

Because this *is* the rainy day: a discussion paper on home care and informal caregiving for seniors with chronic health conditions

February, 2011



THE CHANGE FOUNDATION

HEALTH CARE DESERVES
OUR FINEST THOUGHT

About The Change Foundation

The Change Foundation is an independent policy think tank, intent on changing the health-care debate, health-care practice and the health-care experience in Ontario.

A charitable foundation established in 1996 and funded through an endowment, The Change Foundation leads and leverages research, policy analysis, quality improvement and strategic engagement to enable a more integrated health-care system in Ontario designed with individuals and caregivers top of mind.

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“The comfort of home is the best gift we could give them as their children....
It’s not because we’re wealthy but rather because this is the rainy day.”
—A daughter about her parents who are both frail and elderly.

INTRODUCTION

Can we provide good care at home for seniors with chronic health conditions? If so, at what cost? And to whom? To explore these questions, The Change Foundation commissioned leading home-care expert Dr. John Hirdes, (Professor, University of Waterloo and Scientific Director, Homewood Research Institute), to examine data on Ontario seniors with chronic conditions to help us understand how they use home-care services, what their health-care needs are as they move from hospital to home and/or community care, and what the implications are for their caregivers.

Dr. Hirdes and his research team delved into rich, detailed data about home-care use in Ontario from 2004 to 2008. The picture that emerges illustrates the need for action to address three objectives:

- to better align home-care services to seniors’ needs;
- to realign resources from acute to community care; and
- to use home care more strategically to provide seniors and their informal caregivers with care and support tailored to their needs as well as to help solve health system problems.

One of these problems is the growing number of Alternate Level of Care (ALC) patients—a term for people who are in hospital beds but could be cared for more appropriately in other settings. Although there are a number of possible destinations from ALC—retirement homes, assisted living/supportive housing, rehabilitation facility—this work focuses on seniors in ALC beds who are waiting to be discharged home with services tailored to their needs or who are waiting for a long-term care placement.

An examination of the data also suggests that we must be careful not to simply transfer problems from hospital to home. For home care to be the solution for seniors with chronic health conditions, their caregivers—family and friends—need to receive adequate support. Without it, they may be unable to cope, their own health could deteriorate, and as a result, their loved one could end up back in hospital. An examination of one subset of seniors in Ontario—those with congestive heart failure—points to the importance of chronic disease management, especially when multiple medications are in order. The role of primary care in coordinating care needs for this population is particularly critical and speaks to the need for a more integrated system. This commentary will share worrisome new data about the failure to follow best practices in treating seniors with congestive heart failure. The data (discussed later in this commentary) is yet another example of the disconnect that exists between primary care and the rest of the health-care system. This systemic failure to communicate and connect sends many seniors on a troubling trajectory back to hospital. This failure can be averted if we act on what we know now.

Questions prompted by the data analysis include:

- What sort of warning signs should health-care professionals be looking for in seniors to prevent or offset problems with discharge or transition from hospital to home and/or community care? How should these signs be heeded to help seniors go back home and live independently longer?

- Why do some ALC patients with moderate-priority needs for home care end up in long-term care facilities, and others return home? Although 63% of ALC clients have high- or very-high-priority needs, 37%—more than one in three—have needs no more urgent or complex than those of people being cared for at home. What factors are involved in the decision-making? And how do we explain the wide regional variation (a 20% difference across Local Health Integration Networks) between the percentage who go home and who go to long-term care?
- With chronic diseases on the rise, why is disease management still lacking? Why do one-third of senior home-care clients with Chronic Heart Failure (CHF) not receive the recommended medications? What is—or should be—the role of primary care in managing chronic diseases and in promoting self care? How could primary care and home care work together more effectively?
- Who are informal caregivers today? Who will they be tomorrow? Will they be able to contribute as much as the system expects them to? Where is the tipping point for caregiver support?
- How can the system be responsive to caregiver needs and ensure the sustainability of this invaluable resource?

We hope that this Change Foundation commentary, underpinned by Dr. Hirdes' data findings and other sources, will contribute to an informed discussion about a relevant and timely topic—one in which the real questions all too often get obscured by talk about sustainability, shame, or who is to blame. Instead, we need to focus on solutions that will help seniors and caregivers, respect their contributions and begin to address larger health system issues.

Yes, people are living longer and many want to stay at home. Yes, we have growing numbers of frail elderly people in Ontario and a shrinking pool of informal caregivers and provincial resources. But as this commentary will show, we have the information and analysis—and incentive—to shift to a more strategic use of home-care services. We also have some promising new approaches, such as the Aging at Home Strategy and the Integrated Client Care Project, that are still in early stages but represent a commitment to this shift.

However, to get ahead of the grey tsunami, we will ultimately need new ways to deliver care to seniors and support to their caregivers. This will mean altering the balance of health-care-dollar allocations—changing how we slice the pie, deliberately cutting it differently to better meet the evolving needs of the elderly and their caregivers.

THE CURRENT SITUATION IN ONTARIO

Home is where the heart is—and where most seniors want their care—but to keep them (and often, their hearts) healthy enough to be at home, we need to better align Ontario's home-care services with their needs, and we need to support the family and friends who are providing invaluable care.

One of the provincial government's key initiatives for seniors is the Aging at Home Strategy. A four-year, \$1.1 billion strategy (not yet fully implemented, or evaluated), it will provide a range of community-based services to help seniors stay healthy and live independently in their own homes—connected to their families and communities—for as long as possible.

One question we need to address: How long is possible? When seniors become frail and are cared for at home, a substantial part of that care falls to family members (particularly spouses and children), and friends and neighbours. Is it reasonable to expect that seniors with chronic conditions will receive good care at home? And at what cost to their friends and families?

By enhancing home-care services, creating more nursing outreach teams for high-risk seniors, meeting more complex health needs at home, and locating services such as rehabilitation and restorative beds outside hospital, the Aging at Home Strategy is expected to reduce the number of ALC patients. Having fewer people waiting in hospital for transfer to a long-term care (LTC) home or other setting will reduce the overall cost of care. It will also relieve the pressure on hospitals and free up more beds, which will cut wait times for hospital and emergency services, making the system more efficient.

Preparing for an aging population

In the next 25 years, Ontario, like other jurisdictions, will face a rising tide of seniors who may have complex health-care needs. In 2009, seniors made up just over 10% of our population. By 2036, their number is expected to more than double, and nearly one of every four Ontarians—4.2 million people—will be 65 or older (Government of Ontario 2010). And the oldest groups will grow most quickly: the number of people 75 and older will be 2.5 times larger, while the number of people 90 and older will triple.

In just five years—for the first time in our province’s history—people over 65 will outnumber children ages 0 to 14. And this is a significant challenge because 80% of care is provided by informal caregivers (Wiles, 2003).

As people age, they are more likely to have two or more chronic conditions—such as heart disease, respiratory disease, arthritis, diabetes, or osteoporosis—that threaten their health and require ongoing care. A recent report by the Canadian Institute of Health Information (CIHI) points out that the number of chronic diseases, rather than age, is the major driver for health-care service use. Seniors with three and more chronic diseases use health care three times more than those who do not have chronic diseases. In Ontario, 75% of seniors have more than one chronic disease (CIHI, 2011).¹

At the same time that we are faced with a dramatic increase in the number of seniors who will need care, we are seeing an equally dramatic *decrease* in the number of family members on hand to provide it—and also in their ability and willingness to do so. According to Statistics Canada, in 2006:

- the number of nuclear families had fallen by 18% in just five years (since 2001)
- 51.5% of the population was not married
- 42.7% of households had no children
- one in four families was led by a single parent (up 8% since 2001).

More people are living alone and have fewer family members to help them. Before we can assume that most Ontarians will age well at home, we must answer some key questions:

- When seniors develop chronic health conditions, what are their care needs?
- To what degree can these needs be met at home?
- How will that care be shared between informal and formal caregivers?
- What are the costs to families, friends and neighbours (known as “informal caregivers”) of providing additional care at home?
- What supports will these informal caregivers need to take care of their loved ones and maintain their own health?
- When is home the right place to provide care and when do we need to consider alternatives?

UNDERSTANDING THE NEEDS OF SENIORS WITH CHRONIC HEALTH CONDITIONS

A clearer picture of the needs of seniors using home-care services is emerging as we analyse the data gleaned from a tool called the Resident Assessment Instrument–Home Care (RAI–HC). In Ontario, every adult referred to a Community Care Access Centre (CCAC) for home care, who receives uninterrupted care for more than 60 days (known as a long-stay client), is assessed using the RAI–HC. So is every adult ALC patient waiting for a spot in a long-term-care home.

The provincial RAI–HC database includes comprehensive information on one million long-stay home-care clients and 60,000 ALC patients—including their health status, preferences and needs. CCAC case managers use those data to help plan each person’s care. The RAI–HC records have been linked to CCAC service and discharge records, making it possible to track clients’ experiences—what services they received, when they were discharged from the CCAC, and why.

The University of Waterloo research team analyzed the RAI–HC data with a focus on three specific areas:

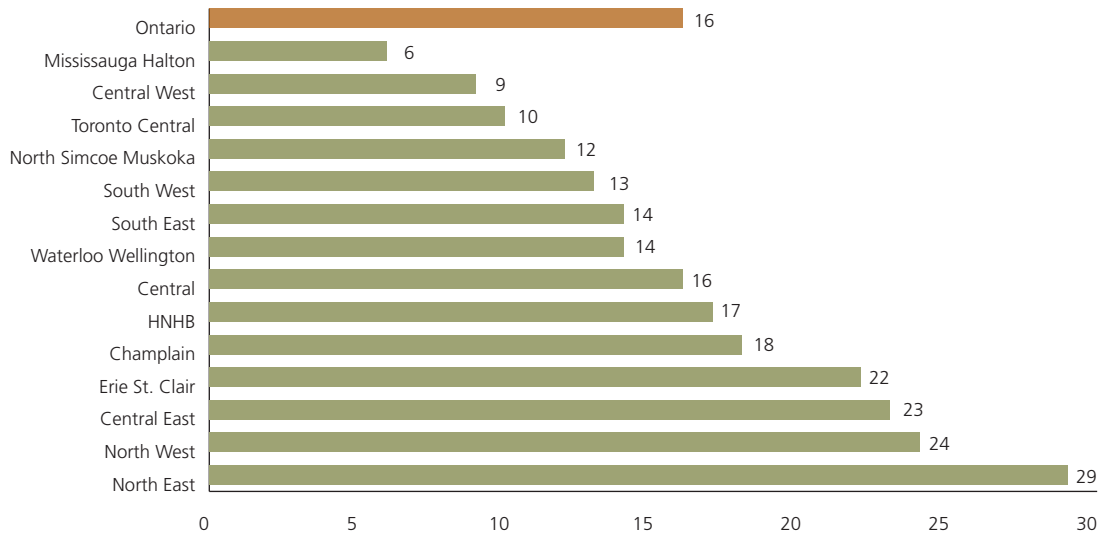
1. the health needs of ALC patients waiting to be discharged to long-term care (LTC). Do they all require placement in LTC, or could some manage to live at home, with appropriate services? How do their needs compare to those of people already being cared for at home?
2. the services provided for people with congestive heart failure (CHF) being cared for at home. Are home-care clients with CHF receiving the careful monitoring and disease management that their condition calls for? Is the system able to provide appropriate support and services to help people with this, and other, complex chronic diseases to manage their health conditions at home?
3. the stress that family caregivers experience providing palliative care at home. What kinds of stress? And what factors contribute to it?

¹ This analysis looked at 11 chronic conditions: arthritis, asthma, cancer, chronic pain, depression, diabetes, emphysema or chronic obstructive pulmonary disease, heart disease, high blood pressure, a mood disorder other than depression and stroke.

Tipping the scales: What determines destination—long-term care or home?

In 2004, about 10% of acute care beds in Ontario hospitals were being used by ALC patients—people who no longer needed hospital care, but couldn't be discharged due to a lack of support in the community. More than half of them (55%) were waiting for spots in LTC. The percentage fluctuates, but has risen considerably since. In 2008, ALC patients were using one of every five acute care beds (20%), and by December 2010 that figure had inched back down to 16 % (OHA 2010).

Figure 1: Percent of Acute and Other In-patient Care Beds Occupied by ALC Patients by LHIN

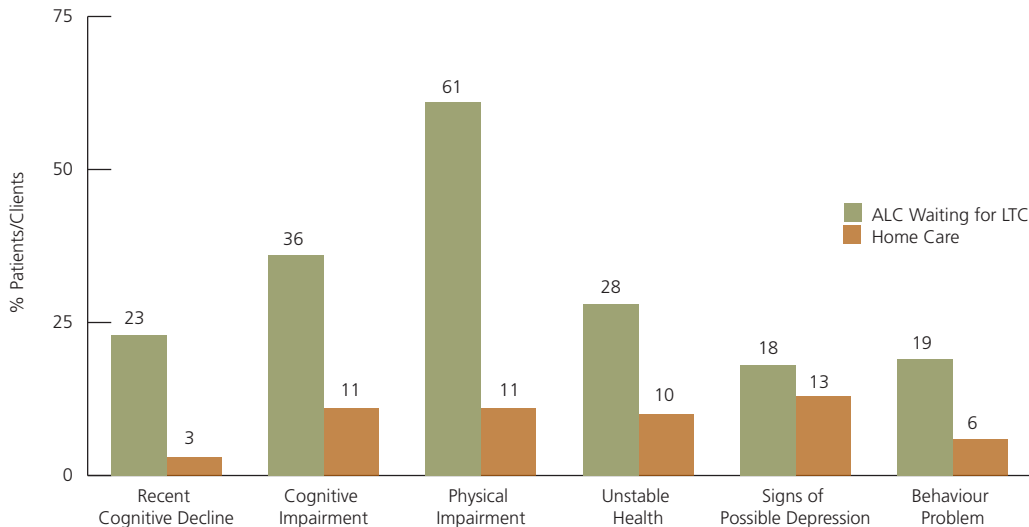


Source: OHA ALC Survey Results, December 2010

The inability to move ALC patients out of hospital and into more appropriate care settings creates serious problems for all involved. For hospitals, it contributes to overcrowded emergency departments and cancelled surgeries. For patients—a higher risk of acquiring an infection and failure to get the therapy they need to recover and retain or regain their mobility.

What is it about ALC patients that makes it so difficult for the health-care system to meet their needs? The RAI–HC data analysis showed that certain health conditions are more likely than others to prevent a patient’s successful discharge home, and to lead to the patient being designated ALC and waiting for placement in LTC. For example, more than 60% of ALC patients who are waiting for a spot in LTC have physical impairment; 36% have cognitive impairment; and 23% have recently experienced cognitive decline (see Figure 2).

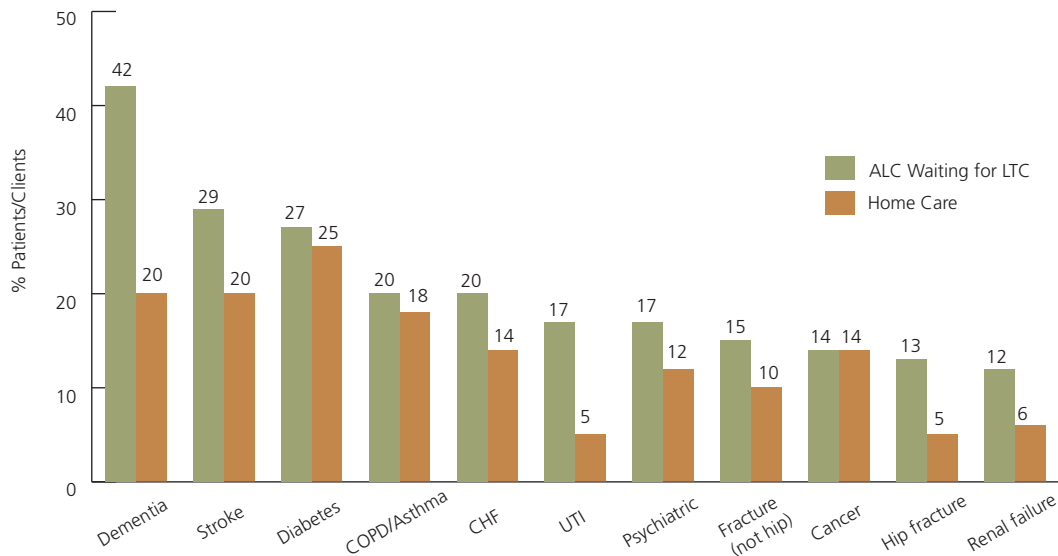
Figure 2: Clinical Characteristics of ALC Patients and Home–Care Clients (65+), Ontario, 2007-2008



Source: ideas for health, University of Waterloo, 2010

They are also more likely to have dementia, diabetes, CHF or other chronic conditions (see Figure 3) and often two or more of these—making their health needs more complex.

Figure 3: Selected Diagnoses for ALC Patients and Home-Care Clients (age 65+), Ontario, 2007-2008



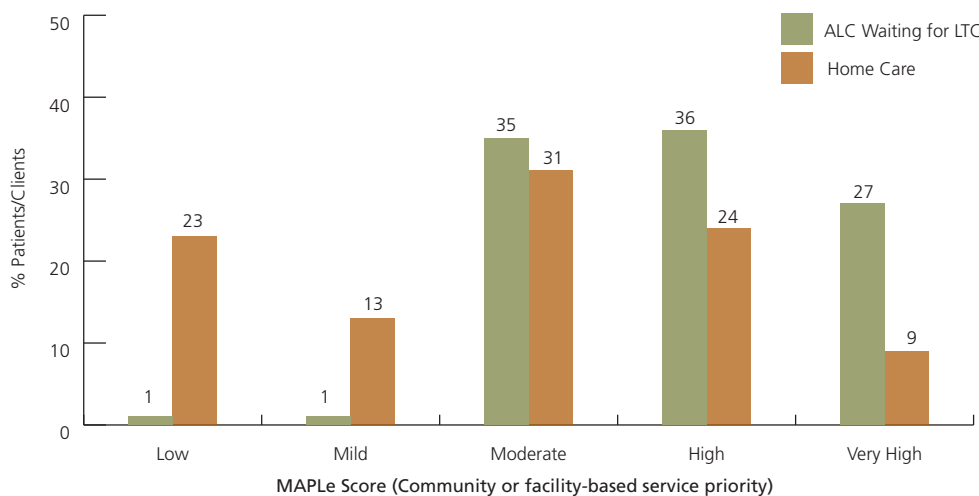
Source: ideas for health, University of Waterloo, 2010

However, health conditions aren't the only factors that keep patients in hospital and prevent them from going home. Behavioural problems can also play a part, as can issues with medication management, living conditions or caregiver availability. All of these are important factors in discharge planning and decision-making.

A close look at the data shows that ALC patients waiting for LTC spots tend to be older than seniors who are receiving care at home (close to half are over 85), more likely to live alone (40% versus 34%), and more likely to have problems communicating. These are factors in the Method for Assigning Priority Levels (MAPLe)—a decision-support algorithm used by CCACs to help them assign a priority ranking to patients, based on their needs for care.

Figure 4 compares the priority levels of ALC patients with those of home-care clients, based on their MAPLe scores. A large proportion of the ALC group (63%) have high- or very-high-priority needs, which understandably makes them candidates for institutional care. But what about the 35% of ALC patients—more than one in three—whose health needs are no more urgent or complex than those of the home-care clients? According to the RAI-HC data, the health of some ALC patients in Ontario is not that different from the health of patients who get to go home. So, what tips the scales? What determines if someone goes home with home-care services or is discharged, instead, to LTC?

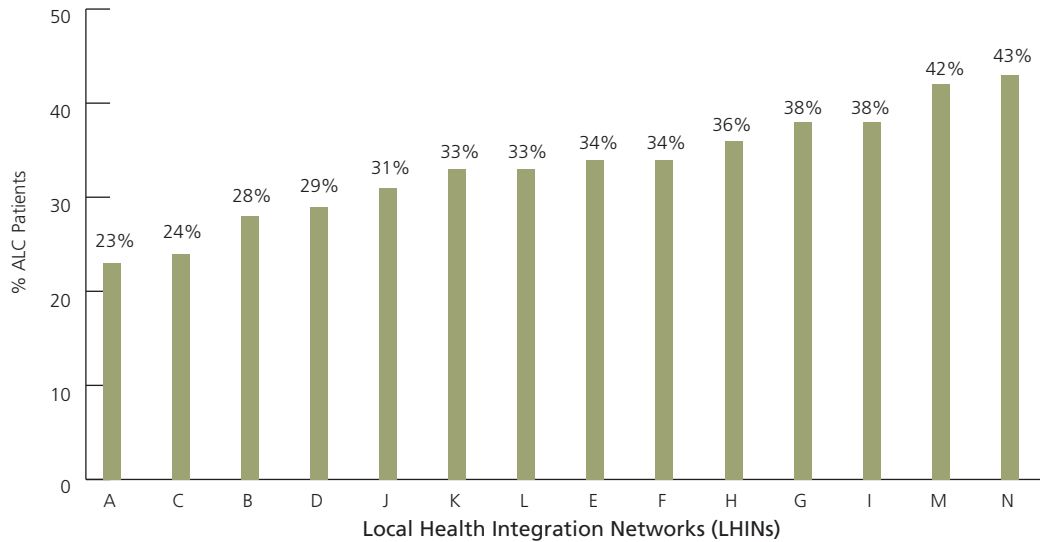
Figure 4: Patient Priority Level for Access to Community or Facility-based Services (age 65+), Ontario, 2007-2008



Source: ideas for health, University of Waterloo, 2010

The data also show that geography plays as big, or bigger, a part as health needs in determining whether ALC patients go home or to long-term care. Figure 5 shows that despite having similar health needs for home-care and support services, ALC patients in some regions are more likely to go to LTC, while those in other regions are more likely to be discharged home with supportive services.

Figure 5: Percentage of ALC Patients with Moderate MAPLe Priority Admitted to Long-term Care over 6 Months, by LHIN, Ontario, 2004-2008



Source: ideas for health, University of Waterloo, 2010

Whether patients end up at home or in LTC also depends on cognitive status, signs of depression and the availability of informal support at home. Do they have family or friends to help with their care? Are those caregivers able to cope?

Caregivers of ALC patients

According to the RAI-HC data, caregivers of ALC patients are three times more likely to feel stressed than those caring for someone at home, and most (87%) believe the patient would be better off in another setting. Everyone agrees: people should not be in hospital if they don't need acute care. But what should the health system do for a person who doesn't need hospital care but who is frail or has highly complex needs?

To help more ALC patients cross that line from hospital to home with supportive care, we need to look closely and critically at the characteristics of patients who *can* be successfully cared for at home. A little more support could allow more people to be safely shifted from ALC to home, increasing capacity and productivity in the acute care sector, reducing the cost of care, and improving the quality of life for individuals and their families. In fact, some regions are now sending ALC patients home to wait for their LTC placements, and are finding that sometimes—as the person's condition improves—LTC is no longer the best option.

However, the line between ALC and home care can be crossed in both directions. Just as it is possible to provide extra support that will allow more people to go home, the opposite is true: if someone with complex needs who is receiving care at home loses a degree of support—a spouse becomes ill, a neighbour moves away—that person may quickly end up in hospital.

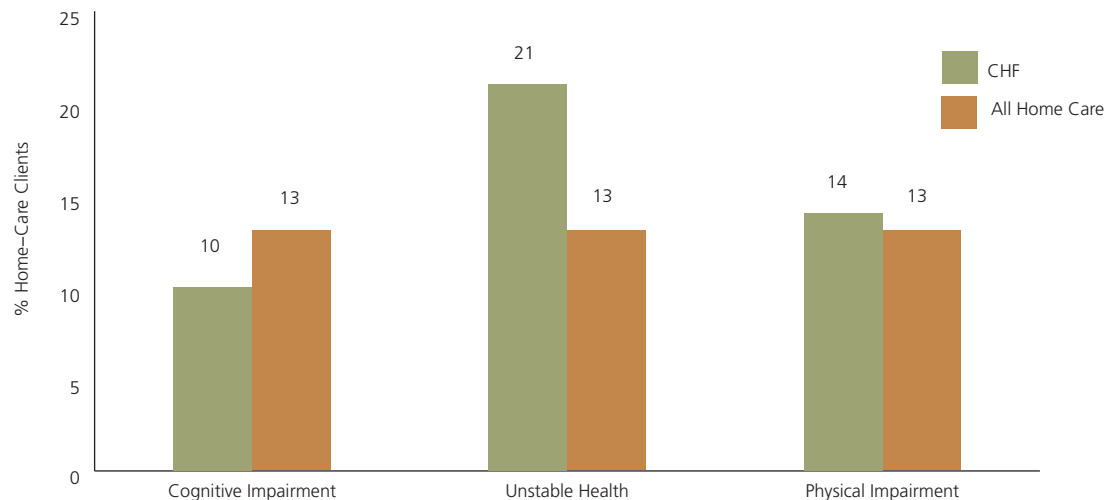
A CAUTIONARY TALE ABOUT MANAGING CONGESTIVE HEART FAILURE AT HOME: WHERE IS PRIMARY CARE?

If more ALC patients are to be discharged home, the system's capacity to provide a high quality of home care will be under increasing pressure. There is no doubt that the complexity of care available at home has changed dramatically in the past 20 years, with therapies such as IV and dialysis now routinely provided there. But given that almost 90% of home-care clients 65 and older have two or more chronic conditions, it's important to determine just how effective home-care services are at meeting complex needs. To help answer this question, our researchers looked at one specific group: the 15% of older home-care clients (65+) who have congestive heart failure (CHF).

CHF is the fourth-most-common chronic disease in Canada, and the risk of developing it increases with age. With the aging of the population, the incidence of CHF is expected to double over the next 30 years. A complex, stressful and expensive illness, CHF requires complicated and costly treatments, and people who have it are hospitalized frequently and must be closely monitored. They have to watch their diet and their fluid intake, and most require exercise or physical therapy.

The RAI-HC data confirmed that people with CHF who are cared for at home have highly complex needs. They have about the same level of physical impairment as overall home-care clients—and less cognitive impairment—but a much higher proportion of CHF patients have unstable health. Also, if the condition is not treated appropriately, their health is more likely to suddenly and rapidly deteriorate, leading to frequent hospital readmissions.

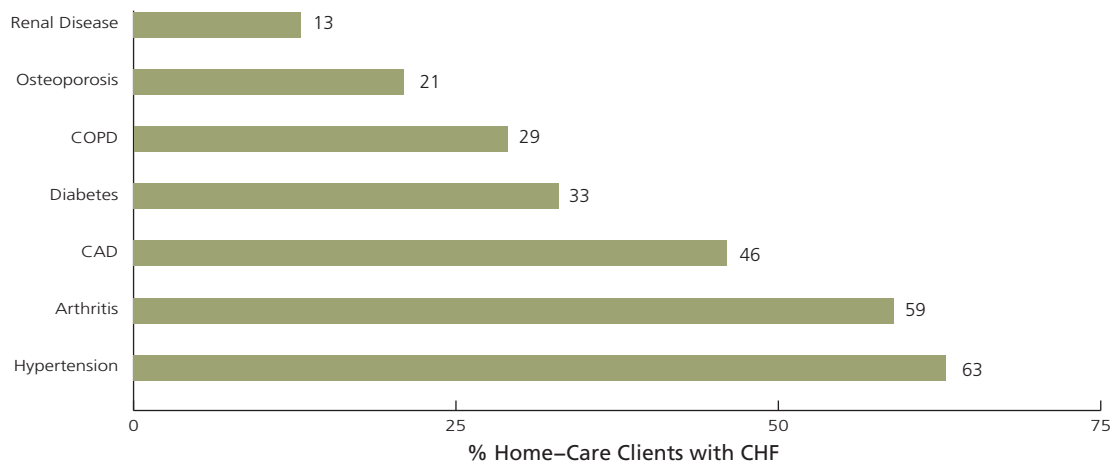
Figure 6: Rates of Cognitive and Physical Impairment, and Unstable Health among Home-Care Clients with CHF (65+), Ontario, 2004-2007



Source: ideas for health, University of Waterloo, 2010

Almost half have more than five other conditions, such as hypertension, arthritis, coronary artery disease and diabetes (Figure 7). More conditions and medications complicate their care, and this likely explains why people with CHF need more monitoring and receive more intensive care than overall home-care clients and make greater use of support services such as homemaking, nursing and meals.

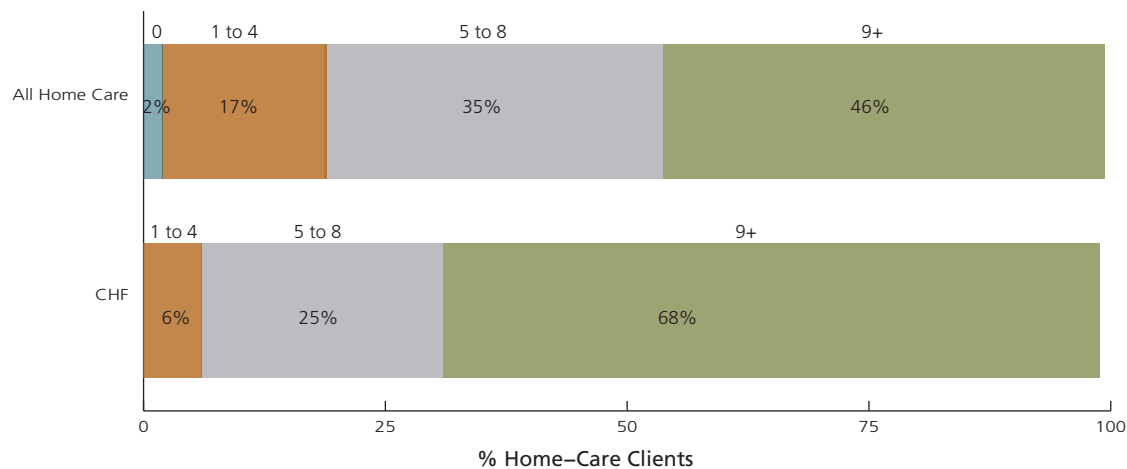
Figure 7: Common Comorbidities of Older Home-Care Clients with CHF (65+), Ontario, 2004-2007



Source: ideas for health, University of Waterloo, 2010

Almost half of CHF patients experience pain every day and 68% are taking nine or more medications at a time (compared with 46% of overall home-care clients).

Figure 8: Home-care Clients with CHF Use More Medications than All Home-Care Clients, Ontario, 2004-2007



Source: ideas for health, University of Waterloo, 2010

When the U. of Waterloo researchers looked closely at the 21,000 home-care clients with CHF, they raised some serious concerns:

- Only 29%—less than a third—were receiving the recommended front-line therapies for CHF, and 29% were receiving none of the medications recommended for heart failure.
- Optimum medication use varied across the province; some regions did a better job than others at ensuring that clients received the recommended treatments.
- Optimum medication use varied across provincial regions: some areas of the province did a better job than others at ensuring that clients received the recommended treatments. It also varied according to client characteristics: those who were older (85+) and more frail were less likely to receive recommended medications—which may mean that advanced age and frailty are barriers to managing a disease such as CHF at home.
- Overall health outcomes were not good. Within 90 days of discharge from hospital, almost 40% of clients with CHF were readmitted, and almost 25% had visited an emergency department.

Chronic disease management relies heavily on individuals playing a strong role in monitoring and managing their own health and treatments. Should they be elderly, frail and/or have other chronic conditions—perhaps including a loss in cognitive ability—this may not be a reasonable expectation. The fact that 68% of clients with CHF take nine or more medications is in itself a challenge for both client and caregiver: keeping all the medications straight, adhering to dosage schedules and detecting any signs of adverse interaction. Nonetheless, the RAI–HC data show that it is possible to provide high-quality care for people with highly complex health needs at home.

In the case of CHF, primary care providers must ensure that their patients are receiving the recommended treatments and must take a lead in ensuring that appropriate support and care is provided to these high-need patients to help them manage their conditions at home effectively. This change alone could significantly alter the trajectory for many people with CHF—people who now end up back in hospital or in the emergency department. In the current environment, the coordination of services for people with chronic health conditions is extremely fragmented and confusion about who does what further compounds the problem.

HOME CARE: WHO SAVES? WHO PAYS?

The trend of moving services out of institutions and into the home or community is driven, in part, by people's desire to be at home. It is also driven by economics.

Home is one of the most cost-effective places to provide care for seniors with chronic health conditions. That is borne out by the results from a project conducted by The Boston Consulting Group and funded by The Change Foundation and the Community Provider Associations Committee, which includes the Ontario Association of Community Care Access Centres, Ontario Home Care Association, Ontario Community Support Association, Alliance of Professional Associations for Community-based Therapy Services, and the Community Home Care Providers Network.

The project, called Valuing Home and Community Care (VHCC), focused on the Hamilton Niagara Haldimand Brant Region. It showed that care for seniors 75 years old and up in assisted living costs 1.2 to 1.8 times more than home care, while LTC costs 2.2 to 3.4 times more. The economic modeling project found that the region spends about \$48 million a year for home-care services to help seniors over 75 stay in their homes. But it thereby saves about \$60 million in assisted living and LTC costs, plus another \$6 million in hospital costs. That's a saving of \$13 million a year.

While investment in home care has the potential to save the health-care system money, it may cost individuals and the province in other ways:

Very few seniors receiving home care are otherwise managing on their own. Of 131,000 home-care clients 65 and older, 98% are also getting help from an informal caregiver (CIHI 2010). For family and friends, caregiving can be stressful, as already discussed, and it can be expensive as well.

As Figure 12 (Hollander, Liu, and Chappell 2009) shows, older people are caring for older people. Of caregivers age 65 and over, 60% are caring for a spouse, friend, parent or sibling. Adult children—often raising children of their own—are also caring for older parents and friends.

Figure 9: The Relationship between Caregivers and Care Receivers

Care was received by:	Caregivers Aged 45-64		Caregivers Aged 65+	
	n	%	n	%
Spouse/partner	24,805	1.4	70,457	23.3
Father	236,284	13.4	5,331	1.8
Mother	732,406	41.6	22,945	7.6
Brother	7,928	0.5	6,238	2.1
Sister	11,435	0.6	19,684	6.5
Son/daughter/grandson/granddaughter/ son or daughter-in-law	3,136	0.2	729	0.2
Grandfather or grandmother	12,887	0.7	–	–
Father-in-law	82,983	4.7	3,056	1.8
Mother-in-law	218,024	12.4	11,209	7.6
Brother-in-law	9,824	0.6	4,913	2.1
Sister-in-law	5,410	0.3	6,046	6.5
Uncle	16,431	0.9	2,002	0.7
Aunt	50,473	2.9	4,621	1.5
Cousin	9,034	0.5	4,646	1.5
Close Friend	161,053	9.2	89,911	29.7
Neighbour	144,338	8.2	44,750	14.8
Other	32,927	1.9	5,757	1.9
Number of Caregivers	1,759,378	100.0	302,295	100.0

Source: Hollander et al, 2009

For many, caregiving is a full-time job. The average caregiver provides 22 hours of care a week (Posse, et al 2008) in addition to the time spent on paid employment and on other family responsibilities. According to the 2007 General Social Survey, 24% of Canadians missed full work days and 16% were working reduced hours in order to care for an elderly relative (Statistics Canada 2007).

And caregiving is not a short-term commitment. According to the Deloitte 2009 Canadian Survey of Healthcare Consumers:

- 10% of Canadians have a family member who requires constant care;
- 27% of Ontario families have been providing constant care for over two years; and
- one in six Ontarians says these care requirements are having a major impact on their ability to earn family income.

The VHCC project estimates the cost to caregivers in lost productivity alone (in this region alone) at about \$5 million a year—not including emotional and other costs associated with the stress of caring for someone who has complex needs or is being looked after at home. If these are figured in, the cost to families is much higher. According to one analysis, informal caregiving for the elderly—care provided by spouses, children, siblings, friends and neighbours—saved the Canadian health-care system \$25 billion in 2007 (Hollander, Liu, and Chappell 2009). No small contribution, given that total health-care spending that year was \$113 billion (CIHI 2010).

THE FAMILY FACTOR

There is no doubt that with an aging population and the continuing rise of chronic health conditions, we will be relying on informal caregivers more than ever before. But how will it affect them, especially as the number and size of families is decreasing? (Keefe, 2007) How long can informal caregivers support their loved ones as they themselves grow older?

As the following quotes from the VHCC project illustrate, there are implications for opting for home care. On one hand, there is the desire for seniors to live at home as long as possible and there are savings to the health-care system. On the other hand, it can put untenable pressure on family members and friends, and can take a toll on them physically, emotionally and financially. This is especially true if frail seniors live not for weeks or months but for many years with complex needs and chronic conditions. The stress increases if caregivers are providing more than 21 hours of care per week, if the senior is depressed or has cognitive problems, or if behavioural issues are involved (CIHI 2010).

As one daughter said about her mother, “She hated the thought of not living at home—it meant the world to her... [but] in the last few years my mom was living at home, it became more difficult. I was always worried about her falling and felt that if I didn’t check in every day she wouldn’t eat. It was pretty stressful.”

One man, Tom, says, “I feel good when I’m at home. I want to stay here as long as possible.” But the situation is stressful for his wife, Thelma, who insists that Tom go to an adult day program once a week to give her a break. She often spends that entire day in bed, catching up on sleep and relaxing. “It takes my mind off caring for him. I feel happy that I can go somewhere and not think about my responsibilities at home.”

Said a daughter about her parents who are both frail and elderly: “The comfort of home is the best gift we could give them as children...It’s not because we’re wealthy but rather because this is the rainy day.” At the same time, she and other members of her family believe they have made a “monumental sacrifice” to make the home care possible. “Consistency is the key to success—my parents have a very elaborate schedule of care. If one piece gets disrupted, it is chaos.”

Even for seniors who can manage without an informal caregiver, there are stresses:

“I’ve had two loves in my life,” said John, “my wife and my farm. Now that my wife has passed, I can’t imagine leaving this farm...However, I wish that there was an opportunity to have someone to talk to.”

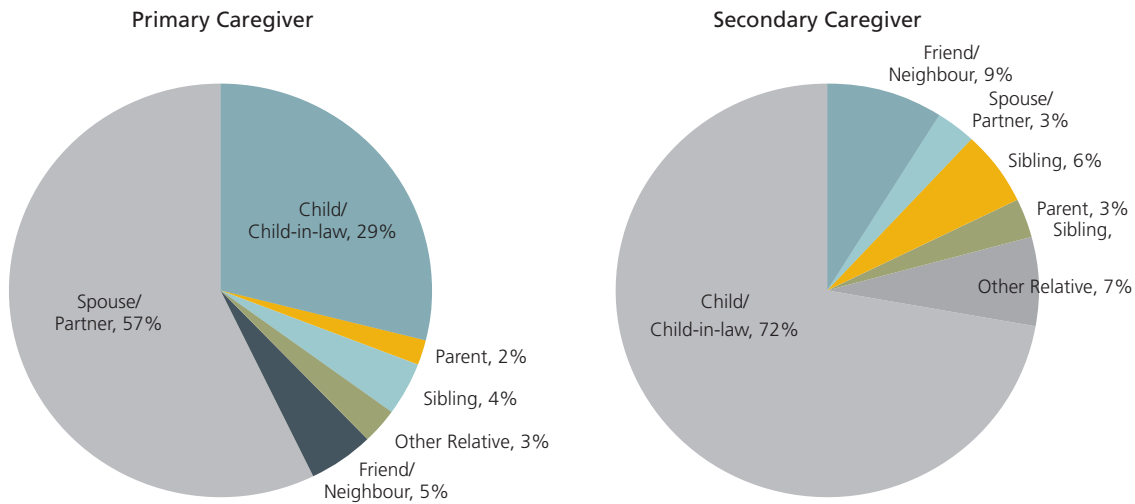
“I’m a people person and it can get lonely at home,” said Violet. “I have a great circle of friends but it’s hard to get together...I appreciate the company of my [personal support worker]. I would be much lonelier without her. I would likely move to assisted living without [her].”

Clearly there are benefits and costs to being cared for at home. Many seniors value being at home but they and/or their caregivers may pay a price in terms of cost, time away from work, anxiety, stress or loneliness.

THE STRESS OF CARING FOR A LOVED ONE AT END OF LIFE

The third component of the research we commissioned looked at the predictors of caregiver distress among palliative care patients in Ontario, mining interRAI–Palliative Care (PC). It is a similar tool to the RAI–HC, but specifically for assessing the needs of palliative care clients and their families. It can help us increase our understanding of the stresses family members undergo when caring for someone at home at end of life. The researchers looked at RAI–PC data on 3,929 clients who received palliative home care in Ontario between 2007 and 2009 (Foebel, Hirdes, et al 2011). Most of the care was provided by a spouse or partner and/or an adult child.

Figure 10: Primary and Secondary Informal Caregiver’s Relationships to the Palliative Home–Care Client, Ontario, 2006–2008

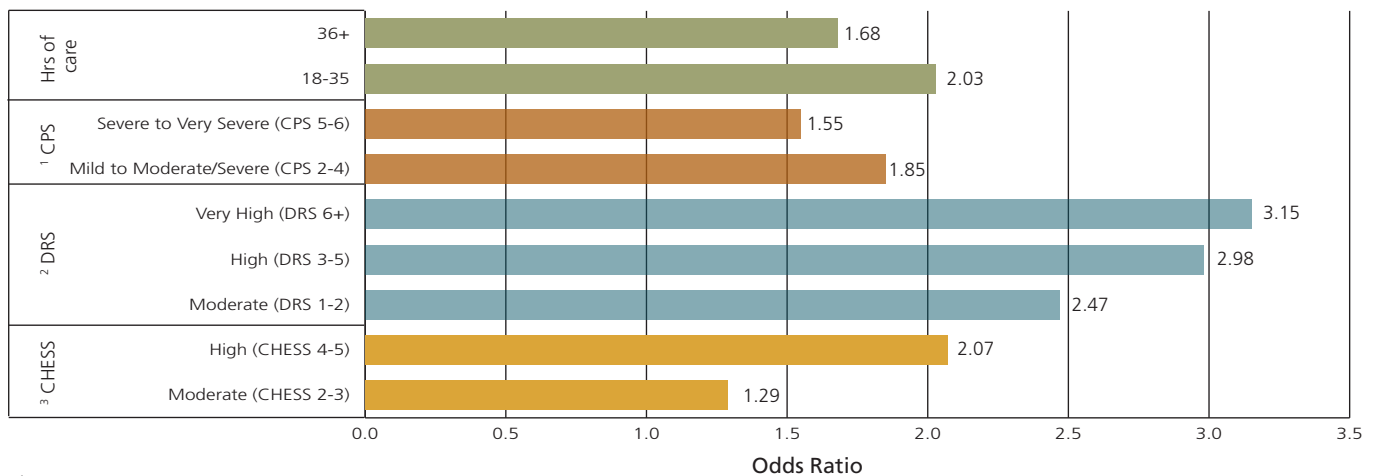


Source: ideas for health, University of Waterloo, 2010

Most of these informal caregivers seemed to be coping, although nearly one in four (23%) reported signs and symptoms of stress, such as not being able to continue their caregiving activities; feeling distressed, angry or depressed; and/or feeling overwhelmed by the person’s illness. This is significantly higher than the 16% of informal caregivers (nearly 20,000 people) who reported stress in an analysis of broader RAI–HC data (CIHI 2010).

Predictably enough, caregivers’ stress increases with the number of hours of care they provide. When caregivers were asked how much care they had provided in the last three days, their responses showed that their distress was highest when they provided between 18-to-35 hours of care. But interestingly enough, as the palliative patient’s health condition progresses, and the caregiver provides more than 36 hours of care, he or she learns to cope with the demands—and the stress declines (see Figure 11).

Figure 11: Risk of Caregiver Distress–Palliative Care, Ontario, 2006-2008



¹ Cognitive Impairment Scale (CPS) is used to rate cognitive status of the client.
² Depression Rating Scale (DRS) is used as a clinical indicator of depression.
³ Change in Health, End-stage disease and Signs and Symptoms(CHESS) is used to detect frailty and instability in health.

Source: ideas for health, University of Waterloo, 2010

The picture is similar for cognitive impairment. When the patient’s cognition starts deteriorating, the caregiver is likely to experience high levels of distress, but as the deterioration continues over a period of time, she or he learns to cope. This suggests that it is especially important to support caregivers earlier on, when the patient’s condition starts changing. At a critical period of time, it could help them maintain an ability and willingness to care for their loved one to the end of life.

As for depressive symptoms and deterioration of health, these risk factors seem to affect caregiver distress in a direct, straightforward manner. For example, caregivers feel less stress if the dying person continues to find meaning in life. The higher the patient's level of depressive symptoms, the more distressed the caregiver (see Figure 11).

Caregivers also find it more stressful as the patient gets closer to death and needs increasing help with daily living activities such as bathing and eating. The sicker the person gets—the more bladder or bowel problems, for instance, and the higher level of care required—the harder caregiving becomes for family members. It's also extremely hard on family caregivers if the dying person's pain is not adequately controlled.

The health-care system (government, agencies and providers) can do a great deal to reduce the stress on informal palliative caregivers—such as increasing the intensity of home-care services and supports as a dying person's health deteriorates, and paying much more attention to the mental health of both patient and caregiver. This is the approach that the Ontario Association of Community Care Access Centres (OACCAC) is currently testing as part of its Integrated Client Care Project (ICCP), in partnership with the Ministry of Health and Long-Term Care and the University of Toronto's Rotman School of Business.

OACCAC has identified palliative-care patients and four other client groups with complex needs who would benefit from more-integrated, client-centred services (the frail elderly, medically complex children, people with chronic diseases and people who need wound care). The services will include:

- a care coordinator—someone highly skilled at assessing needs, planning care, monitoring health outcomes, helping clients and their families navigate the system and connecting them with other services in the community; and
- teams of care providers with specialized training in one of the five areas.

The project is piloting this approach with palliative care and wound care in different parts of Ontario. It will be interesting to see the impact that this client-centred, integrated care will have on family-caregiver stress.

WHAT GOES AROUND COMES AROUND—FOR THE HEALTH SYSTEM AND BEYOND

Putting more responsibility for care on families and friends may help contain or reduce health-care costs in the short term but increase them over time. Caregivers often neglect their own health and become ill, increasing the burden on the health-care system (Duxbury, Higgins, and Schroeder 2009). Caregivers are likely to suffer from hypertension, chronic back pain, and other health complications caused by caregiving (Duxbury, 2009, Coombs, 2007). When caregivers become stressed or ill, they are more likely to take their loved ones to hospital, or to place them in LTC, which also increases care costs.

What's more, the cost of informal caregiving goes beyond the health-care system and affects society as a whole:

A 1999 Health Canada report estimated that caregiver absenteeism costs Canadian employers about \$2.7 billion a year—an amount which has likely increased significantly with the aging of the population in the past 12 years. When people take time off work to provide care, it affects their careers, lifetime earning potential and pensions, which, in turn, decreases tax revenues (Duxbury, Higgins, and Schroeder 2009) and increases the demand for social welfare programs.

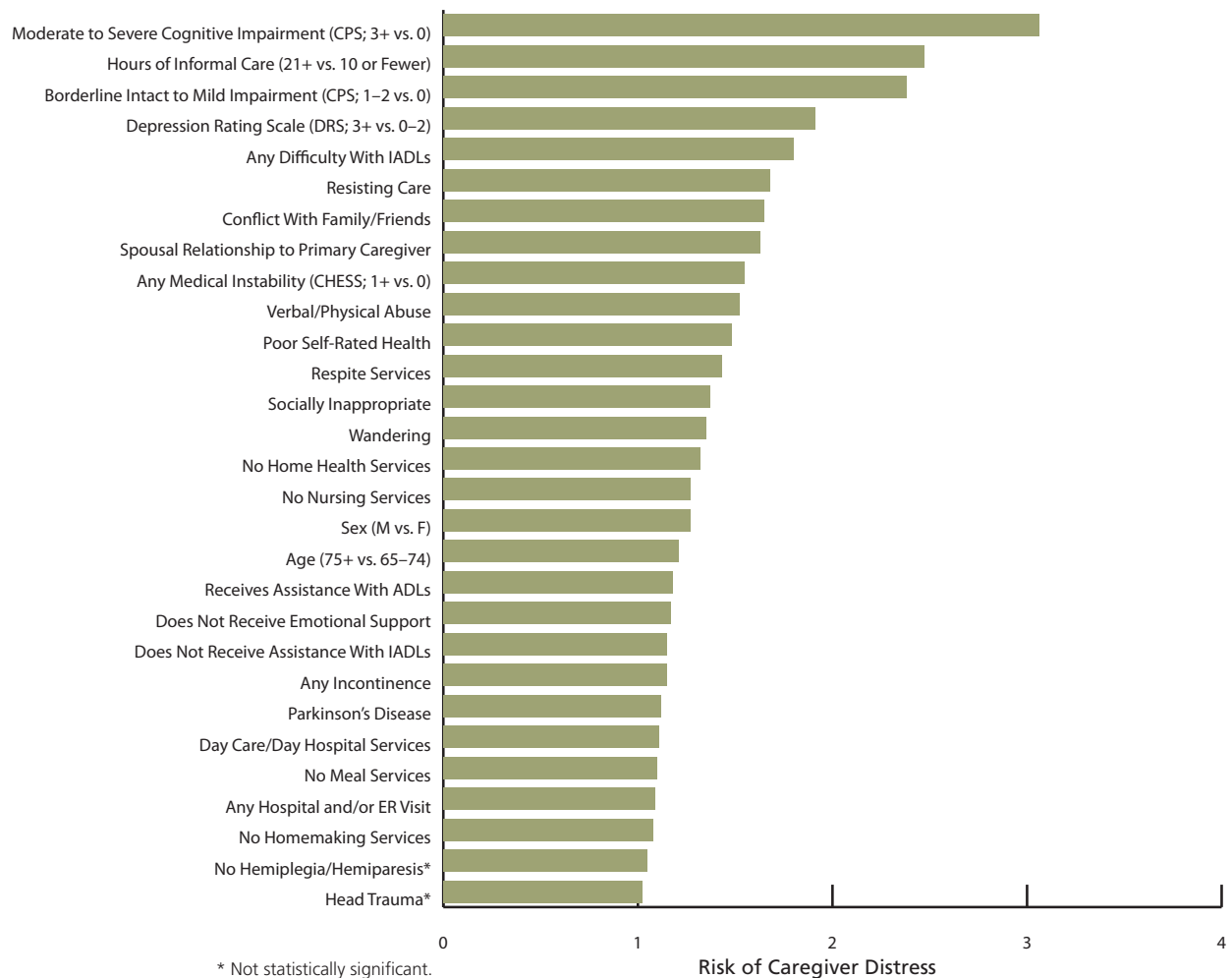
Given the aging of our population, and frail seniors' increasingly complex health needs, how realistic is it to expect families and friends to take on larger burdens of care? In Ontario, for our Aging at Home Strategy to work, we must pay more attention to caregivers' needs—identifying signs of stress in caregivers early on, for example, and providing a range of supports to help reduce the physical, emotional and financial price they pay.

Easing the stress

There is much that can be done to ease the stress. Figure 10 showed the risk for caregiver distress for palliative care, and our next table, Figure 12, does the same for caregiver distress in general—with both tables using Resident Assessment Instrument (RAI) data from a 2010 Canadian Institute for Health Information (CIHI) report.

Now that we know the factors involved—hours of care provided, degree of illness or level of needs, cognitive problems, etc.—and their impacts, we could also use the RAI to identify high-risk clients. It is possible to take action—increasing services and supports for them—before caregivers start to pay too high a price. What would a truly client- and family-centred approach look like? Picture government, employers and the volunteer sector stepping up their support in a system-wide, multi-level response, to maintain quality of life for both the caregiver and the cared-for.

Figure 12: Risk Factors for Caregiver Distress, Ontario, 2007-2008



Source: Home Care Reporting System, 2007-2008, CIHI

Home-care services are vital, but on their own they aren't enough to support seniors with chronic health conditions and their informal caregivers. The system needs to look beyond these services to other options that can reduce the isolation and loneliness that is sometimes part of giving, or receiving, care at home. These include a range of day and respite programs, caregiver support programs and supportive housing units in sufficient quantity to meet growing needs.

There are also supports outside the health-care system, including employer-sponsored programs that make it easier for workers to balance their jobs and their caregiver responsibilities; and financial assistance programs such as caregiver tax credits and the compassionate care benefit offered to people who are caring for someone at end of life.

Complex care, complex costs

When assessing the costs and benefits of meeting more of seniors' complex health needs in their homes, Ontario must look beyond the direct costs of care to the indirect costs and burdens that fall on families. Decisions must be made in a way that takes people's actual needs into account.

CONCLUDING NOTES

The rich interRAI data underpinning much of this work allows us to identify the needs of seniors with chronic diseases, to flag factors that can lead to unnecessary and costly hospitalization or long-term-care placement, and provides decision makers with the evidence and opportunity to match seniors with high intensity needs with timely services so they can stay at home longer. This resource also pinpoints the critical junctures when informal caregivers need support—again, evidence and insights that should be acted on strategically.

The data also raises questions that need answers:

- Why do some parts of the province do better than others at aligning services to seniors' needs?
- How can this rich source of information be used by health delivery organizations and policy makers to provide more appropriate services for seniors and better system planning?
- How do we make home care and primary care work together—and with seniors and caregivers—to improve health-care experiences and outcomes?
- How do we get closer to a more integrated system so we can provide the communication and coordination that seniors and caregivers seek?

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- To improve the experience of caregivers and individuals as they move in, out of, and across the health-care system over time.

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- To make caregivers and individuals in need of health care part of the health-care discussion about how to find solutions to improve their experiences.
- To stimulate new ways of thinking, behaving, and interacting to foster improved health care for people, especially when they are in transitions.
- To generate robust and independent research and policy analysis of health-care issues related to improving the experience of individuals and caregivers as they navigate the health-care system.
- To lead informed discussion and strategic engagement with the stewards, stakeholders and users of the health-care system.

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