.ca/seniors.

The Canadian Caregiver Coalition has put together a framework for a Canadian Caregiver Strategy that would include maintaining the health and well-being of caregivers, increasing the availability and flexibility of respite, minimizing the financial burden, increasing access to information and education, creating flexible workplaces, and investing in research on caregiving.⁵³ The Canadian Caregiver Coalition, as well as the Special Senate Committee on Aging, have recommended a National Family Caregiver Strategy to ensure that Canadian caregivers are able to continue caring for their loved ones while maintaining their own health, well-being, and quality of life.^{44, 53}

Some Canadian home care programs are piloting a tool to assess the needs of caregivers called CARE (Caregiver's Aspirations Realities and Expectations).⁵⁴ Use of this tool in a home care setting increased awareness of caregivers' needs among providers, gave credence to the role of caregivers, and served to validate their concerns. A version of this tool is currently being piloted in different home care settings and there are plans for further testing. To date, it has been shown to be a promising and appropriate tool to assess the caregivers of those receiving home care services.⁵⁴

Caregivers often believe it is crucial for them to be involved in making decisions about their loved ones, but they don't feel entitled to ask questions or don't know the appropriate questions to ask.

EMERGING PRACTICE**Alberta's Caregiver Support**

Under Alberta's Continuing Care Strategy, Aging in the Right Place, a demonstration project aiming to increase support for caregivers was carried out in Edmonton. The demonstration project strived to address caregiver burden through a systematic approach by using validated assessment tools to pinpoint areas of need, and offering both publicly funded respite services and referrals to community support services to meet those needs.

Participants in the program were caregivers who provided more than four hours of care a day and who indicated they needed additional support. The participants were interviewed and assessed using the CARE assessment tool (short version).⁵⁴ Prior to participating in the project, caregivers were receiving, on average, five hours per week of respite services. Under the program, ten additional hours were added for caregivers' respite based on assessed need.

Preliminary results are showing that this enhanced service successfully reduces the feelings of caregiver burden typically associated with caregiving. Benefits to project caregivers have included improvements to their emotional and physical health, to the quality of personal relationships and energy levels, and an increased knowledge of formal and informal supports available to them. Project caregivers reported they used their additional respite time to participate or complete activities that they had difficulty with before, such as going to the gym, buying groceries, and socializing. Interviews with caregivers indicated a need for additional support, such as emergency respite, extra days in a day program, easier access to facility respite, matching the age and language of respite providers with care recipients/caregivers, having a consistent care provider, and receiving more support in making health decisions.⁵⁵

IN SUMMARY

As seniors' needs increase, the average hours of care provided by family caregivers also increases significantly. Yet there is no corresponding increase in the levels of publicly funded home care support. The data in this section clearly show that many caregivers are considerably stressed from caring for people with significant impairments, particularly when home care support does not increase to match the needs.

A burned-out caregiver cannot help anyone. He or she may become another patient for the system to support, and without the extensive involvement of a primary caregiver, the home care recipient will need to move into a long-term care facility sooner. Whether it is more rapid placement for their loved ones into a long-term care facility, or extra hours and resources for home care, family caregivers who cannot cope need more support.

A burned-out
caregiver cannot
help anyone

A CAREGIVER'S STORY

Lucy McMillan*

Twenty years ago, Lucy McMillan was teaching at a university abroad. During a sabbatical, she returned home to Canada and realized that her parents, both over age 75 at the time, were no longer managing well on their own. Lucy moved back home to care for them in their small rural community.

In 1996, after her mother's stroke and her father's hip replacement, Lucy moved all three of them to a house in a nearby city that had more health resources and more job opportunities for her.

Lucy works in a creative field with irregular hours, which has allowed her some flexibility to remain at home to care for her parents. She was initially approved for only minimal home care support because she was perceived to be managing well. As a result, Lucy needed to hire a private agency to take over her parents' care when she was away from home for her work. However, as her parents moved into their 90s, they suffered a number of health issues and hospitalizations, and as a result qualified for more comprehensive home care services.

After her mother (who had cognitive difficulties) was upset when a male aide arrived to give her a bath, Lucy began to negotiate a self-managed home care package with the provincial government. Money is deposited into an account for her to purchase home care services, allowing her to choose the providers and the hours of care that she needs. However, the amount received is based on minimum wages. In order to be able to hire high quality care, Lucy purchases fewer hours of care while providing the remaining hours of care herself.

Lucy's mother died a few years ago, and her father is now both blind and deaf. Lucy says she chose to look after her parents without realizing the consequences to her career, social life, and finances, but is glad that she has given her parents the gift of staying out of long-term care, and of being together until her mother's death. With her parents' different health issues—particularly her mother's cognitive decline—she says they would have been required to live in separate nursing homes.

Note: Publicly funded self-managed home care programs are available in British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec, New Brunswick, Nova Scotia, Prince Edward Island, and Newfoundland and Labrador, as well as through the Veterans Independence Program.¹

* Names have been changed

¹ Spalding, K., J.R. Watkins, and A.P. Williams, *Self Managed Care Programs in Canada: A Report to Health Canada*. 2006.

Integration matters



Integrating home care into the larger health care system can ensure that seamless transitions are created for patients, their families, and providers in a way that leads to higher quality care, greater efficiency, and sustainability. It is particularly important in home care to ensure that there are strong connections and good communication between home care, hospitals, and primary health care.^{56, 57}

Reviews of Canadian and international studies show that integrated systems of care for seniors can lead to maintained health, well-being, independence, and increased satisfaction, and can reduce the demand for more expensive care in hospitals and long-term care homes.^{12, 58, 59} Better integration would also help to identify seniors who need home care services but who are currently falling through the cracks of the system.

In this section, we profile some practices and programs that are successfully integrating home care with other parts of the health care system, both in Canada and abroad. Two international examples, from Australia and Denmark, demonstrate system-wide integration of care for seniors.

Integrating home care with hospitals

Seniors are referred to home care services by a variety of sources, but they are most likely to be referred through a hospital. There is an increased sense of urgency to discharge patients out of hospitals as soon as possible, preferably to their homes rather than to long-term care facilities.

This policy direction has meant that many more patients who are still vulnerable are being discharged home.²⁹ Smooth transitions are essential to ensure that patients are discharged safely and will be appropriately supported at home.

Families sometimes question whether their loved ones should leave the hospital while they are still vulnerable, but prolonged hospitalization can also expose seniors to problems such as harmful drug interactions or hospital-acquired infections, and can delay their access to the therapy they need to regain mobility and strength. In addition, an unfamiliar and confining hospital environment can lead to depression and delirium, particularly among people with dementia.^{20, 21} Prolonged hospitalizations can jeopardize a senior's ability to return home.

Many hospitals have established geriatric teams to prepare patients for their eventual return home and to help build their capacities to remain independent. However, short-term, hospital-based geriatric care without follow-up is not as effective at preventing patients from returning to the emergency department as are home- or community-based programs, and those coordinated with primary care.^{60, 61} The role of the case manager is crucial to help ensure smooth transitions and ongoing coordinated care.

PROMISING PRACTICE

Partnering for Patients, Alberta

In Red Deer, Alberta, home care case managers work in hospital emergency departments to assess patients to determine the best care path for the patient, whether it is hospital admission, home care, or a long-term care facility. The case manager works with the emergency department staff and patients to do this planning and to ensure that it is safe to discharge the patient home with home care supports and referrals to community-based services, including the transfer of pertinent health information. This Partnering for Patients home care program is also aligned with primary care, allowing appropriate transitions and follow-up. The case manager also visits with general patients in the emergency department to educate them about home care options. This pilot project allowed nearly half (46%) of the patients to avoid hospital admission by being directed to home care.⁶²

PROMISING PRACTICE**Transitional Restorative Care Program**

Rehabilitation services, such as physiotherapy and occupational therapy, play a key role in helping patients regain enough strength and mobility to return home.

At the Rouge Valley Health System – Ajax and Pickering hospital campus (Ontario), a new transitional restorative care program helps prepare patients to return home from the hospital and resume their daily activities. Patients receive physical and/or occupational therapy to increase their strength, stamina, and independence, helping them to return to routine activities such as getting out of bed, dressing, and walking. Physiotherapy helps to recondition patients who often become more frail and immobile due to being in hospitals for long periods of time. The restorative bed unit is equipped to help older patients regain their strength and confidence so that they may safely return home, rather than continue to wait in hospital for long-term care facility placement. Patients stay an average of 45–90 days in the restorative bed unit.⁶³

Restorative beds are also being added to hospitals in the Ottawa region in an effort to enable more seniors to return home from hospital, leading to fewer placements in long-term care homes.⁶⁴

Similar programs in hospitals would help to alleviate the pressure of the Alternate Level of Care issue. In the absence of such programs, even providing ALC patients with some form of physiotherapy and exercise to counteract the effects of immobility could be helpful.

Integrating home care and primary health care

Home care and primary care have largely remained separate parts of the health care system, each referring to one another's services but not integrated. This is changing as policy-makers and health professionals work towards mutual goals of patient-centred care and sustainability.

The College of Family Physicians of Canada has emphasized the importance of the family physician to the home care team. Family physicians are typically the primary point of contact in the health care system for vulnerable seniors; they can advocate for home care services for their patients and help them to navigate through the system, as well as provide house calls.⁶⁵ It is particularly important for home care clients with high MAPLe scores to have access to primary health care, and in harsh Canadian winters, house calls may be necessary for housebound vulnerable seniors.

A persistent challenge in the care of vulnerable seniors is a lack of family physicians with specialized training in Care of the Elderly and the lack of specialist geriatricians.⁴⁴ The College of Family Physicians noted that in 2007 there were only 130 family physicians with Care of the Elderly training across Canada, and only 211 geriatricians nationally.⁶⁶ Additional training and specialization can improve the care of seniors with complex needs and have been associated with more appropriate use of health care services, improved mental health, and better general functioning.⁶⁷

To advance education for physicians in the care of seniors, the Canadian Geriatrics Society, together with the National Initiative for the Care of the Elderly, have developed core competencies for medical students in Canada. The intent is to establish a minimum set of standards that potential

Education
about the care of seniors
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doctors must meet before completing their undergraduate training. Both organizations propose that these standards be incorporated into the accreditation process for medical schools and that students be evaluated on these competencies as part of the Medical Council of Canada's qualifying examination.⁶⁸

Other challenges to integrating home care with primary care include lack of information and communication across sectors and providers, lack of structured discharge summaries, and problems with transitions.⁶⁵ In one study, 30% of physicians reported having no knowledge of recent hospitalizations of their patients. Patients were twice as likely to report post-discharge complications when their physicians were not notified of their hospitalization.⁶⁹ Further complicating the continuity of care is an often incomplete, delayed, or missing discharge summary,⁷⁰ which details changes in medications and follow-up recommendations. Far too often, the system continues to rely on patients and families to relay critical medical information to their family physicians.

Education about the care of seniors should include information about the importance and stresses of family caregiving. Seniors visit their family doctors, on average, five times a year. Their primary care provider, whether a family doctor or member of an interprofessional team, is in a position to identify family caregivers at risk for burnout. Education about family caregivers and ways to assess stress should be considered for all health professionals that work with seniors in home care.

PROMISING PRACTICE

The National Partnership Project

The National Partnership Project, a demonstration project that ran between 2003 and 2006, tested new ways of integrating home care and primary care services. Home care case managers in Calgary and in Halton/Peel (Ontario) were formally linked with family physicians to expand the role of home care in chronic disease management.⁷¹

The results were promising, including better quality of care, a better use of resources, enhanced community chronic disease management, and the potential for improved cost management. Physicians said they appreciated the collaboration, the joint decision-making, and the consistency of dealing with one dedicated home care case manager, rather than many. Variations of the partnership approach have since been implemented in Southwest Ontario, the Ottawa region, and British Columbia.^{71, 72}

Other innovative programs have demonstrated the potential for nurse practitioners to help in the function of house calls, acting as a conduit between the patient and family, home care, and primary care.⁷³

Technology is a missing link

For most home care programs, there is inconsistent and limited communication among the people involved in a senior's care. This lack of communication means that the case managers and front line providers who go into the home can lack important information about the person's care plan, potential health risks, and changes in health status. A 2008 Ontario study of front line providers showed that more than one quarter (27%) of respondents were not satisfied with the information provided to them before their first encounter with a client.⁷⁴ In particular, there was a persistent lack of information about a patient's medical history. Almost two-thirds (65%) of regulated health professionals reported having to ask clients to repeat some or all of their health histories, and a quarter (25%) had to repeat an assessment or test with their last clients. More than one-third of respondents (34%) relied on clients to pass along information to other providers. The lack of continuity of care and the resulting misinformation and miscommunication may put seniors at increased risk.

Technology is often described as the “missing link” between home care and other sectors, such as hospitals and primary care. An electronic health record (EHR) can overcome many barriers in chronic disease management⁷⁵ and enable effective and efficient delivery of services across sectors. In 2007, the Canadian Home Care Association and Canada Health Infoway collaborated on a project to assess the readiness and potential use of information and communications technology (ICT) in the home care sector.⁷⁶ The assessment showed that many promising projects are being piloted, such as remote monitoring to help clients better manage their own conditions, and improved communication among the various professionals who provide care to clients. The resulting project report called for targeted investments in technology for home care to advance development of the sector and its integration with primary care.⁷⁷

Although there is currently a push across Canada to implement electronic health records in physicians’ offices and hospitals, the use of electronic health records in home care has received relatively little research or policy development. Cost concerns and training requirements are considered to be the most significant barriers to implementing an electronic health record in this sector.⁷⁸

Integration across the continuum

The integration of services provides the most benefits when multiple levels and methods are used and implemented.⁵⁷ One useful framework for integrating health care, continuing care, and community care services includes a 10-point list of best practices that enable integration across sectors such as hospitals, primary healthcare, and other social services.⁵⁶ Figure 11 is a graphic representation of this framework as it applies to seniors.

Helping clients to navigate the complex patchwork of home care and health care services through a case manager is a crucial aspect of providing coordinated and integrated care. From a system perspective, services can be integrated using methods such as amalgamating various care delivery systems under a single administration, or by coordinating different services and sectors under a common umbrella.⁷³ The following examples illustrate different successful approaches.

EMERGING PRACTICE

The Client Health Related Information System (CHRIS) Story

In Ontario, the Association of Community Care Access Centres (CCACs) has been spreading the use of the Client Health Related Information System (or CHRIS, as it is more commonly known). CHRIS is a web-based client management system with four key components: case management, service provisioning, reporting, and financial management. It combines both resource planning and client management, alleviating the previous challenges of multiple data entries, the need to fax important client information, and multiple referrals.⁷⁹ The Association developed its own electronic system because software providers were not able to meet all their needs.

Some key features of CHRIS include:

- direct link to assessments, where CHRIS and the RAI-HC function as one seamless application, allowing automated entry of information and availability of a quick summary of results;
- automated file transfer for providers and agencies, allowing important information to flow between case managers, agencies, and providers;
- geographic coding and mapping for referrals to case managers and providers; and
- seamless integration within the CCAC’s Document Management System, setting the foundation for better automation of document workflow within and outside of CCACs.⁸⁰

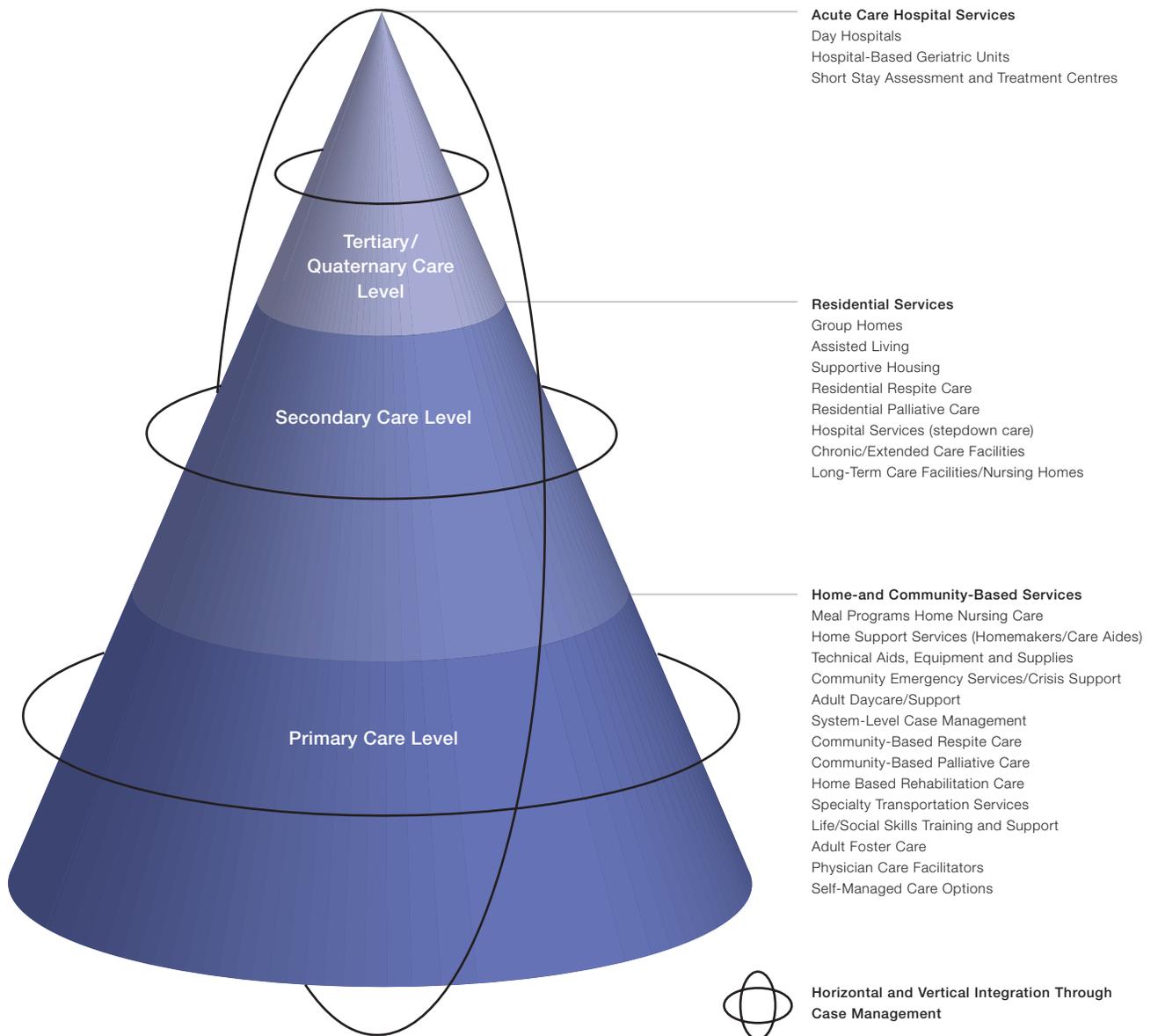
Nearly all (96%) of CCAC staff are supported by CHRIS, with plans for continued integration with other agencies and providers. Challenges included some issues with integrity of the data, interfaces with existing client data systems, and culture changes associated with balancing human care and electronic care to best meet the needs of clients. These challenges were overcome through building trust, communicating, planning, and working collaboratively.^{79, 80}

FIGURE 11

Framework for integrated continuing care for the elderly

Hollander and Prince created a framework for organizing an integrated system of care across various sectors and at multiple levels. This framework outlines the philosophical and policy prerequisites, administrative and clinical best practices, as well as

linkage mechanisms for linking hospitals, primary healthcare, and other social services. Linkages between and within levels are made primarily through case management. They have applied their framework to different populations, including seniors, and have described integration within a full system.



Source: Reproduced with permission from Hollander, M.J. & Prince, M.J. (2008). Organizing healthcare delivery systems for persons with ongoing care needs and their families. *Healthcare Quarterly*, 11(1), pp. 44-55.

INTERNATIONAL EXPERIENCE

National Home Care Strategy, Australia

The goal of Australia's National Aged Care System, which began in 1985, is to provide equal access to home care across the country.⁴ Australia's current national strategy divides the home care services that fall under each level of government (national, state, and territorial), and targets five specific groups with access challenges: Aboriginal Australians, people from culturally and linguistically diverse backgrounds, people suffering from dementia, people in rural areas, and those who are financially disadvantaged persons.⁴

Under this system, care is provided to seniors in Australia through a number of government programs: Home and Community Care, Community Aged Care Packages, Extended Aged Care at Home Packages, and assistance provided by Day Therapy Centres and Respite Care.⁹¹

Home and Community Care (HACC) This program comprises the majority of home and community services available in Australia.⁹³ Services are offered to ensure that older Australians (and younger people with a disability) are able to be more independent at home and in the community, thereby reducing inappropriate admissions to long-term residential care. Services can include case management, personal care, nursing care, homemaking assistance, respite care, and many other community supports for the client as well as the caregiver.⁹²

Community Aged Care Packages This package provides support services for seniors with complex care needs living at home who would otherwise be eligible for admission to low-level care in long-term care facilities. Services provided are coordinated

through a care coordinator and are more extensive than those falling under the Home and Community Care program. Approval must be given by an Aged Care Assessment Team before the coordinated package of care can be provided.^{91, 94}

Extended Aged Care at Home Packages This coordinated package of care is designed for care recipients who are eligible for high-level residential care. The goal is to deliver care at home that is equivalent to that received at a residential care facility. In 2006, specific dementia packages were added for people who exhibit challenging behaviour and psychological symptoms associated with dementia. Approval must be given by an Aged Care Assessment Team before the coordinated package of care can be provided.^{91, 94}

Transition Care/Care Awaiting Placement These programs have been introduced over the last decade to help people recover after a major illness or catastrophic event and following a period in hospital.

Health/Hospital Services in the Home These services are progressively being introduced into the health/aged care system as a way of assisting recovery but also avoiding the need for people to move to more expensive care options.

Day Therapy Centres Day Therapy Centres provide a range of therapies such as physiotherapy, speech therapy, and occupational therapy, aimed at helping older people regain or retain the capacity needed to remain in their own homes or in low-level residential care.⁹¹ Increasingly the services being offered are through clinic and home-based approaches.

Caregiver Support Caregivers in Australia have had a government-funded program and financial support options available to them over the past decade. The National Respite for Carers Program allows caregivers to take a much needed break from their roles. There are two types of financial payments that Australian caregivers may be able to access:

The study found fewer people in the PRISMA program experienced functional decline compared to seniors not in the program, and there were fewer admissions to emergency departments.

- A Carer Payment option may be available to those who provide constant care in the home to any individual over the age 16 who has a severe disability or medical condition, or to a frail senior.⁹⁵
- Caregivers may also be eligible for the Carer Allowance, which is a supplementary payment that can be paid in addition to wages or other income support payments.⁹⁶

Australia recently announced a National Carer Strategy in August 2011, which adds the following financial initiatives on top of the Carer Payment and Allowance options already available (only those related to vulnerable seniors will be discussed here):

- Caregivers who receive an income support payment (other than Carer Payment) and Carer Allowance are now entitled to a bereavement payment following the death of the person for whom they are caring.
- The Carer Supplement initiative will affect caregivers whose income support payment has been reduced to nil. They now qualify for an annual Carer Supplement.⁹⁷

The Australian Institute of Health and Welfare (AIHW), which provides health information and statistics, has played a key role in improving the quality of data and information collected and reported about home and community care programs. The Institute works closely with all levels of government to allow for national consistency and comparability of data and reporting.⁹³

More information is available at agedcareaustralia.gov.au

INTERNATIONAL EXPERIENCE

Integrated Home Service, Denmark

Denmark, which has invested more heavily in home care than other Organisation for Economic Co-operation and Development (OECD) countries, may hold some clues to better integration and cost-effectiveness.

In 1987, Denmark stopped building new long-term care facilities and focused legislation and resources on developing their home care sector, as well as assisted living options.⁸⁸ Municipalities are charged for the daily fees of hospital beds when patients are ready to be discharged, which encourages the expansion of home care services.⁸⁹ Home care programs that provide nursing care, meals, home adaptations, day care, financial assistance, and transportation, as well as access to 24-hour care services, have been shown to be cost-effective substitutes for long-term care facilities.⁸⁹ Health and social care services for seniors are integrated and coordinated through case management, interdisciplinary teams, cross-setting care, and common training programs.⁸⁸

Preventive home visits for seniors are provided to all citizens over 75 years to encourage them to make better use of resources and allow them to remain independent. The Danish government provides various service alternatives that allow seniors and their families to choose the services they need and prefer.⁸⁸

Denmark's social service and health care system provides comprehensive medical and social care benefits at no direct cost to the patient, although Denmark does have a high taxation rate.⁹⁰ Denmark has a policy structure that involves all levels of government in bearing responsibility for their citizens' health. The national government develops legislative frameworks for social and health policies and distributes income from taxes to regional and local authorities. Regional (county) authorities are responsible for health care services including hospitals, family doctors, specialists, as well as other health services such as dental services and physiotherapy. Local (municipal) authorities provide social care, including home care.⁸⁸

PROMISING PRACTICE**PRISMA Integrative Health Service Program**

In 2006, about 14% of the Quebec's population was over age 65,⁸¹ and more than three-quarters (77%) of seniors had at least one select chronic condition.⁸² A model of integrated care called the Program of Research to Integrate Services for the Maintenance of Autonomy (PRISMA) was developed to address many of the challenges of delivering comprehensive health care services to an aging population. Seniors who are eligible for services are over age 65, have moderate to severe disabilities, show potential for staying at home, and need two or more services.⁸³

The PRISMA model is based on six key elements.⁸⁴

- **Coordination of organizations and services** Coordination first occurs at the governance level to bring together health care and social services, then at the management level to coordinate services, and finally at the operational level to bring together an interdisciplinary team.
- **A single point of entry** This provides a portal for people to access all the services they need through a single source, rather than expecting them to seek out services from multiple sectors and providers to meet their needs.
- **Case management** Case managers provide an initial assessment and are involved with planning and coordination of services with the patient and family. They also act as patient advocates.
- **An individualized service plan** This plan is based on the assessment and is developed by the case manager in discussion with the multidisciplinary team, as well as with the client and caregiver.
- **A standardized assessment** To evaluate clients' needs and determine the right package of services, a standardized assessment tool (the Functional Autonomy Measurement System, known by its French acronym as SMAF) is used to measure functional

independence, communication, and mental functions. This tool is being used in several regions of Quebec to inform financing of long-term care facilities and home care services.

- **Electronic records** A computerized clinical chart provides an electronic record that enables communication between the health care team as well as between organizations.

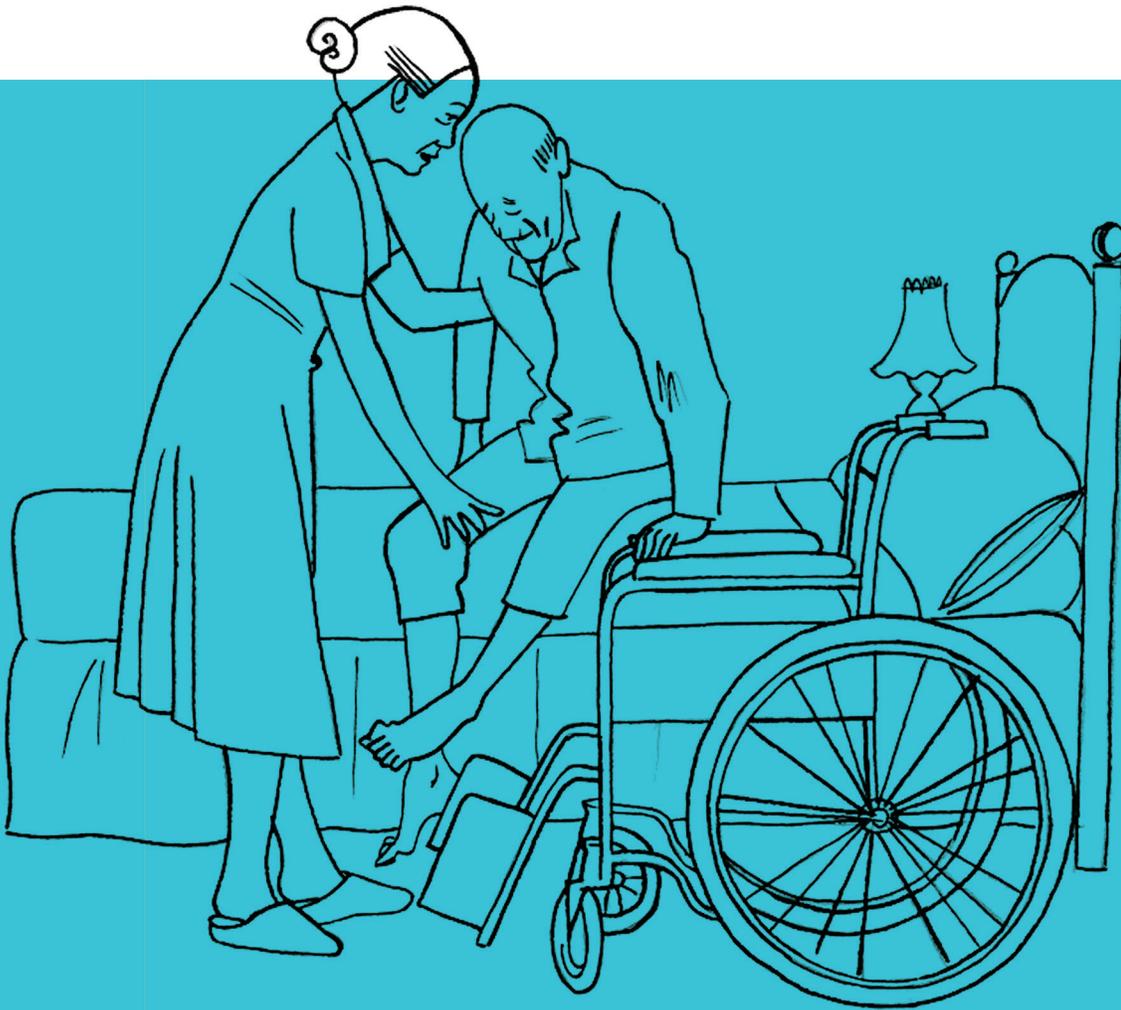
The PRISMA group conducted a four-year study to evaluate the impact of the model on the ability of seniors to remain in their homes. The study found fewer people in the PRISMA program experienced functional decline compared to seniors not in the program, and there were fewer admissions to emergency departments. Satisfaction and empowerment levels were higher among the PRISMA participants compared to seniors not participating in the program.^{84, 85}

Since 2005, Quebec's Ministry of Health and Social Services generalized the PRISMA model across the province by merging all public hospitals, long-term care facilities, and home care agencies under single organizations within a region, organized into 95 health and social services centres across the province. The next step in implementation involves functional integration within the merged structures. The PRISMA model has been expanded to other regions in Quebec, and a pilot project has been initiated in France. The PRISMA group is working closely with policy-makers towards a more integrated system in Quebec.^{86, 87}

IN SUMMARY

Home care needs to be viewed as a critical part of an integrated health care system. Integration of a wide range of services, particularly for seniors, can improve health outcomes, reduce emergency department visits and hospitalizations, and lower rates of placement in long-term care homes. The practices profiled in this section provide both ideas and strategies for governments to consider.

Challenges in home care



As we have seen in previous sections, care and support—whether it is from home care providers, family caregivers, or both—is necessary for vulnerable seniors to maintain their independence and dignity at home. But several significant challenges need to be considered in planning and policy for home care to ensure that all family caregivers and providers will be able to provide quality care.

Support for family caregivers

Policy shifts towards shorter hospital stays and returning patients back home as soon as possible, even with home care support, assumes that family caregivers are available to take on the majority of the caregiving.

This assumption can put a significant burden on family caregivers, and there are concerns that burdens may increase in the future. Studies of future needs and the availability of caregivers have shown that within the next 30 years, the proportion of those over age 80 is expected to increase significantly, and the number of seniors with a disability and requiring assistance could double. In addition, the narrowing gap in life expectancy between men and women suggests that the number of older spouses caring for their disabled partners will increase.⁹⁸⁻¹⁰⁰

Furthermore, the pool of family caregivers is expected to decrease due to changes such as smaller family sizes, childlessness, and adult children who are still working and unable to be caregivers.¹⁰⁰ The proportion of elderly women with no surviving children is expected to increase significantly in the next 30 years.^{98, 99} In addition, among those who are divorced, it is more difficult to find support from family.⁹⁸⁻¹⁰⁰

These demographic and social changes will increase the need for more support through home care. The Canadian Community Health Survey data show that many caregivers who are still in the workforce reduce their hours, use their vacation or sick time, or take unpaid leave to look after a loved one (see Figure 10D). Caregivers would benefit from workplace policies that allow greater flexibility.

There seems to be a dual expectation of older Canadians to provide care to their family members and continue to contribute to the workforce. The proportion of workers aged 55–64 has risen in the last decade,¹⁰² and recent changes to the Canada Pension Plan means that fewer benefits will be paid to those who retire earlier, with increased benefits received if an individual retires as late as age 70.¹⁰¹ Some older workers will need to stay in the workforce longer in to build up their assets and ensure they have a livable income when they do retire. The proportion of workers aged 55–64 has risen over the last decade.¹⁰²

Other countries are supporting caregivers by implementing pension security policies for caregivers (Germany, France, Norway, Sweden, and the United Kingdom), giving tax credits (the United States has a non-refundable caregiver tax credit), and providing non-taxable allowances.⁹⁸ Some Canadian provinces and territories are following suit. Tax credits are provided to caregivers in Manitoba and Saskatchewan, while in Nova Scotia, eligible caregivers are provided monthly compensation.¹⁰³⁻¹⁰⁵ The federal government also offers a range of federal tax credits, including the new Family Caregiver Tax Credit, effective January 2012.¹⁰⁶

In 2011, Manitoba took the lead in Canada by announcing a Caregiver Recognition Act, which includes creating guiding principles about caregivers, a progress report every two years, and a Caregiver Advisory Committee.¹⁰⁷

As mentioned earlier, a National Family Caregiver Strategy that includes financial support, workplace protection, provisions for respite, training/education, and other support would go a long way towards sustaining caregivers now and in the future. Other countries have begun moving towards formal national caregiver strategies,

while some are just beginning to define the challenges. In the United Kingdom, acts of parliament and two national caregiver strategies have been developed to support caregivers. Caregivers have the right to request needs assessments, supportive services, and a flexible work schedule.¹⁰⁸

Likewise, in the United States, both Medicare and Medicaid services have launched caregiver initiatives, as has the Veterans Administration. The Administration on Aging supports caregivers through a National Family Caregiver Support Program, and by providing financial support and counselling. New Zealand also launched a national caregiver strategy in 2008, requiring government agencies to report on measureable actions until 2013.¹⁰⁸ Australia's recent caregiver strategy is outlined in the previous section.

Recruiting and retaining a home care workforce

Pan-Canadian consultations on the challenges of expanding the home care system to meet the demands of an aging population revealed several recurring themes: compensation, standardized education and training, quality assurance, and working conditions.¹⁰⁹ There are current challenges as well as the looming reality of an aging workforce and its effects on the number of people available to do this work in the future.¹¹⁰

Hospitals, home care organizations, and long-term care facilities often struggle to recruit young people to health care professions, but their shared challenges end there. Hospitals and long-term care facilities typically offer regular hours, better wages and benefits, provide more opportunities for career growth and mentorship, and have more modern work environments and technologies. For these reasons, hospitals and long-term care facilities tend to be the employer of choice for people in health care careers, which can make it difficult to retain home care workers. Furthermore, health human resource planning has tended to focus on recruiting professionals such as doctors and nurses, leaving a dearth of personal support workers to fill positions in hospitals, long-term care facilities, and homes.¹⁰⁹

Wage discrepancies can be significant. In Ontario, for example, there is a mean wage gap between hospitals and home care settings of \$4.55 per hour for personal support workers, and of \$3.67 per hour between long-term care facilities and home care.¹¹¹ Both Nova Scotia and Saskatchewan have implemented legislation that governs wages for personal support workers.¹⁰⁹ In addition to wage parity, equitable benefits and travel compensation are issues that need to be addressed.

Another issue is the unpredictable nature of home care work. Home care providers—most often personal support workers—commonly work part-time or casual hours. Their work is often on-call and involves split shifts, pay-per-visit, and hourly pay without regular and guaranteed hours. This type of casual employment has been linked to a high turnover of workers.¹⁰⁹

In addition, a lack of consistency in home care providers can interfere with a patient's care. It is not uncommon for a client to receive care from multiple providers, each a couple of times per week, often working in isolation from one another. With increasing needs (i.e., more hours and/or seven-day care), more providers are required and the people involved may also change.⁷⁴

The 2003 Canadian Home Care Human Resources Study,¹¹² as well as more recent provincial studies,¹¹¹⁻¹¹⁴ provide some information about personal support workers: they are more likely to be female than male, more likely to be middle-aged or older, and many have other jobs in addition to their work in home care. For example, in one Ontario survey, 28% of personal support workers said they worked solely in multiple settings,¹¹³ which reflects the casual and episodic nature of the work.

People are attracted to home and community care because of the direct relationships they can build with clients, but if short-term or episodic work assignments do not allow them to get to know people, it can reduce their commitment to stay in this field of work.¹¹⁴ Among the top three reasons for personal support workers leaving their jobs are low wages, lack of benefits, and lack of job security.¹¹² Continuity of care benefits both the personal support worker and the person receiving home care. A high turnover of workers can affect the continuity of care of someone receiving home care, and having to develop trusting relationships with a regular stream of new care providers can affect quality of life, particularly for those with dementia.

Unlike other members of the home care team such as nurses or physiotherapists, personal support workers are unregulated. However, most provinces and territories in Canada currently require formal training for new personal support workers, usually at the community college level. Alberta, British Columbia, the Yukon, Newfoundland and Labrador, Nova Scotia, Ontario, and Quebec provide standard curricula within their province or territory. Challenges include having personal support workers without formal training who are already in the system, as well as having variable entry requirements and different course lengths and content. This makes it difficult for personal support workers to transfer across provinces and territories; further standardization within provinces and territories, adhering to some national guidelines, would help to ensure consistency.¹⁰⁹

The Senate Committee on Aging has said there is a role for the federal government in recognizing and supporting education for personal support workers by helping to bring about a national standard.⁴⁴ Some work on developing

national educational standards for personal care providers working in home, community, and long-term care facilities is already underway through collaboration between the Association of Canadian Community Colleges and the Canadian Association of Continuing Care Educators. These national standards are working to achieve consistent terminology, provide a way to assess and compare credentials across the country, and establish a framework for developing educational curricula which will provide guidelines for achieving consistency in educational requirements across Canada.¹¹⁵ Many provinces are already offering some incentives in the form of bursaries, student loan reductions, and other financial assistance to cover the costs of training. An increase in salaries may be a natural result of standardized education.¹⁰⁹

In some Canadian provinces, personal support registries are enabling some degree of standardization and accountability. In 2010, British Columbia created a registry for care aides and community health workers. The intent is to protect vulnerable clients and ensure a similar standard of care across the province.¹¹⁶ Ontario is also developing a personal support worker registry, to be place in 2012,¹¹⁷ and Nova Scotia has a registry in development for the province's continuing care assistants.¹¹⁸

Incentives such as competitive wages and benefits, maximized scopes of practice, opportunities for career development and continuing education, and modern technologies are necessary to recruit home care workers and to keep them.

Determining value for money

The growing need for home care for our aging population—and concerns about its costs—is a topic of discussion in many developed countries. The financial sustainability of continuing care for seniors (defined as both home care and long-term care facilities) has been identified as the most important long-term care priority among countries tracked by the Organisation for Economic Co-operation and Development (OECD).¹⁰⁰

**A greater burden
may be placed on spouses who may be
frail and disabled themselves.**

The high costs of dementia

As noted earlier in the report, at least 20% of home care clients in four of the five regions we examined have dementia. The Alzheimer's Society of Canada projects that by 2038, new cases of dementia among seniors will be 2.5 times higher than in 2008, with all cases of dementia affecting 2.8% of the Canadian population. Nearly two-thirds (62%) of Canadian seniors with dementia will be living in their own homes. This will substantially increase the burden on their communities and caregivers.¹

Caregivers of patients with dementia provide 75% more care than other caregivers and experience nearly 20% higher levels of stress. The demands on the caregiver tend to increase as the disease progresses.²

It is projected that the total annual economic burden due to dementia, which includes direct costs, indirect costs, and family caregiver costs (i.e., lost wages) will amount to \$153 billion per year in 2038, compared to \$115 billion in 2008 (calculated in future dollars).¹

¹ Alzheimer Society of Canada, *Rising Tide: The Impact of Dementia in Canada*. 2010, Alzheimer Society of Canada: Toronto.

² Alzheimer Society of Ontario, *A profile of Ontario's home care clients with Alzheimer's disease or other dementias*. 2005, Alzheimer Society of Ontario.

Most OECD countries have been encouraging home care to delay or avoid the costs of long-term facility care, and to meet the preferences of the public.^{100, 119} However, the proportion of the GDP spent on home care is generally less than that spent on long-term care institutions in most OECD countries with a few exceptions, most notably Denmark (see Figure 12).

Canada has a large gap between spending on long-term care institutions (1.0% of GDP) and home care (0.2% of GDP), compared to countries that also separate their continuing care spending data into home care and long-term care categories (see Figure 12).

Future increases in continuing care expenditures depend on a number of factors. Due to changing demographic trends of smaller families, increasing childlessness, family mobility, and increasing life expectancy, there will be fewer adult children available to take on the caregiving role for their aging parents. A greater burden may be placed on spouses who may be frail and disabled themselves. Both factors are expected to increase the demand for home care services.^{98, 119}

The ongoing discussions about Canada's aging population and the increased public demand to stay at home as long as possible are raising questions about whether home care offers the best value for money. First, it is important to note that home care may not be cost-effective or appropriate in all circumstances, particularly when it involves the care of clients with severe disabilities.¹⁰⁰ In addition, home care is often considered a cost-effective option because much of the caregiving is done by family members. When these hidden costs were tallied (using 2002 data), the overall costs for care given by Canadian family caregivers over 45 years of age caring for those age 65 and older was estimated at nearly \$25 billion per year, based on hourly rates for professionals (at 2007 rates).⁴¹

As noted in the section on integration, home care is most cost-effective when it is integrated with other parts of the health care system. A growing body of research suggests that when home care is properly integrated into the health care system, it can cost-effectively substitute for long-term facility care and hospital care, as well as decrease the rates of placement into long-term care facilities.^{7, 12, 13}

Value for money: Is home care a cost-effective solution to the Alternate Level of Care (ALC) issue?

It has been estimated that ALC patients use more than 7,500 beds in Canadian hospitals every day, and ALC bed use exceeds 2.4 million days over a year.¹⁹ In 2007–2008, the percentage of hospital beds being used for ALC patients in eight provinces ranged from 2% in Saskatchewan and Prince Edward Island to a high of 7% in Newfoundland and Labrador and Ontario in.¹⁸

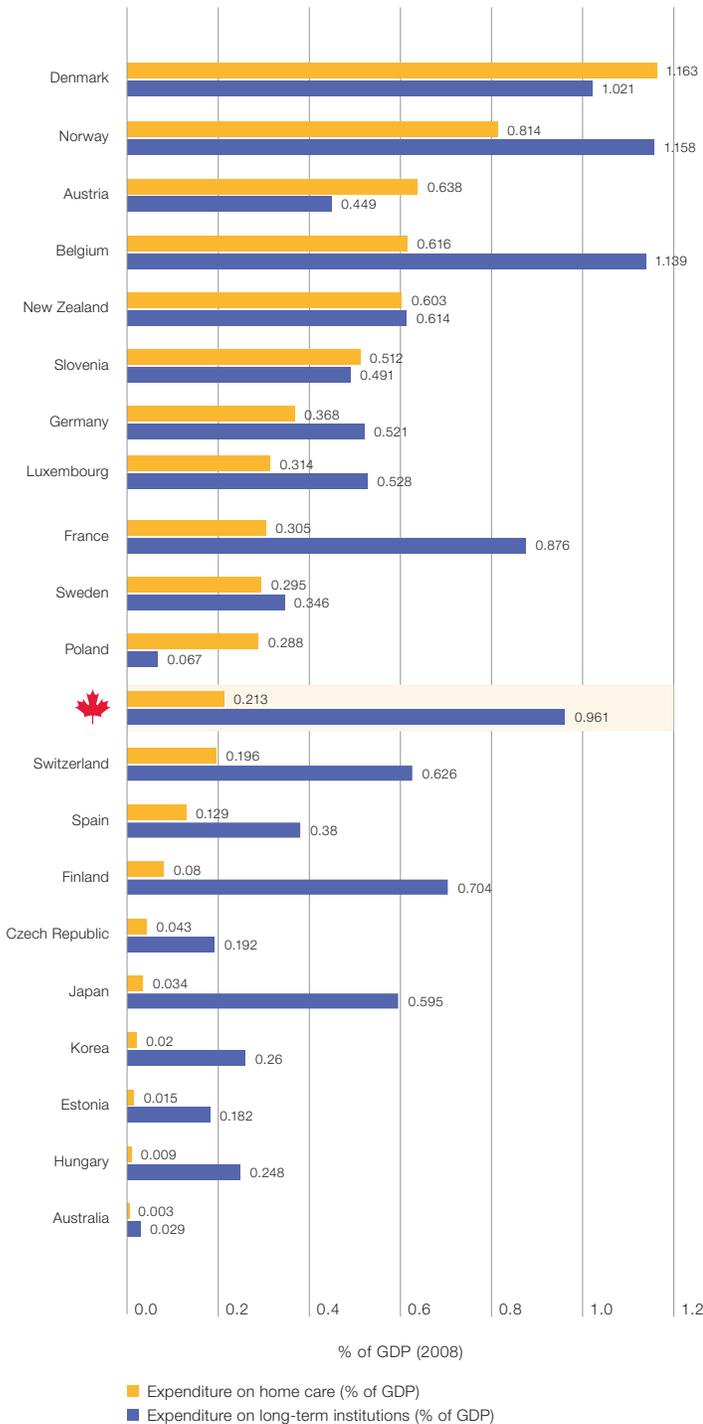
A report on Ontario's health care costs states that in March 2010, there were more than 3,000 ALC patients awaiting placement. This costs hospitals an estimated \$450 per day. In comparison, an estimate of the average cost for maximum levels of home care services in Ontario is about \$100 per day. Even if the maximum level of home care is raised to \$130 per day, there would be a cost saving of \$320 per day. Every 10% shift of ALC patients awaiting long-term care placement to home care can result in \$35 million in savings.¹²⁰

**Home care
is most cost-effective when
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of the health care system.**

FIGURE 12
Public expenditure on home care versus long-term care in OECD countries

Public spending on long-term care institutions is higher than spending on home care in many OECD countries.

Source: OECD Health Data 2011 (data collected in 2008). http://stats.oecd.org/index.aspx?DataSetCode=HEALTH_STAT



The report recommends that the Ontario government invest funds earmarked for its Aging at Home strategy into home care services. It also recommends shifting funds from hospital to home care for specific groups of ALC patients who can be appropriately discharged home with the right supports.¹²⁰ Restorative programs in hospital may help to ensure that patients do not experience further deterioration and are able to return home, rather than be placed in long-term care homes. The right level of home care supports is critical for these vulnerable patients. Without it, patients may be readmitted to hospital and need to be admitted to long-term facilities sooner.

Value for money: Is home care a cost-effective substitute for long term care?

Studies were conducted in various parts of Ontario to determine whether home and community care services can provide safe, appropriate, and cost-effective alternatives to residential long-term care. People waiting for long-term care in each region were divided into sub-groups based on indicators of need using RAI-HC data. The researchers then developed vignettes of typical cases, which were reviewed by an expert panel of front-line case managers.^{7, 35, 36}

The findings indicated that one of the key reasons people were waiting for long-term care was that they were unable to carry out activities such as house cleaning, preparing meals, and managing medications (IADLs), and this caused a decline in their ability to live independently.⁷ As noted earlier in the report, 95–98% of home care clients captured in our RAI-HC data analysis have difficulty with IADLs. Loss of IADL functions often precedes the loss of ADL functions. Navigating the system and managing the various services was also difficult for older seniors.³⁶

The researchers constructed home care packages to support these typical clients and estimated costs for each package over 13 weeks. These packages included a mix of services such as case management, transportation, home maintenance, nutrition and socialization, personal care and support, professional services, support for their family caregivers, and an emergency response system.^{35, 36}

People in the highest needs groups were omitted from this part of the study because they were unable to carry out many activities of daily living (either ADL or IADL) without help, had cognitive difficulties, and did not have a family caregiver residing with them. It was not considered safe for these people to live at home.⁷

Researchers then compared the expected costs of the home care packages to those of equivalent long-term facility costs expected over the same period of time. When the costs for the home care packages were less than or equal to the estimated long-term care facility cost,³ home care was considered to be cost-effective. They estimated that between 14% and 37% of people who were waiting for long-term care could be supported safely and cost-effectively in home care.^{7, 35, 36}

It is important to look at those numbers in context. About 20% of those on long-term care wait lists in one urban region had mild to moderate levels of need, and would be easier to support at home or in supportive housing. However, for another 20%, long-term care seemed to be the only safe option due to the fact that they had high needs and lacked family caregivers. A third group could be safely and appropriately supported at home, but the costs would be higher than residential care.⁷ These findings confirm other research that home care can be less expensive than long-term care facilities for clients with lower needs and whose health is relatively stable.⁴ Further research on actual costs would confirm these findings.

In these Ontario studies, some important trends emerged. It was evident that being without a family caregiver was a tipping point for entering residential care earlier than might otherwise be required. In the absence of a caregiver, placement in a long-term care facility was often triggered by the inability to cook, clean, and run errands. If they do not have assistance, seniors who otherwise may be functioning well may not be able to live independently. Home care—or assisted living, if it is available—can provide the supports for these people who need only a light level

of care. This helps to delay or prevent the need for many to move to long-term care facilities, and potentially keeps seniors out of hospitals.⁷

Most regions offer some type of home support services for IADLs through their community care programs. However, some of these services are only partially subsidized, requiring clients to pay the rest out-of-pocket. Community support services such as transportation, delivery of meals, homemaking services, and respite services are also available, typically with some user fees, through not-for-profit organizations.⁵ The Local Health Integration Networks (LHINs) in Ontario are piloting the RAI-CHA, an assessment of community health needs. Assessment of needs for these types of services can identify the needs of a frail elderly population earlier, resulting in providing appropriate interventions, and potentially preventing hospitalization and avoiding premature placement into

The data
available in the home
care sector is
steadily growing.

long-term care facilities.¹²¹

The burden of out-of-pocket costs for support services or additional home care services must be part of any analysis of the cost-effectiveness of home care and carefully considered in government aging strategies. The OECD suggests that most seniors with high needs face catastrophic out-of-pocket costs for continuing care (whether at home or in a long-term care facility), and there needs to be some arrangement for universal eligibility and coverage by governments to provide basic protection. The OECD suggests that long-term care policies need to include targeted eligibility criteria, a specific basket of services, and cost-sharing between governments and clients to ensure sustainability. Many countries, including most Canadian provinces,¹²² provide cash benefits for self-managed care where the client and family decide how best to use funds allocated to them. Since many seniors prefer to receive services in their home, suitable housing also needs to be considered as part of government aging strategies.¹⁰⁰

Research and policy development opportunities

The data available in the home care sector is steadily growing. The RAI-HC data provide valuable information about the presence of risk factors for adverse events, allowing providers to intervene proactively. As more Canadian jurisdictions adopt the RAI assessments, and in particular the home care assessment, this will create a larger database to inform research and policy development. Further data on the needs and health profile of caregivers are also needed.

Other areas of research that would facilitate policy development and improvement of care for seniors include analyses of the impact of community support services in preventing decline, the cost-effectiveness of integrated home care programs, and the quality and safety evaluations of home care programs.

Including caregiver assessments and monitoring as part of the regular home care assessment process would be an important step towards supporting caregivers in their role. Understanding the needs of caregivers, which change as the home care recipient's needs change, is crucial to being able to provide appropriate supports for caregivers and identifying the risks of burnout before they become unable

to function.

IN SUMMARY

Challenges in home care include lack of supports for family caregivers, challenges in the recruitment and retention of home care workers, and determining how best to allocate funds to ensure the most appropriate care for seniors. We have highlighted some of the limited research on the cost-effectiveness of home care; what is missing from this discussion is the value of remaining in one's home as long as possible, including the comfort of familiar surroundings and the ability to receive personalized attention from both home care workers and family caregivers.

Among OECD countries, Canada has one of the larger gaps between spending on long-term care institutions and home care. This raises questions about the appropriate balance between the two, particularly since many caregivers of high-needs seniors—who may also be seniors themselves—are struggling with limited hours of home care support and are becoming overburdened.

Concluding Comments

The findings in this report turn the spotlight on some common themes and concerns about home care services.

About one-third of the seniors in our analyses of home care recipients have high needs, often involving both physical disability and cognitive impairment such as dementia. Despite this, they may receive only a few hours more of publicly funded home care each week than seniors assessed with moderate needs.

Most provinces and territories limit the number of hours or spending on a person's home care. In some provinces, this limit is equivalent to the cost of care in a long-term care facility. The result is that many high-needs seniors are receiving intensive support from highly stressed family caregivers who are being stretched beyond their capacity. Those caring for seniors with dementia are suffering most of all, reporting the highest levels of stress, social isolation, depression, and chronic health problems.

Many family caregivers of high-needs seniors are at a breaking point. Both the caregiver and vulnerable senior are at risk in these situations. Distressed caregivers may become unable to provide good quality care to their loved ones, and they may significantly compromise their own health as well. Family caregivers are the backbone of the home care system; they need to be adequately supported for the system to work. If the care needs of seniors and the support needs of their caregivers are not adequately addressed, then a further burden will be placed on Canada's health care system.

At the same time, the health care system is trying to address the Alternate Level of Care (ALC) issue, and home care may help to alleviate acute care pressures. A large proportion of hospital beds are occupied by patients who no longer need intensive medical care. Most are seniors. While many are waiting for beds in long-term care facilities, there are increasing efforts to help more ALC patients return home with appropriate home care supports. The availability of family caregivers and their ability to manage are key factors in these efforts.

Between increasing public demand for home care and the ALC issue, it is not surprising that the number of home care recipients has grown by 51% in the last decade.

All governments in Canada are aware of the significant growth of home care in the last decade, the current demand to expand services, and the persistent and emerging challenges that exist. In response, some provinces and territories have launched comprehensive aging-in-place and continuing care strategies with home care as a focus. These are promising efforts, but more program specifics and investments are needed.

Canadians clearly want to stay in their homes as long as possible. With this in mind, and with an understanding that there are many issues worthy of attention, we believe that governments and the health system need to consider the following elements when looking at the future of home care policy and programming in Canada:

Recognize that home care has become a cornerstone of the health care system

The innovative practices in this report are underpinned by the understanding that home care is an integral part of the health care system, and not something that happens off-side in the community. This requires a shift in the way home care is understood, valued, and integrated into the health system—and in the way that health care dollars are allocated. Part of this includes ensuring that home care workers have better and more integrated training and comparable wages and benefits to improve quality of care, reduce turnover, and provide a sufficient workforce for the future.

Provide ongoing support for family caregivers and immediate relief for those in distress

Caregivers need to be formally assessed and supported as clients of home care services, and their level of stress needs to be continually monitored. Family caregivers need the system to acknowledge their critical contributions and recognize that they are burning out, provide a rapid response, and offer choices. Families in distress might need their loved one to be fast-tracked into a long-term care facility, with extra hours of home care and respite while they wait; some might prefer to keep their loved one at home, but with more types of support and hours of care; still others may just need a period of respite.

Many caregivers are seniors themselves, with one or more chronic conditions. Failing to provide adequate support to family caregivers is not only a burden on them and the vulnerable seniors in their care, but is also a potential increased burden on the health care system. Other caregivers are still in the workforce and need to juggle work responsibilities, family care giving, and their own health and well-being. Flexible working arrangements will help those who are managing work and caregiving at the same time.

Adapt or expand what is working

The innovative practices profiled in this report offer successful programs and policies that others can adapt. Some of the most successful programs bring together home care, primary health care, and acute care under a single coordinating body. They also provide geriatric assessments, offer one single point of contact (a case manager) to organize a senior's services, and set up systems for good communication and consistency of care between different providers. Australia's national home care strategy includes a number of programs and initiatives that Canadian provinces and territories can draw upon. The Canadian Home Care Association is developing harmonized principles of home care that will provide a set of achievable standards while ensuring flexibility across the country. The harmonized principles are expected to be completed in the summer of 2012, with discussion about implementation to follow.

Although provinces and territories assess their home care clients, many are using different methods of assessment, which makes it difficult to compare services and data across the country. The internationally respected Resident Assessment Instrument–Home Care (RAI-HC) provides a standardized way to assess clients' needs and provides data for providers, policy-makers, and researchers to monitor and improve quality, determine how and where to allocate resources, and standardize services. Many provinces and territories are in the process of implementing the RAI-HC. Those that are using other forms of assessment and data collection may want to consider ways to make their data interoperable or comparable to the RAI-HC.

Consider new home care options before new investments in long-term care facilities

The OECD data show that Canada places a much higher value on long-term care facilities than home care compared to many other countries. This does not match public demand for home care. Before a decision is made to invest in new long-term care facilities, governments should ensure they have adequately assessed their population's needs and the appropriate balance of spending between long-term care, home care, and other appropriate community-based services.

Finally, the ongoing discussions about health system priorities and approaches that will follow the expiry of the 2004 health accord provide an opportunity to openly discuss home care issues, and for the provinces and territories to collaborate on a path forward. The Health Council of Canada believes that the findings and innovative practices in this report point to the necessary first steps on this path.

Data Sources

RAI-HC

Home care professionals use the Resident Assessment Instrument – Home Care (RAI-HC) to assess the strengths, preferences, and needs of home care clients to develop a person-centred care plan and allocate services.

The RAI-HC is part of an integrated suite of instruments that includes assessments used in nursing homes, home care, palliative care, assisted living, hospitals, and mental health settings. These have a common core set of items. The standardized assessments are based on information from a variety of sources (such as the provider, family caregiver, and client) and are used for care planning, outcomes measurement, resource allocation, prioritization, and monitoring quality. The RAI assessments have been tested in several countries, and in different languages, and were found to have strong reliability and validity.

We have used data (when sample size permits) from the RAI-HC assessment instrument from five Canadian regions that have completed the implementation process: the Yukon (145 clients), the Northern Health Authority in British Columbia (1,356 clients), the Winnipeg Regional Health Authority (8,344 clients), Ontario (125,724 clients), and Nova Scotia (10,493 clients). Data in each region are collected by the regional health authority of each jurisdiction, while Ontario's data are collected by the Community Care Access Centres (CCACs). The findings were verified by senior officials responsible for RAI-HC data collection in each region.

The RAI-HC data provide information on individuals who are receiving publicly funded home care (or who are expected to receive it) for a longer-term period of more than 60 days. Home care clients receiving home care services for a shorter period of time or services that are not typically managed by a case manager are not captured in our data. We have chosen to examine a subset of the full RAI-HC data, consisting of seniors aged 65 years or older.

The prevalence samples were based on assessments done for people who received home care in a given year. For seniors with multiple assessments, the one done closest to July 1 of that year was selected. The prevalence samples represent a cross-section of people who received home care in that year and include a mixture of new intakes and existing clients.

In the case of the Winnipeg Regional Health Authority (WRHA) and the Northern Health Authority in British Columbia, data were only obtained from longer-term home care clients in the specific health region. In the remaining provinces and territory, data represent longer-term home care clients in the province or territory during the time frame examined. Data from 2010 were used for the Northern Health Authority in British Columbia, the Yukon, and Ontario; data from 2007 were used for the Winnipeg Regional Health Authority and Nova Scotia, which were the most recent valid data available at the time of writing.

This sample is not intended to be representative of all of Canada, and the data from specific health authorities in British Columbia and Manitoba should not be considered representative of the province as a whole. Data from each region should be viewed as independent from the others. By profiling data from these regions, we are able to see a snapshot of the variability in services and programs, as well as trends that exist across all five regions examined.

It is important to note that British Columbia has implemented the RAI-HC across all regions, but only data from the Northern Health Authority were available at the time of writing. Most provinces and territories are at various stages of implementation of the RAI-HC. Some, but not all, provinces and territories submit their RAI-HC data to the Canadian Institute for Health Information's Home Care Reporting System.

In comparing caregiver distress, we have also profiled some international jurisdictions. Of the 13 countries that submit interRAI data to international repositories, current RAI-HC data from four countries were available at the time of writing. Data were provided courtesy of inter-RAI members in Finland, New Zealand, Belgium, and the United States (Michigan and Massachusetts). The New Zealand (820 clients) and Belgium (2,300 clients) results are both obtained from pilot implementations conducted in 2009. The Michigan (3,608 clients) and Massachusetts (2,101 clients) samples are from RAI-HC assessments among Medicaid clients in 2008. The Finland (3,601 clients) sample is based on RAI-HC assessments done by home care agencies collaborating with the Finnish National Institute for Health and Welfare in 2009.

2008–2009 Canadian Community Health Survey (CCHS): Healthy Aging

The 2008–2009 Canadian Community Health Survey – Healthy Aging component explores the health of Canadians aged 45 and over by examining the various factors that have an impact on healthy aging. Data were collected by Statistics Canada between December 2008 and November 2009 targeting Canadians aged 45 and over living in private occupied dwellings across 10 provinces. Residents in all territories, people living on Indian reserves or Crown lands, people living in institutions, full-time members of the Canadian Forces, and residents of some remote regions were not included in the survey. The final sample consisted of 30,865 participants who were interviewed via telephone or in person.

The CCHS data set was used to supplement information gained from the RAI-HC data, as it provides the perspectives of seniors and caregivers on their health and experiences. We obtained the public use micro data file (PUMF) for this survey from Statistics Canada and our methods and analyses were verified by Statistics Canada personnel.

In our analyses, we only examined responses from people 65 years and older, except for caregiver data, where we examined the responses from all participants. To more accurately represent the population, data were weighted by age, gender, geography, and other characteristics based on recent census data. The data of those receiving professional assistance do not distinguish between public or private care.

Organisation for Economic Cooperation and Development (OECD) Health Data 2011

Health Expenditure and Finance Data presented in OECD Health Data 2011 are based on the 2008 Joint OECD-Eurostat – WHO Health Accounts (SHA) Data Collection and the OECD Health Data Questionnaire. The OECD National Accounts provided the gross domestic product (GDP) aggregates for each country.

We used public health expenditure data from the OECD database to depict public expenditure (based on a percentage of a country's gross domestic product) on home care compared to long-term care. We examined data from countries which provided information on both for these aspects of continuing care. The OECD defines these two categories in the following ways:

Long-term nursing care at home This definition comprises long-term nursing and personal care services provided to patients at home who need assistance on a continuing basis due to chronic impairments and a reduced degree of independence and activities of daily living. It includes nursing and personal care services, and services in support of informal (family) care related to ADL restrictions.

Inpatient long-term nursing and personal care This definition comprises nursing care delivered to inpatients (within a long-term care institution or community facility) who need assistance on a continuing basis due to chronic impairments and a reduced degree of independence and activities of daily living.

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