

A middle-aged man with short, graying hair is sitting in a wooden chair. He is wearing a brown and blue argyle sweater over a light blue collared shirt. He has a slight smile and is looking directly at the camera. The background is a blurred home interior with a vase of pink flowers and framed pictures on a shelf.

The Reality of Caring

Distress among the caregivers of home care patients

Let's make our health system healthier

Health Quality Ontario is the provincial advisor on the quality of health care. We are motivated by this single-minded purpose: better health for all Ontarians.

Who We Are

We are a scientifically rigorous group with diverse areas of expertise. We strive for complete objectivity, and look at things from a vantage point that allows us to see the forest and the trees. We work in partnership with health care providers and organizations across the system, and engage with patients themselves, to help initiate substantial and sustainable change to the province's complex health system.

What We Do

We define the meaning of quality as it pertains to health care, and provide strategic advice so all the parts of the system can improve. We also analyze virtually all aspects of Ontario's health care. This includes looking at the overall health of Ontarians, how well different areas of the system are working together, and most

importantly, patient experience. We then produce comprehensive, objective reports based on data, facts and the voices of patients, caregivers and those who work each day in the health system. As well, we make recommendations on how to improve care using the best evidence. Finally, we support large-scale quality improvements by working with our partners to facilitate ways for health care providers to learn from each other and share innovative approaches.

Why It Matters

We recognize that, as a system, there is much to be proud of, but also that it often falls short of being the best it can be. Plus, certain vulnerable segments of the population are not receiving acceptable levels of attention. Our intent at Health Quality Ontario is to continuously improve the quality of health care in this province regardless of who you are or where you live. We are driven by the desire to make the system better, and by the inarguable fact that better has no limit.

System Performance Reporting

Since 2006, Health Quality Ontario has been creating a better health system by reporting on its performance. Our public reporting not only gives Ontarians the information they need to understand about their health system, it can also lead to direct improvements. Our public reporting products include: Measuring Up, our yearly report on the health system's performance,

specialized reports that delve into focused topics and online reporting of health system indicators.

The Common Quality Agenda

The Common Quality Agenda is the name for a set of measures or indicators selected by Health Quality Ontario in collaboration with health system partners to focus performance reporting. Health Quality Ontario uses the Common Quality Agenda to focus improvement efforts and to track long-term progress in meeting health system goals to make the health system more transparent and accountable. The indicators promote integrated, patient-centred care and form the foundation of our yearly report, Measuring Up. As we grow our public reporting on health system performance, the Common Quality Agenda will evolve and serve as a cornerstone for all of our public reporting products.

Learn more about *Health Quality Ontario* at www.hqontario.ca

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On the cover: Nghi, in his home in Toronto. See page 7 for his story. We thank Nghi and the other people who share with us their experiences in Ontario's health system. (Cover photo by Roger Yip)

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Photo by Roger Yip

Foreword



Dr. Joshua Tepper
President and Chief
Executive Officer

Without the province's home care system, many of the people living in Ontario who are ill, elderly or disabled would need to stay in long-term care homes, hospitals or other health facilities. Instead, with the help of the paid professional nurses, therapists, personal support workers and others who provide provincially funded home care to patients with ever-more-complex needs, they are able to remain in the comfort and familiarity of their own homes.

But there are others who also play a crucial role in helping the ill, elderly or disabled continue to live at home, and they are the family members, friends and neighbours who act as their unpaid caregivers. The importance of these caregivers to the health system is being increasingly recognized. And so is the heavy burden caregiving can place on some of them, and the distress that burden can cause.

Considering the difficulties and emotional strain often involved in looking after a loved one who is in frail health or physically or cognitively impaired, it's not possible to aim to eliminate caregiver distress. But it's important to better understand it and what steps might be taken to minimize distress where possible.

The Reality of Caring examines this distress using the caregiver distress indicator from the Common Quality Agenda. The CQA is a set of indicators developed by Health Quality Ontario in partnership with others in the health sector to measure overall health system performance. Ontario's home care system tracks distress among their patients' caregivers. The caregiver distress indicator is based on that tracking, and measures distress among the caregivers of patients who receive publicly funded home care over a long or indefinite period.

Distress among this group of caregivers has doubled in recent years, as reported in *Measuring Up 2015*, Health Quality Ontario's yearly report on how the province's health system is performing. *The Reality of Caring* examines the characteristics of the patients they look after, and the factors that appear to trigger distress among the caregivers. And because data can't tell us everything, caregivers were also consulted in the development of the report, and some of their experiences are shared in it.

The Reality of Caring adds to what we know about caregiver distress from previous reports and recognizes some of the initiatives already underway to deal with the issue.

The government of Ontario has made home and community care a priority in its Patients First strategy for health system transformation, and has identified supporting caregivers as a key component of home and community care. As well, home care providers and associations are undertaking initiatives to implement family-centred care that recognizes the key role of unpaid caregivers and addresses their needs. Many other groups are also involved. For example, The Change Foundation, an

independent policy think tank on health care in Ontario, is focused on improving both the patient and caregiver experience in its current strategic plan.

While progress is being made, the difficulty remains that we don't know much about caregivers other than what we are able to learn about them from the data collected on the patients they care for. It's time to move forward on policies to not only improve support for caregivers and thereby ultimately provide better care for home care patients in Ontario, but also to gain a better, ongoing, understanding of this critical part of our health workforce.

Sincerely,



Dr. Joshua Tepper
President and Chief Executive Officer
Health Quality Ontario

Executive Summary

Measuring Up 2015, Health Quality Ontario's yearly report on how the province's health system is performing, showed a doubling of distress among the family members, friends and neighbours who are the unpaid caregivers of long-stay home care patients.

Long-stay patients are those who receive publicly funded home care, provided by paid home care workers, for a long or indefinite period of time because of disability, frail health or chronic conditions such as dementia. Many of them are elderly.

The *Measuring Up* data showed that among the 97% of long-stay home care patients who also received care from an unpaid caregiver in 2013/14, one-third had caregivers who experienced distress, anger or depression in relation to their caregiving role, or were unable to continue in that role. That rate of distress had more than doubled since 2009/10.

The health system relies on family members and other unpaid caregivers to look after people who require care and assistance to stay in their homes. For people who receive publicly funded

home care, there may be many hours each day when professional home care workers are not in attendance caring for the patient.

With dramatic growth projected in the number of older people in the province, who more frequently require help to stay in their homes, it's likely family, friends and neighbours who act as caregivers will be needed more than ever. So it's important to take a closer look at caregiver distress, as this report does, to consider its causes and its potential impact on caregivers in Ontario as well as on the people they look after.

The report focuses on long-stay home care patients and their caregivers because that is a group for which detailed data are available. What we found was that over a five-year period (2009/10 to 2013/14), long-stay home care patients were becoming collectively older and were increasingly affected by cognitive impairment, functional disability and frail health.

- Those with mild to very severe cognitive impairment increased to 62.2% from 38.1%.

- Those experiencing moderate to very severe impairment in their ability to perform activities of daily living increased to 44.5% from 27.6%.
- Those with slightly to highly unstable health conditions increased to 43.2% from 27.3%.

Also, in the most recent year of data available (2013/14) the caregivers who helped look after home care patients were generally more distressed the more cognitively impaired, functionally disabled and frail the patients were.

- Among patients with moderately severe to very severe impairment in cognitive abilities, 54.5% had caregivers who were distressed.
- When patients needed extensive assistance with or were dependent in some activities of daily living, 48.7% had distressed caregivers.
- When patients were at the two most severe levels of health instability, 56.1% had caregivers who were distressed.

Finally, higher rates of distress among caregivers were also associated with providing more hours of care.

- On average, patients whose caregivers experienced distress received 31.5 hours per week of care from those caregivers, compared to the 17.1 hours per week received by patients whose caregivers were not distressed.

Our data findings were reinforced by what we heard from the panel of experienced caregivers who provided us with a ground-level view on caregiver distress. They described how challenging it was to look after high-needs patients, and how time-intensive caregiving was, so that it often had a negative effect on their working lives, personal relationships, social activities, hobbies and other pastimes.

Caregivers are an integral part of caring for people at home. As home and community care in Ontario evolve, it's important to focus on the caregivers of those people who directly receive publicly funded home care. We must listen to what caregivers tell us about their distress.

We also need better data that focus directly on caregivers' needs and experiences instead of looking at caregivers only as extensions of the people for whom they care. Such data will not only provide better evidence on which to base action, but also serve as a tool to monitor progress on the issues that affect caregivers and, ultimately, provide guidance on how we can best support them.

Caregivers are an integral part of caring for people at home.

1. Introduction: The Price of Caring

Photo of Nghi taken by Roger Yip,
see Nghi's story on the next page.



Nghi: Trying to do the right thing

Nghi is facing a dilemma. The former trading supervisor for a stock brokerage needs to return to work after spending years caring for his mother in his Thornhill home.

“I have to find a job soon,” says 50-year-old Nghi. “I can’t afford to not work anymore . . . either that or sell the house.”

He is single, doesn’t have kids, and his sister lives in the U.S., so there’s no one else available to look after Muon, who’s 79 and has vascular dementia and chronic asthma. She receives publicly funded home care from a personal support worker to help her bathe, but depends on her son the rest of the time and can’t be left alone for more than a few hours.

“Oh no, she would burn the house down,” says Nghi. “She’ll cook for herself and then forget to turn off the stove.”

Nghi has been a caregiver to Muon since she began needing help about 15 years ago. She lived on her own in a downtown Toronto apartment, but he would need to visit her at least once or twice a week to prepare enough food for her to last a week each time, and look after much of the household cleaning.

Seven years ago, when Muon became very forgetful and clearly wasn’t taking her medication even when he phoned to remind her, Nghi brought her to live with him. Now, she is still able to get around with a cane, but her cognitive impairment – forgetfulness, confusion and minor hallucinations – is serious enough for her to need supervision. On a couple of occasions in the past, she was found wandering outside by police.

“She doesn’t remember she lives with me and she went out looking for me – twice – one time in the winter with no coat,” says Nghi. “She doesn’t remember when she gets back.”

With the assistance of the home care workers, and a home security camera he can monitor on his cellphone during the brief periods his mother is alone, Nghi is still able to get out of the house a bit, but not long enough to hold a job.

“When you take care of someone you need time to go out,” he notes. “If you make it 24 hours you’re going to get stressed out pretty fast.”

Now that the bills are piling up and Nghi needs to return to work, he’s getting very anxious about how to ensure his mother’s safety and happiness.

“If it’s not safe to keep her at home, then I will have to put her in a (nursing) home,” he says, and that’s something he doesn’t want to do. Nghi is hoping Muon will get more hours of home care, or some other assistance, to allow her to remain with him.

Providing care to a family member, friend or neighbour who is sick or disabled often allows the person receiving the care to remain in the comfort and familiarity of their own home. Without that care, they might need to be admitted to a hospital or long-term care home.

In Ontario, 97% of adults receiving publicly funded home care over a long or indefinite period of time have at least one unpaid caregiver also providing care to them in their homes.[1] Usually, it's a family member such as a spouse or adult child, another relative, a friend, or a neighbour who supplements the care delivered by home care nurses, therapists, personal support workers and others.

For the unpaid caregivers, however, caring often comes at a personal cost. In 2013/14, among long-stay home care clients who had a caregiver, one-third had caregivers who experienced distress, anger or depression in relation to their caregiving role, or were unable to continue in that role. That rate of distress, at 33.3%, had more than doubled from 15.6% in 2009/10.[2]

Why we should care about caregivers

For a variety of reasons, unpaid caregivers may reach a point where they are unable to continue

providing care. In fact, the proportion of Ontario long-stay home care patients with caregivers who were not able to continue looking after them more than doubled to 13.8% in 2013/14 from 6.6% in 2009/10.[3]

The health system relies on caregivers to help look after the ill, elderly and disabled in their homes. In Ontario, the majority of care in the home is provided by unpaid caregivers. While the true value of their caregiving is not measurable in dollars, the monetary value of the time they spend providing care, or of the actual services they perform, can be estimated.

According to a 2009 study, it would cost more than \$25 billion annually, at market rates for wages and benefits, to pay professional care providers to deliver the hours of care provided across Canada by caregivers over 45 years old looking after seniors over 65 years old.[4] The 2009 figure for Ontario, estimated by population distribution, would be about \$10 billion. Another study estimated the care provided by caregivers in Canada in 2012 was equivalent to the work of 1.2 million full-time employees.[5]

If more caregivers become unable to continue providing care, more of the people they look after will need to be accommodated in long-term care homes and hospitals. Those people could suffer because they will no longer be able to live in their

own homes, as most wish to do. A survey done for the Canada Mortgage and Housing Corporation indicated 87% of people aged 55 or older planned to remain in their homes for as long as possible even if their health status changed.[6]

There could also be a substantial cost to the health system if more caregivers discontinue caregiving. Home care currently costs the provincial government about \$45 per day[7], compared to \$135 per day for a long-term care bed* and \$450 per day for a hospital bed.[8]

Demographic and social change make it likely that more caregivers will be needed:

- The proportion of older people in Ontario, who more frequently need the assistance of caregivers, is growing. The number of people aged 65 and older is expected to more than double to more than 4.5 million by 2041 from about 2.1 million in 2013, while the number of those 75 and older is projected to jump to 2.7 million from 923,000.[9]
- Ontario's long-term care homes don't appear to have the capacity to absorb the growth of the older senior population in Ontario. Between 2009/10 and 2013/14, the number of long-term care home beds in the province grew to 76,500 from 75,000[10], an increase of 2%, while the number of Ontario residents older than 75 increased to 950,000 from 855,000[11], an increase of 11%.

* Not including client copay contribution

- Families and the pool of potential caregivers they provide are getting smaller, and the women who have historically done much of the most intense caregiving are increasingly employed in the workplace instead of available at home to look after ailing or frail family members.[12]

For all these reasons, if we want to minimize the distress experienced by caregivers for the sake of their own well-being, as well as allow them to continue in the crucial role they play in the health system, we need to identify ways to support them.

To that end, this report will look at caregiver distress in relation to long-stay home care patients in Ontario, a group on which detailed data are available. It will examine what may be contributing to the distress for caregivers and what has changed in recent years that may help explain the increase in their distress.

The report will also offer a more intimate perspective on caregiver distress, as provided by a panel of caregivers with long-term experience looking after ill, elderly or disabled family members, friends or neighbours.

Home care in Ontario

In Ontario, publicly funded home care services support people with health issues who have difficulty caring for themselves in their homes. Services include nursing, personal support, physiotherapy, occupational therapy, social work, nutritional counselling, speech-language therapy and the provision of medical supplies. Those who receive these home care services are referred to as home care patients.

Ontario's home care system is divided into 14 geographic areas in which care is administered locally by Community Care Access Centres (CCACs). The Ministry of Health and Long-Term Care is in the midst of reform to improve the delivery of home care services.

People may be referred for home care by hospitals, doctors or their own families, or they may apply themselves.

Currently, Ontario provides about 6.5 million nursing visits and 27 million hours of personal support and homemaking services to more than 600,000 home care patients per year. The majority of home care services provided in 2014/15 were for personal support and homemaking (74%), while 22% were for nursing and 5% were for therapy and social work.

Other services to help people stay in their homes, such as Meals on Wheels, adult day programs and transportation, are also available. These services are provided by community support service agencies that are funded through the province's Local Health Integration Networks.

People can also pay out of pocket to hire private caregivers to provide care in the home.

A few hours for some, 24/7 for others

For some caregivers, caregiving may involve driving their loved one to medical appointments and visiting them regularly to help out with difficult household tasks or just make sure everything is OK. But for others, it can be round-the-clock work involving tasks such as wound care and tube feeding that are done by medical professionals in hospitals, as well as lifting, feeding, moving, washing and changing their loved one while attempting to keep up with their own jobs, child rearing and housekeeping.

“You have to learn a lot and you have to learn quickly while you’re doing all this other stuff,” said a member of the panel of caregivers consulted by Health Quality Ontario for this report. “We do 24/7,” she noted. “There are no breaks. We do Christmas Day.”

The panel was formed to provide firsthand perspective for the report on the stressors caregivers face. Another member described how it took her months to begin to recover from five exhausting and socially isolating years of acting as informal nurse, case coordinator, medical researcher and care manager as well as cook, cleaner, banker and driver for her husband as he struggled with a series of surgeries and illnesses.

“It was just too much, the whole thing,” she recalled.



2. Home Care Patients: The Growing Need for Help

In Ontario, patients who receive publicly funded home care are assessed and tracked for various health conditions, to make sure they receive appropriate care and support as those conditions change, and to monitor the needs and performance of the home care system as a whole.

Very detailed assessments are done on adult long-stay home care patients, a group that in 2013/14 accounted for about one-third of all home care patients, or 200,960 out of a total of 630,026 patients.[13]

Of the approximately \$1.5 billion spent that year directly on providing care to home care patients[†] (not including administrative or supply costs, for example), slightly less than two-thirds (\$919 million) was spent on long-stay patients.[14]

Among people receiving home care, long-stay patients generally have the most complex needs and require the most care and services. Their assessments are standardized and focus on specific aspects of their health and abilities, as well as tracking distress among their caregivers.

This report focuses on a subgroup of long-stay home care patients for whom the most relevant data were available for analysis. We know that in 2013/14 there were 114,537 patients in this

group, that 97% of them had at least one caregiver who provided them with help in coping with their illness or disability, and that a third of that 97% had caregivers who were distressed.

The data gathered on this group[15] showed that between 2009/10 and 2013/14, Ontario long-stay home care patients who had a caregiver became collectively older and were affected to a greater degree by the conditions often associated with aging: cognitive impairment, physical disability and frail health.

[†] This figure is the expenditure by CCACs on the purchase of home care services for patients, from the providers to whom those services are contracted out

Increase in age

Over this period, the average age of long-stay home care patients with a caregiver increased to 78.9 years old from 77.4. The proportion of patients aged 75 or older climbed to 73% from 70.3%, while those aged 18–74 declined to 27% from 29.7%.

Increase in age



Average age of long-stay home care patients with a caregiver

77.4
years
2009/10

78.9
years
2013/14

Increase in dementias

Also over this period, the prevalence of Alzheimer's disease and other dementias among all long-stay home care patients with a caregiver increased to 28.6% from 19.5%.

The percentage of patients exhibiting especially difficult behaviours associated with dementias also increased. The proportion whose behaviour was physically abusive, verbally abusive or disruptive, or who resisted care, rose to 11.5% from 6.7%, and those who wandered, often without attention to safety, increased to 3.2% from 2.1%.

More patients living with dementias

Prevalence of Alzheimer's disease and other dementias among all long-stay home care patients with a caregiver



2009/10



2013/14

Decline in cognitive performance

The Cognitive Performance Scale (CPS) measures cognitive abilities such as decision-making, making oneself understood, and short-term memory. Results are presented on a scale of 0 to 6, with 0 indicating the person is cognitively intact and 6 indicating very severe impairment.

Between 2009/10 and 2013/14, among long-stay home care patients who had a caregiver, the proportion of patients with mild to very severe cognitive impairment (with scores ranging from 2 to 6) grew to 62.2% from 38.1%, while the proportion with borderline or no cognitive impairment (scores of 1 or 0) shrank to 37.8% from 61.9%. The percentage with moderately severe to very severe impairment (scores of 4 to 6) rose to 10.1% from 5.8%. (Figure 2.1)

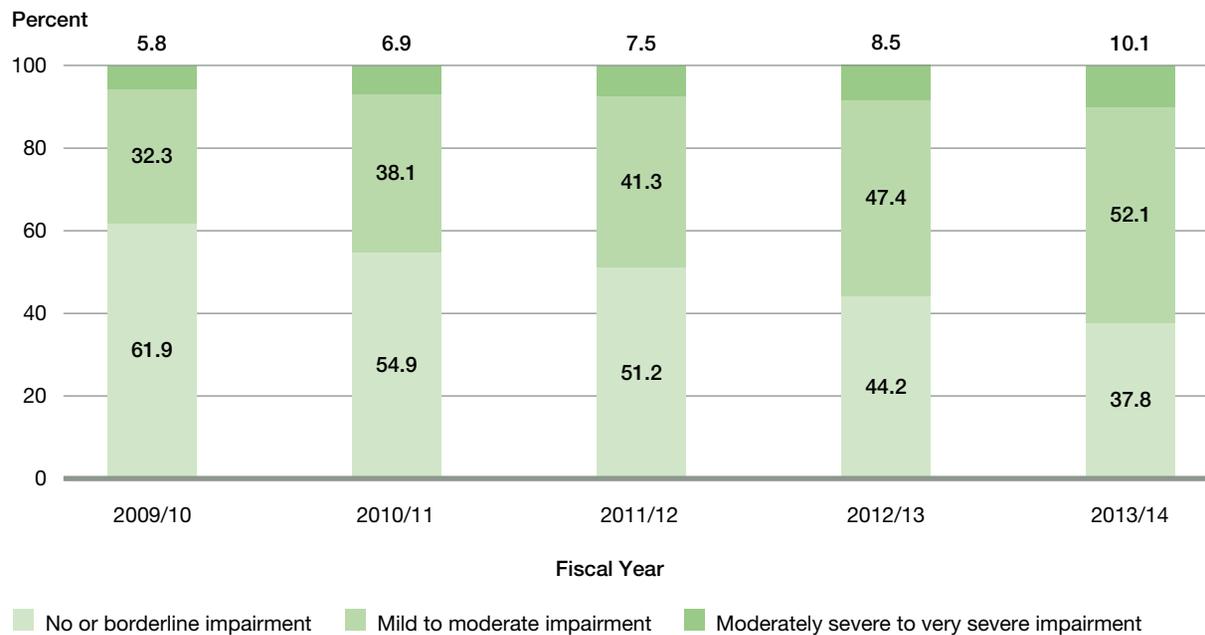
Proportion of patients with mild to very severe cognitive impairment

38.1% **62.2%**

2009/10 2013/14
(Mild to very severe impairment: scores 2–6)

FIGURE 2.1

Cognitive Performance Scale (CPS) scores among long-stay home care patients with a primary caregiver, in Ontario, 2009/10 to 2013/14



Data source: Resident Assessment Instrument-Home Care (RAI-HC), University of Waterloo. **Notes:** Cognitive Performance Scale scores: no or borderline impairment = 0–1; mild to moderate impairment = 2–3; moderately severe, severe and very severe impairment = 4–6.

Decline in ability to perform activities of daily living

The Activities of Daily Living (ADL) Hierarchy Scale measures an individual's ability to perform ordinary day-to-day tasks in four areas: personal hygiene (such as washing their face or combing their hair), toilet use, locomotion (such as walking or using a wheelchair), and eating. Scores range from 0, which means the person is independent in all areas, to 6, which means the individual is totally dependent on others.

Between 2009/10 and 2013/14, among long-stay home care patients with a caregiver, the proportion who were moderately to very severely impaired in their ability to perform activities of daily living (with ADL scores ranging from 2 to 6) grew to 44.5% from 27.6%, while the proportion who showed little or no impairment (scores of 1 or 0) shrank to 55.5% from 72.4%. The segment of patients with the three most severe levels of impairment (4 to 6) expanded to 12.6% from 7.7%. (Figure 2.2)

Proportion who were moderately to very severely impaired in their ability to perform activities of daily living

27.6% **44.5%**

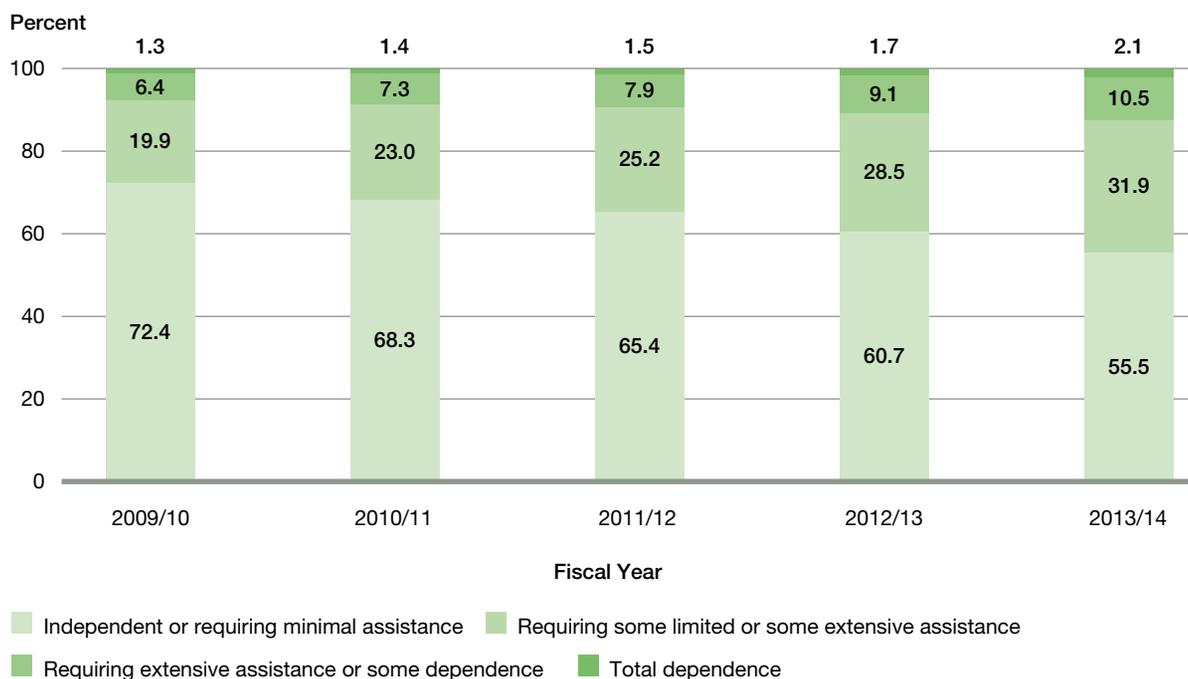
2009/10

2013/14

(Moderately to very severely impaired: scores 2–6)

FIGURE 2.2

Activities of Daily Living (ADL) Hierarchy Scale scores among long-stay home care patients with a primary caregiver, in Ontario, 2009/10 to 2013/14



Data source: Resident Assessment Instrument-Home Care (RAI-HC), University of Waterloo. **Notes:** Activities of Daily Living (personal hygiene, toilet use, locomotion, eating) Hierarchy Scale scores: independent in all areas or needs supervision in one area = 0–1; limited assistance in one area or extensive assistance to total dependence in personal hygiene or toilet use = 2–3; extensive assistance to total dependence in locomotion or eating = 4–5; totally dependent in all areas = 6

Decline in health

The Changes in Health, End-Stage Disease, Signs, and Symptoms (CHESS) Scale indicates probability of decline in health. It measures a combination of factors such as shortness of breath, presence of end-stage disease, decrease in food or fluid intake, and changes in decision-making or functional abilities. CHESS results are presented on a scale of 0 to 5, with higher scores associated with greater health instability and higher risk of outcomes such as hospitalization or death.

Among long-stay home care patients with a caregiver, the proportion with slightly to highly unstable health conditions (with CHESS scores of 2 to 5) increased to 43.2% in 2013/14 from 27.3% in 2009/10, while those who were stable or nearly stable (scores of 0 or 1) decreased to 56.8% from 72.7%. The segment of patients with the highest instability scores (4 or 5) grew to 3.6% from 1.4%. (Figure 2.3)

Proportion with slightly to highly unstable health conditions

27.3% 43.2%

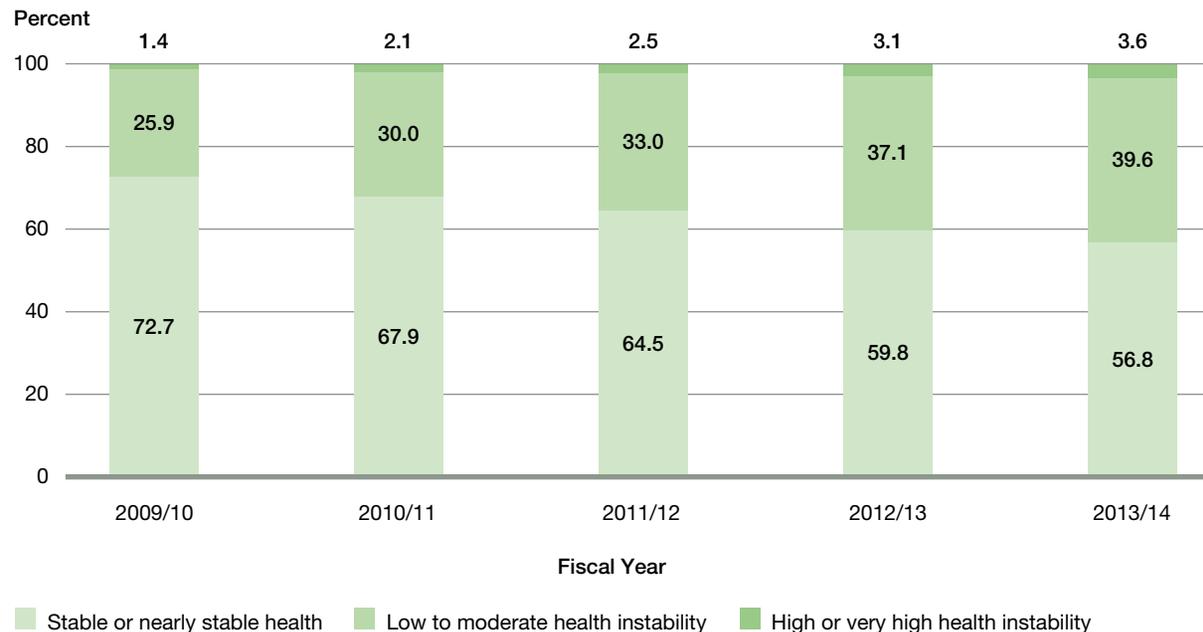
2009/10

2013/14

(Slightly to highly unstable health conditions: scores 2–5)

FIGURE 2.3

Changes in Health, End-Stage Disease, Signs, and Symptoms (CHESS) Scale scores among long-stay home care patients with a primary caregiver, in Ontario, 2009/10 to 2013/14



Data source: Resident Assessment Instrument-Home Care (RAI-HC), University of Waterloo. **Notes:** Changes in Health, End-Stage Disease, Signs, and Symptoms Scale scores: patients who have no or minimal health instability = 0–1; patients with low to moderate health instability = 2–3; patients with high or very high health instability = 4–5

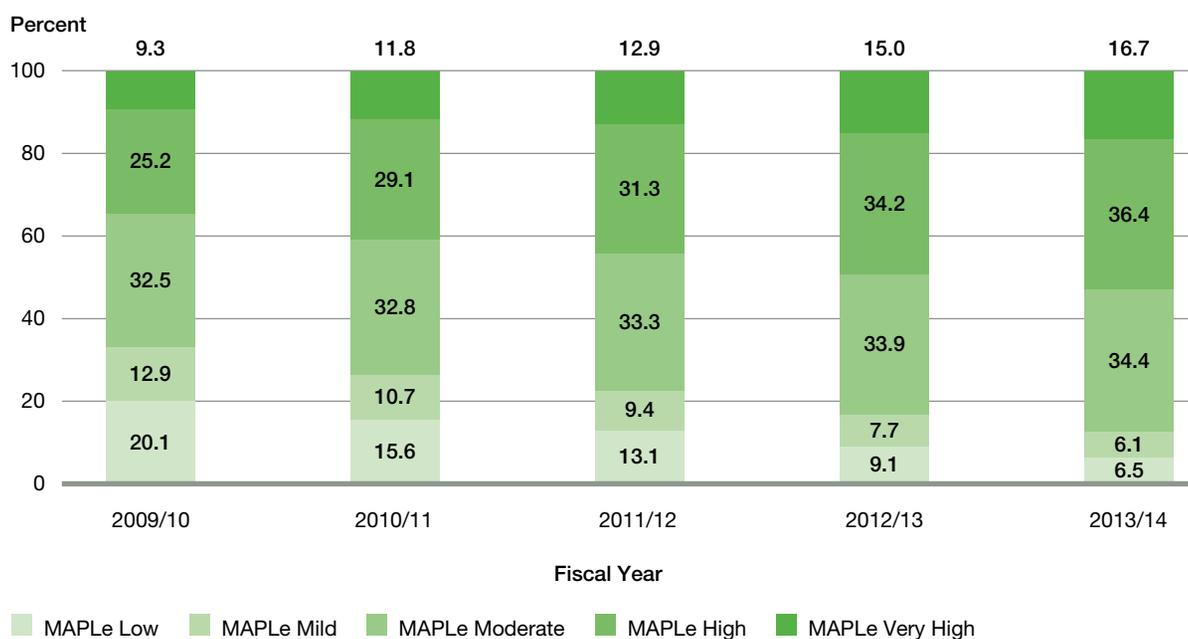
Decline in cognition, functioning and behaviour combined

The Method for Assigning Priority Levels (MAPLe) is an algorithm or formula designed to indicate an individual's risk of unfavourable outcomes. It measures a combination of factors such as cognitive functioning, dependence on others to perform activities of daily living, the presence of behavioural issues, the frequency of falls, and difficulties managing medication. Higher MAPLe scores are associated with increased risk of decline and of being admitted to a long-term care home within 90 days.

Between 2009/10 and 2013/14, among long-stay home care patients with a caregiver, the proportion with a High or Very High risk of adverse outcomes based on MAPLe scores grew to 53% from 34.5%. Over the same period, the proportion of patients at Low or Mild risk shrank to 12.6% from 33%, while the segment at Moderate risk grew to 34.4% from 32.5%. (Figure 2.4)

FIGURE 2.4

Method for Assigning Priority Levels (MAPLe) among long-stay home care patients with a primary caregiver, in Ontario, 2009/10 to 2013/14



Data source: Resident Assessment Instrument-Home Care (RAI-HC), University of Waterloo. **Notes:** The Method for Assigning Priority Levels (MAPLe) algorithm categorizes patients into five priority levels, based on their risk of adverse outcomes. Patients with a Low MAPLe score have no major functional, cognitive, behavioral, or environmental problems and are considered self-reliant. Mild to Very High MAPLe scores indicate the presence of Activities of Daily Living (ADL) impairment, cognitive impairment, wandering, behaviour problems and risk in the home.

An overall decline in the condition of long-stay home care patients is also indicated by statistics gathered by the Ontario Association of Community Care Access Centres. According to the association, the proportion of long-stay home care patients with multiple chronic and complex health issues increased to 68.5% in 2014/15 from 37.4% in 2009/10. Over the same period, the segment of long-stay patients with less intensive care needs decreased to 31.5% from 62.6%.^[16]

In summary

From 2009/10 to 2013/14, Ontario long-stay home care patients who had a caregiver became collectively older and were affected to a greater degree by the conditions often associated with aging: cognitive impairment, functional disability and frail health.

Their average age increased and the proportion of them who were over the age of 75 increased. A greater proportion had dementia, and the percentage exhibiting difficult behaviours associated with dementia also climbed. The proportion who were cognitively impaired increased, as did the percentage who were impaired in their ability to perform activities of daily living such as washing their face, using the toilet or eating.

Overall, a greater proportion of long-stay home care patients with a caregiver had health conditions that put them at risk of hospitalization or death, and more were affected by combinations of cognitive and functional problems that made it more likely they would be admitted to a long-term care home.



3. Caregiving: The Pattern of Distress

Photo of Carole Ann taken by Roger Yip, see Carole Ann's story on the next page.

Carole Ann: Doing it all on her own

For Carole Ann, one of many low points during her husband Bill's five-year ordeal of ankle surgeries, infections and heart problems came when she awoke one night in their Toronto home to find he had hobbled to the bathroom, in a medicated haze, to look for a pain pill shortly after she had given him one. It hit her then that even night-time slumber was no longer available for rest from the endless cycle of caregiving tasks that had taken over her life.

"It worried me that I couldn't even sleep," says Carole Ann, "and I was so tired."

Bill, now 70, had nine operations on one ankle over five years to insert ankle replacements, remove them due to repeated infections, remove a plate and pins from an old ankle fracture, and finally to fuse the ankle. The fourth surgery had to be delayed when he was found to have congestive heart failure and irregular heart rhythm.

Carole Ann, now 66, spent those five years changing Bill's bandages, managing his intravenous line, juggling his medications, and helping him with personal care since he was on crutches the whole time. She also shouldered his share of the household duties in addition to her own.

She initially had help with the medical tasks from home care nurses. But there were often long waits for the nurses when they were held up with

other patients, and some seemed unprepared for handling Bill's care, so Carole Ann ended up doing most of the work herself. "I made a mistake in taking it over, but you're like a hamster on a wheel," she says, explaining that since looking after Bill took up so much of her time and energy, she didn't have any left to try to figure out how to get better home care for him.

The couple says no one ever came to their home to assess Bill's needs, nor were they offered a personal support worker to help him with activities such as showering. "I knew nothing, we knew nothing, and no one told us anything," recalls Carole Ann. They didn't even know home care sometimes includes personal support workers.

"That's one thing that's been very frustrating," says Bill, "that there are a ton of resources available, but there's no way to find out who they are and where they are."

One resource they were thrilled to learn about, after Bill's sixth surgery, was the community clinic where they could book appointments for nurses to perform his wound care there, instead of waiting for a nurse to come to their home. "We were quite frankly gobsmacked by the quality of the care," says Carole Ann. "They were the best thing about the whole five years, and it was the first time I

relaxed, that I didn't have to monitor their work or do research on it, or watch them carefully."

Carole Ann was also exhausted by trying to ensure Bill got the medical care he needed, particularly amid the frustration of having years go by before the old plate and pins in Bill's ankle were identified as the source of his infections. On more than one occasion, says Carole Ann, she felt hospital staff pressed her to take her husband home when she thought it wasn't safe – once when he was not stable on his heart medication, another time when there was blood seeping through his cast and running off the bed to the floor, and another when he was incoherent and ended up needing a blood transfusion.

Then there was the guilt to deal with – Carole Ann's guilt at wanting relief from the burden of caregiving, and Bill's guilt at seeing his wife so overburdened while not being able to help her.

"She was welded into it like a trap," says Bill. "But she never did drop me off in a basket at the church, I'm happy to report."

Carole Ann dissolves into tears as she describes how hard it was to bottle up her feelings so she wouldn't make Bill feel worse than he already did, and how helpless she felt. "The biggest frustration was not having any support and not being able to trust the people I should have been able to trust."

A family commitment

Over the years that caregiver distress more than doubled, the overwhelming majority of patients continued to receive assistance at home from their children or the spouses of their children. The next-largest caregiving group were patients' spouses, followed by other relatives, and then their friends and neighbours.

Between 2009/10 and 2013/14, the percentage of patients cared for by a child or child-in-law remained stable at around 71%, while the segment cared for by a spouse continued to be about 33% and the group cared for by another relative stayed at approximately 19%. The proportion who received care from friends and neighbours declined to 9.2% from 11.4%. Note that the data used here^[17] record up to two caregivers per patient, so these percentages add up to more than 100%.

Overall living arrangements between caregivers and patients did not change significantly during the period when caregiver distress increased. The proportion of patients who co-resided with a caregiver remained steady at around 55%.

What did change, however, was the amount of time caregivers spent looking after long-stay home care patients. The average amount of care provided rose to 21.9 hours per week in 2013/14, from 18.8 hours in 2009/10.

Connecting the dots

We looked at the relationship between the characteristics of long-stay home care patients that changed significantly between 2009/10 and 2013/14, and the rate of caregiver distress associated with those characteristics in 2013/14. The data showed caregivers were generally more distressed the older, more impaired and sicker the care recipient was.

Patient age

Caregiver distress rates were higher for older patients. The caregivers of 34.1% of patients aged 75 and older were distressed, while the figure was 31.1% when patients were 18 to 74.

Dementia

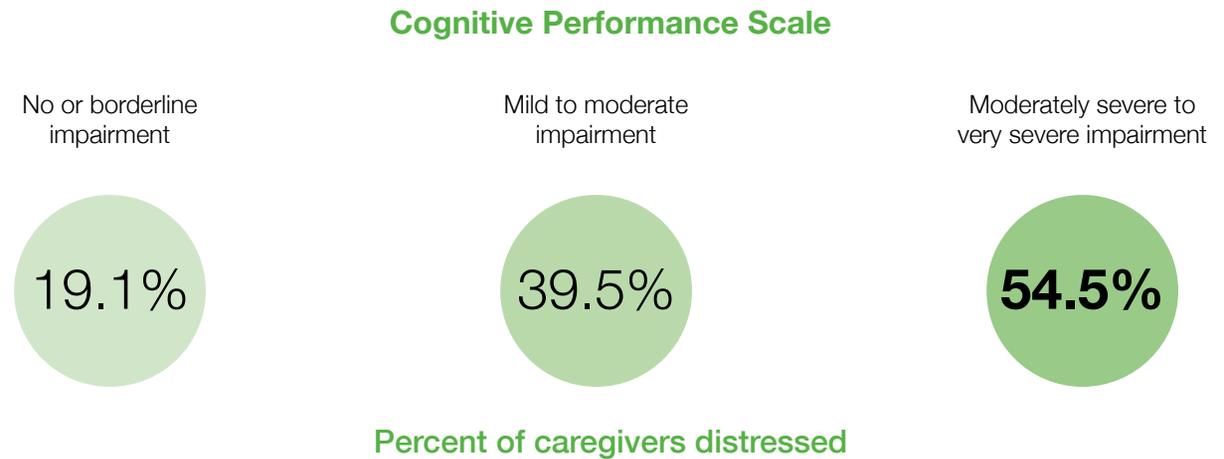
Nearly half (49.2%) of patients with Alzheimer's disease or other dementias had caregivers who were distressed. Among patients who exhibited difficult behaviours associated with dementia – being physically or verbally abusive, disruptive or resisting care, and wandering (moving about without apparent attention to safety) – more than 60% had caregivers who were distressed.

Cognitive impairment

Distress among the caregivers of patients with cognitive impairment, as shown by Cognitive Performance Scale (CPS) scores, increased as the level of impairment increased. Among patients with moderately severe to very severe impairment (scores of 4 to 6) in abilities such as decision-making, making themselves understood and short-term memory, 54.5% had caregivers who were distressed. The distress rate was 39.5% when patients had mild to moderate impairment (scores of 2 or 3) and 19.1% when they had borderline or no impairment (scores of 1 or 0). (Figure 3.1)

FIGURE 3.1

Caregiver distress by long-stay home care patients' Cognitive Performance Scale (CPS) scores, in Ontario, 2013/14



Data source: Resident Assessment Instrument-Home Care (RAI-HC), University of Waterloo. **Notes:** Cognitive Performance Scale scores: no or borderline impairment = 0–1; mild to moderate impairment = 2–3; moderately severe, severe and very severe impairment = 4–6.

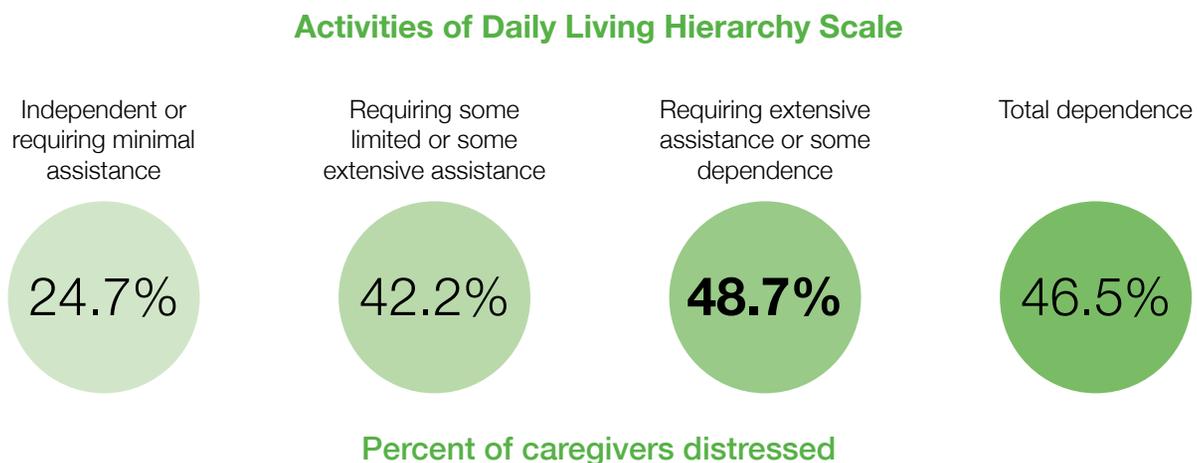
Impairment in activities of daily living

As patients deteriorated in their ability to perform activities of daily living such as washing themselves, using the toilet, moving about or eating, as shown by Activities of Daily Living (ADL) Hierarchy Scale scores, the distress rate among their caregivers climbed, though it dropped slightly when they were totally dependent in all activities of daily living.

When patients needed extensive assistance with or were dependent in some activities (ADL scores of 4 or 5), 48.7% had distressed caregivers, while 46.5% of totally dependent patients (scores of 6) had distressed caregivers. The rate was 24.7% for those who needed minimal or no assistance (scores of 1 or 0), but increased to 42.2% when some limited or some extensive assistance was required (scores of 2 or 3). (Figure 3.2)

FIGURE 3.2

Caregiver distress by long-stay home care patients' Activities of Daily Living (ADL) Hierarchy Scale scores, in Ontario, 2013/14



Data source: Resident Assessment Instrument-Home Care (RAI-HC), University of Waterloo. **Notes:** Activities of Daily Living (personal hygiene, toilet use, locomotion, eating) Hierarchy Scale scores: independent in all areas or needs supervision in one area = 0–1; limited assistance in one area or extensive assistance to total dependence in personal hygiene or toilet use = 2–3; extensive assistance to total dependence in locomotion or eating = 4–5; totally dependent in all areas = 6

Frail health

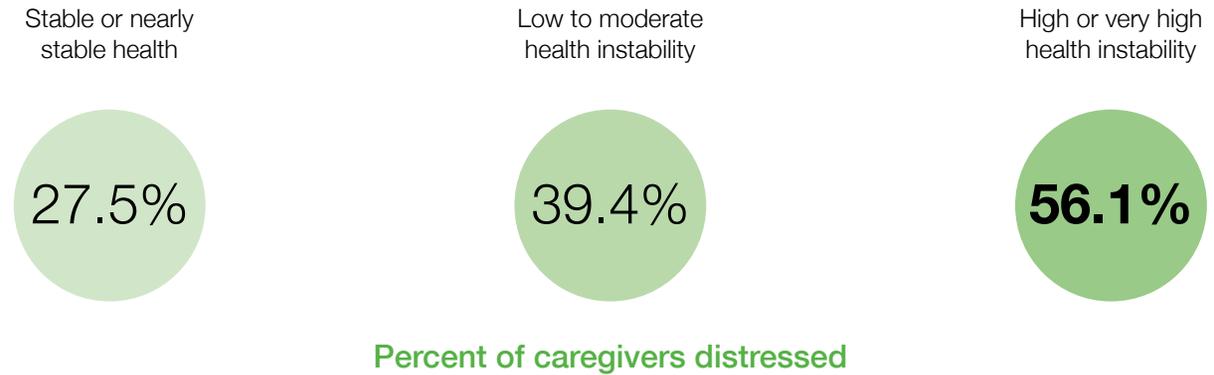
As patients faced increasing risk of adverse health outcomes, as shown by their scores on the Changes in Health, End-Stage Disease, Signs, and Symptoms (CHESS) Scale, there was a corresponding climb in distress among their caregivers.

When patients were at the two most severe levels of health instability (CHESS scores of 4 or 5) on the basis of factors such as shortness of breath, the presence of end-stage disease, and changes in functional abilities, 56.1% had caregivers who were distressed. Among patients with low to moderate health instability (scores of 2 or 3), 39.4% had distressed caregivers, while 27.5% of those who were stable or nearly stable (scores of 0 or 1) had distressed caregivers. (Figure 3.3)

FIGURE 3.3

Caregiver distress by long-stay home care patients' Changes in Health, End-Stage Disease, Signs, and Symptoms (CHESS) Scale scores, in Ontario, 2013/14

Changes in Health, End-Stage Disease, Signs, and Symptoms Scale



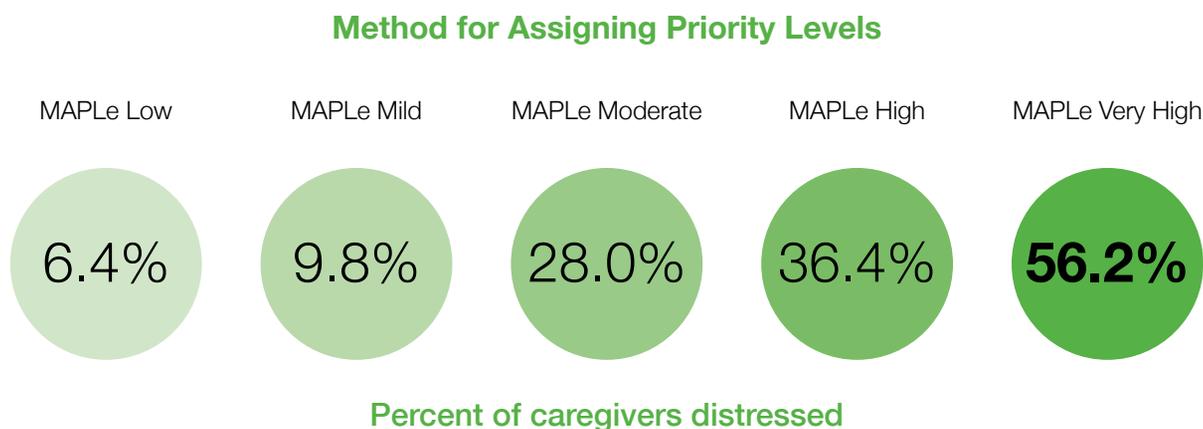
Data source: Resident Assessment Instrument-Home Care (RAI-HC), University of Waterloo. **Notes:** Changes in Health, End-Stage Disease, Signs, and Symptoms Scale scores: patients who have no or minimal health instability = 0–1; patients with low to moderate health instability = 2–3; patients with high or very high health instability = 4–5

Impaired cognition, functioning and behaviour combined

The rate of caregiver distress rose together with increasing patient risk of decline and negative outcomes, as shown by Method for Assigning Priority Levels (MAPLe) scores. Among patients at Very High risk, based on MAPLe's assessment of factors such as cognitive functioning, dependence on others to perform activities of daily living, the presence of behavioural issues, frequency of falls, and difficulties managing medication, 56.2% had distressed caregivers. Caregivers were distressed for 6.4% of patients at Low risk, 9.8% at Mild risk, 28% at Moderate risk and 36.4% at High risk. (Figure 3.4)

FIGURE 3.4

Caregiver distress by long-stay home care patients' Method for Assigning Priority Levels (MAPLe) scores, in Ontario, 2013/14



Data source: Resident Assessment Instrument-Home Care (RAI-HC), University of Waterloo. **Notes:** The Method for Assigning Priority Levels (MAPLe) algorithm categorizes patients into five priority levels, based on their risk of adverse outcomes. Patients with a Low MAPLe score have no major functional, cognitive, behavioral, or environmental problems and are considered self-reliant. Mild to Very High MAPLe scores indicate the presence of Activities of Daily Living (ADL) impairment, cognitive impairment, wandering, behaviour problems and risk in the home.

The time it takes to care

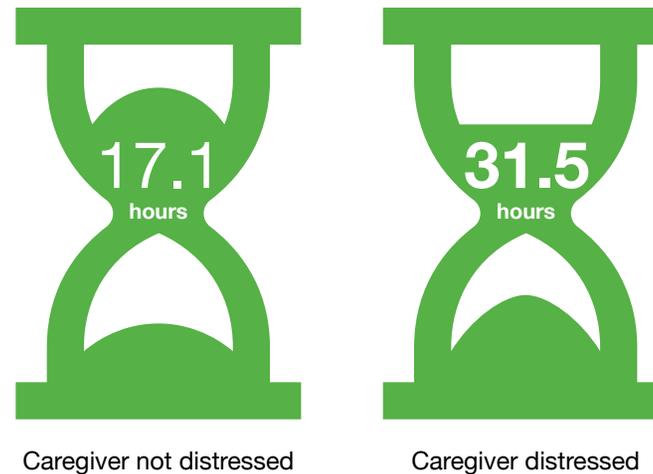
Another characteristic of home care patients that was clearly associated with caregiver distress was the amount of time required for the patient's care. On average in 2013/14, patients whose caregivers experienced distress received 31.5 hours per week of care from those caregivers, compared to the 17.1 hours per week received by patients whose caregivers were not distressed. (Figure 3.5)

The ties that make caregiving more difficult

Patients receiving care from their spouses most often had distressed caregivers, at 47.2%, while the rate was 34% for patients looked after by their children or children-in-law, 27.3% for those assisted by other relatives and 18.1% for those helped by neighbours or friends. (Figure 3.6) The rate of distress was also higher among primary caregivers if they lived in the same homes as the patients (43.5%), than if they didn't (21.5%).[18]

FIGURE 3.5

Average hours of care per week provided by unpaid caregivers of long-stay home care patients, by caregiver distress, in Ontario, 2013/14



Data source: Resident Assessment Instrument-Home Care (RAI-HC), University of Waterloo.

In summary

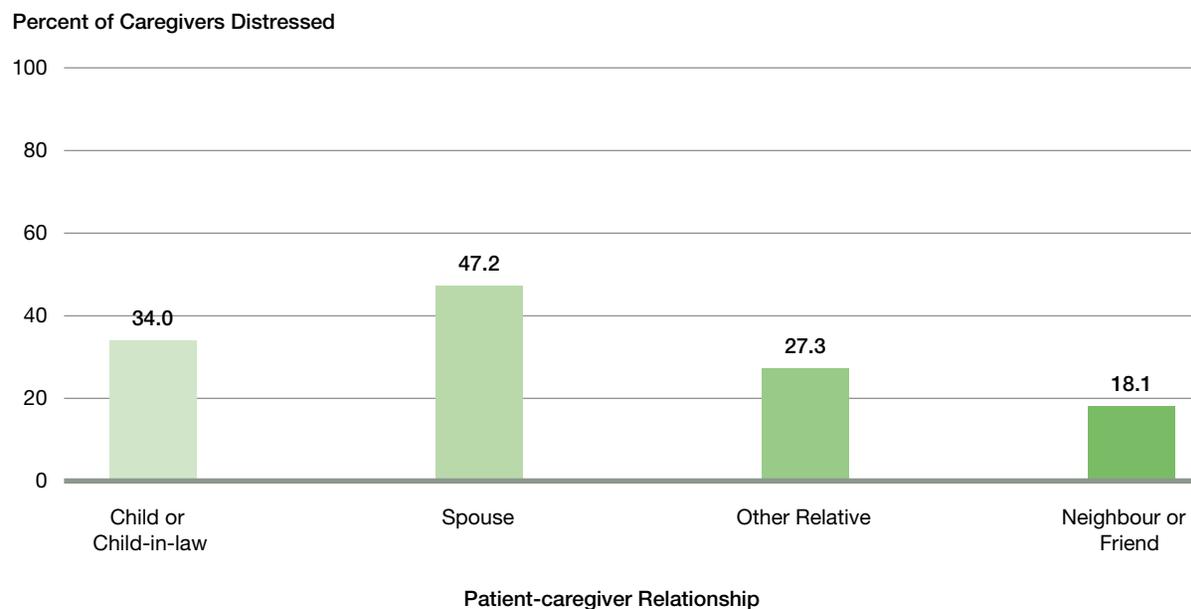
The majority of long-stay home care patients who had a caregiver received assistance at home from their children or the spouses of their children. The next-largest caregiving group were patients' spouses, followed by other relatives, and then their friends and neighbours.

Caregivers were generally more distressed the older, sicker and more cognitively or functionally

impaired the patient was. As well, patients whose caregivers experienced distress received from them, on average, substantially more hours per week of care than were received by patients whose caregivers were not distressed.

Patients who received care from their spouses had the most distressed caregivers, followed by patients looked after by their children or children-in-law. The rate of distress was also higher when primary caregivers lived in the same homes as the patients.

FIGURE 3.6
Caregiver distress by patient-caregiver relationship, in Ontario, 2013/14



Data source: Resident Assessment Instrument-Home Care (RAI-HC), University of Waterloo.

Health consequences of caregiving

Looking after a loved one when they are ill or disabled can be so distressing that one study noted that caregiving is used as a model for examining the health effects of chronic stress. That's because the role often involves long periods of physical and psychological stress as well as a high degree of alertness in a situation that is frequently unpredictable and uncontrollable, and can lead to further stress in other areas of the caregiver's life such as work and family relationships.[19]

Many studies have concluded that caregiving can have negative effects on the caregiver's health, ranging from back problems, migraines, stomach ulcers, hormonal changes, anxiety and depression to early death.[20,21,22,23,24] The research indicates that the aspects of caregiving most clearly associated with detrimental health effects include caring for someone with dementia and/or with serious functional impairment, as well as having to devote a lot of time to the caregiving role. There is also research indicating that the more the caregiver perceives the care recipient to be suffering, the more likely the caregiver is to be depressed.[25]

4. Caregivers: A View From the Ground



To provide personal perspectives on what all the data mean, Health Quality Ontario consulted a panel of caregivers with experience providing care over a long period. During a facilitated discussion, the panel members talked about their experiences as caregivers and how those experiences related to key findings presented to them from the report data.

Between them, the caregivers on the panel had looked after a variety of family members and friends with a wide range of health issues, yet were unanimous in describing the experience as rewarding but extremely difficult, very time-consuming and tremendously stressful.

A long list of new responsibilities

Panel members recounted having to learn to do all kinds of things they felt they had been inadequately prepared for or should have been assisted with.

One panel member recalled how her husband wasn't provided with a personal support worker to help him shower at home following a surgery that left him unable to put any weight on one foot. She tried to help him herself but hadn't received any instruction on how to do that. "He's six foot ten, I'm five foot one," she recalled. "The bathroom was even more messy than when you bathe a dog."

In addition to helping with personal care, the caregivers also found themselves managing medications and doing medical tasks like cleaning wounds, changing bandages and flushing intravenous lines, on top of all their regular household duties.

As well, they often had to take over the patient's household tasks, such as laundry, cleaning and cooking. If the patient had dementia or other cognitive impairment, it meant juggling the caregiving and household tasks while having to supervise them, sometimes around the clock. And if the caregiver had a job outside the home, everything had to be done before or after the workday.

Just the relentless deluge of tasks to complete and issues to manage every day frequently left the caregivers feeling stressed. "You don't balance those things," explained one panel member. "There's always a crisis."

Panel members said the home care their loved ones received was rarely enough, particularly when the patient needed 24-hour supervision or the caregiver had a job. That made caregiving a financial burden as well, when care responsibilities kept caregivers from working, or compelled them to take early retirement and a smaller pension, or forced them to hire private, paid caregivers.

"We were paying for extra help because certainly the CCAC would not provide enough support," said

a woman who hired private caregivers to look after her elderly mother. She noted many families are in a real bind when they have neither the money to pay for the extra help their loved one needs, nor the ability to provide it themselves.

The panel members said home care services were often erratic because home care nurses were so busy that patients and families were left repeatedly waiting for them to show up. Some said the home care workers sometimes didn't seem prepared to deal with the specific needs of the patient, so that the caregivers ended up doing much of their work.

Panel members from central and northern Ontario talked about how getting even minimal home care in those regions was a major challenge. There is much less care available when you are "not living within that envelope of Toronto where the services are," said one. "We don't have the help that other people get at their doorstep," said another.

The caregivers said their role brought emotional stress as well.

They described the guilt they felt about sometimes being tired of caregiving and wanting relief from it. They also felt bad about occasionally losing patience with a sick or cognitively impaired loved one as a result of fatigue and frustration. "Sometimes you get a little grumpy with them, and man does that bring on the guilt," noted one.

The caregivers also discussed how emotionally stressful it was to suddenly be the one making all the decisions if their spouse or parent was too ill or impaired to be involved. One caregiver, who had her own health issues to deal with while caring for her mother, noted she found it very difficult to be responsible for managing her mother's affairs as well as providing the attention and companionship she needed. "You have to spend time with them and really hang out with them, because they're lonely," she explained.

Loneliness was a problem for the caregivers, too. With little time left for jobs, social activities, hobbies or other pastimes, they described themselves as being lonely and isolated and feeling cut off from the rest of the world.

"I have no social life," was the way one panel member put it.

"We don't want the caregiver role to be our whole being," said another.

A seemingly endless battle

The panel members described how the responsibility for decision-making and for managing their loved ones' care becomes a particularly heavy burden when there are so many medical and care issues to deal with. It only adds to the strain, they said,

when the health and home care systems are not as coordinated as they should be, and when it's not clear exactly what services are available and who is eligible to receive them.

According to a panel member who helped look after and organize care for her in-laws, navigating those systems is among the most time-consuming aspects of caregiving. "That's the bulk of the work, really," she said. "I spent probably 20 hours a week in advocacy fighting for them."

All the caregivers said the work involved in obtaining and coordinating care is draining. They noted there are a lot of health professionals trying very hard to make that work as easy as possible and provide quality care, but also many who actually make things more difficult than they should be. The panel members all had stories to tell about having to take matters into their own hands because they felt they needed to protect the wellbeing of their loved ones.

One recalled how she had to push for better care for her 96-year-old mother, who was staying for a short time in a rehab facility, when she developed a painful skin condition that wasn't being addressed. She recounted how a staff member made her feel guilty for pressing to have it dealt with. "I didn't want to make trouble," said the panel member. "I was saving my mom from pain." She ended up taking her mother outside the facility to a specialist, who prescribed treatment that solved the problem.

"The most difficult part for me was the hospitalizations," recalled another panel member who worked 40 years as an occupational therapist and had also worked in the home care sector. She said she saw patients sent home too soon or without a care plan in place. It was very difficult being told her own mother would be going home, she said, when she believed she wasn't well enough.

In summary

To provide a real-life viewpoint on the stressors faced by caregivers, and some perspective on the complexity of the issues behind the data, Health Quality Ontario consulted a panel of caregivers with long-term experience providing care. They described caregiving as rewarding but difficult, time-consuming and stressful, leaving little time for jobs, social activities, hobbies or any other pastimes.

They said trying to obtain quality home care for their loved ones was often extremely frustrating and a significant source of distress. Those from central and northern Ontario said it was very difficult to obtain reliable home care services in those regions.

Walter: Expanding the circle of care

While unpaid caregivers may be experiencing a lot of stress looking after loved ones with increasingly serious health issues, providing care has also been getting more challenging for professional caregivers.

With 20 years' experience as an occupational therapist and three as a Community Care Access Centre care coordinator, Walter has helped provide care for a lot of patients. In his new role as transitional care coordinator for two of Ontario's Health Links, which are networks that facilitate the management of care for patients with multiple health issues, he is responsible for organizing care for some of the highest-needs patients in the health system.

"There certainly is far more complexity," says Walter of the patients he has been coordinating care for in recent years. That complexity applies not only to their medical issues, he explains, but also to other factors relevant to their well-being such as their family situation, social support network, living conditions and mental health.

"We realize that these people need a lot of care and it's about bringing in the entire circle of care with some shared responsibility," says Walter, adding that taking so many factors into consideration for each patient means coordinating home care has become more complicated.

"There are so many moving parts and so many communication needs, that it goes beyond just 'they've got this condition, they need this much help and services and we'll check it every three to six months.' It's far more fluid, and sometimes it's almost daily, it's putting out fires."

Patients' non-professional caregivers also need to be taken into consideration if that network of care is to be maintained. Walter sees first-hand the sources of stress for family members and other unpaid caregivers: the many hours often required for care, the difficulties of managing dementia, the frailty of the patients and the social isolation often created by caregiving. But he adds there's also a lot of frustration among caregivers with trying to obtain home care services that are flexible enough to meet their individual needs.

"I hear it all the time: 'I need more help, and I need the kind of help that will really help,'" says Walter. Sometimes what would really help, he says caregivers tell him, are things like occasional assistance at night so they could get a "real break," or help with getting groceries because they can't leave the patient alone at home, or help taking loved ones to medical appointments.

Walter notes many unpaid caregivers have health problems or are elderly and may need more flexible types of assistance in order to be able to continue caregiving. "They're still trying to hold it together at home, and they're making the meals and they're trying to provide the supervision, but they probably can't drive and they may not be able to walk very well."

The type of flexibility needed might come in the future from a coordinated effort with other community health care partners who currently provide services like Meals on Wheels and transportation, notes Walter. "It's about getting other people to come to the table, so it's the right people leading the work and doing the right work at the right time."

A photograph showing the lower half of two people walking away from the camera on a paved path. They are holding hands. The person on the left is wearing a brown coat and light-colored trousers. The person on the right is wearing a darker brown coat and dark trousers. The path is made of interlocking stones. The background is a bright, sunny outdoor setting with trees and a building. A green rectangular overlay is positioned on the left side of the image, containing the text '5. The Road Ahead' in white.

5. The Road Ahead

Facing a perfect storm

As long-stay home care patients in Ontario become collectively more elderly, ill and impaired, the family and other unpaid caregivers who help look after them are becoming increasingly stressed and burned out. This combination of developments, along with the aging of Ontario's population, may be creating a perfect storm for the provincial health system's capacity to provide home care: a situation where there is a growing need for caregivers amid increasing caregiver distress and decreasing availability of caregivers.

Limiting the stress on caregivers

Of course, it's impossible to eliminate caregiver distress completely. Watching a loved one decline in health or suffer as a result of illness or impairment is upsetting no matter how much assistance and support a caregiver receives.

But caregivers should not have to endure added, avoidable distress as a result of not getting the help they need or being left feeling abandoned and isolated, as described by the members of our panel of caregivers. There are things that can be done to help them cope better with the stresses of caregiving.

The panel members recommended measures such as better preparation and instruction of caregivers for the responsibilities they are taking on; better coordination of home care services so that the burden of organizing care will not fall so much on caregivers; provision of clear information on what home care services are available and who is entitled to them; more consistent and reliable delivery of services; greater availability of respite services such as adult day programs; more services for high-needs patients; and more consideration of caregivers' needs and respect for the important role they play.

Work underway

Some initiatives are already under way to improve the support provided to caregivers in Ontario.

In 2015, the Ministry of Health and Long-Term Care launched *Patients First: A Roadmap to Strengthen Home and Community Care*, which includes a 10-step plan to improve the quality, consistency and integration of home and community care. Since a significant portion of caregiver distress seems to stem from caregiver frustration at not being able to obtain the care they believe their loved one needs, a better, more consistent and more integrated home care system is an important step in reducing caregiver

distress. The *Roadmap* also includes measures aimed specifically at helping caregivers, including:

- Expansion of caregiver supports to ensure caregivers have better resources to care for their loved ones and also to take care of themselves
- Investment in more training and education programs for caregivers
- Creation of a Levels of Care Framework to ensure home care services and assessments are consistent across Ontario, and to provide an easily accessible way for the public to understand the level of care they can expect for their loved one
- Implementation of “bundled care,” under which a group of providers are given a single payment to cover all the care needs of an individual patient
- Implementation of a “self-directed care” option, under which clients and their caregivers are given funds to hire their own provider or purchase services from a provider of their choice
- Development of a one-stop online resource providing information and links to other resources for caregivers[26]

As identified in Quality Improvement Plans, some of Ontario's Community Care Access Centres and home care service providers are undertaking initiatives to implement family-centred care that recognizes the role of caregivers; provide more resources for caregivers; and identify overburdened caregivers before they become distressed.

The Change Foundation, an independent policy think tank on health care in Ontario, is currently examining the interactions family caregivers have with the Ontario health system, in partnership with the Ontario Caregiver Coalition, as part of its 2015–2020 strategic plan.[27] The five-year plan is focused on improving patient and caregiver experiences in Ontario's health system.

Organizations such as the Registered Nurses' Association of Ontario and St. Elizabeth have developed guidelines and programs that recognize the role of caregivers in looking after home care patients.

Health Quality Ontario is actively engaged in working with the Ministry of Health and Long-Term Care, and other partners, on the creation of the Levels of Care Framework to improve the consistency and quality of care across Ontario and provide patients with information about care.

As well, Health Quality Ontario and Local Health Integration Networks are working together to develop quality indicators for home and community care, which can be used to guide performance improvement and accountability in the home care system.

Moving things forward

Caregiver distress has been identified as a concern for many years now in Ontario and elsewhere, yet progress on the issue has been slow. All the initiatives already underway are important steps in addressing the problem, and are critical to truly supporting caregivers and allowing them to continue the crucial role they play in the health system.

Also needed are better data that directly examine the needs and experiences of caregivers. Direct and more in-depth data on caregivers will provide more precise measures of caregiver distress and what causes it, and clearer evidence on which to base initiatives to alleviate that distress.

Our report demonstrates that caregivers are an important part of home care patients' care, and caregivers' well-being may be at risk. As Ontario works to transform home care, it is important to focus on caregivers as well as the patients.

Methods Notes

The Methods Notes provide a brief description of the methods used in this report. For a more detailed description, please see the technical appendix on Health Quality Ontario's website.

Data source

The analysis in this report uses information from Resident Assessment Instrument – Home Care (RAI-HC) assessments. RAI-HC is a standardized, validated and multi-dimensional assessment tool for determining patient needs, measuring changes in clinical status and patient outcomes, and describing relative costs of services and supports that the patient will likely use. In Ontario, adults admitted for Community Care Access Centre home care services receive RAI-HC assessments. Individuals receive an RAI-HC assessment when they are first admitted for home care services, and then at regular intervals every three to six months or annually, depending on the stability and severity of their needs.

Analysis group

We only included assessment information on long-stay home care patients whose assessments were not conducted in the hospital, or within 60 days of being referred for home care services. This was in order to capture the group of home care patients who have been receiving home care services for a sufficient amount of time for their experience to be somewhat reflective of their experience.

Estimating caregiver distress

We estimated caregiver distress among the caregivers of long-stay home care patients who identified in their RAI-HC assessment that they were receiving help from a caregiver, or had someone who would help them if they needed it. Caregivers are family members, friends or neighbours who are relied upon to help or provide support to the person receiving formal home care.

Caregiver distress can be identified in the RAI-HC in two ways:

1. **The caregiver may no longer be able to continue in caring activities.** The caregiver, patient or assessor may believe that the caregiver is no longer able to continue in caring activities. This can be for any reason, including not wanting to continue, being too far away from the patient, having competing priorities such as work or child care, or because of personal health issues.
2. **The caregiver expresses feelings of distress.** The caregiver expresses that he/she is distressed, angry, depressed, or in a conflict because of caring for the patient.

To determine the proportion of caregivers who were distressed, we divided the number of patients whose caregiver could no longer continue in caring activities, or who expressed feelings of distress, by the total number of patients who indicated that they received help from a caregiver.

Describing home care patients

We described the long-stay home care analysis group and caregivers according to several characteristics determined directly from data elements in the RAI-HC. These include age, dementia, caregiver-patient relationship and living arrangement, and extent of help from unpaid caregivers. Other characteristics were calculated by combining multiple data elements into scales, including cognitive performance, activities of daily living, decline in health stability, and a combination of cognition, functioning and behaviour.

Data were not risk-adjusted for factors associated with rates of distress, such as cognitive impairment in the patient, hours of care provided by the caregiver or hours of publicly funded home care provided to the patient.

The long-stay home care population includes patients with stable health conditions. These patients are capable of living independently and/or have a stable support network. Because of their stability, these patients are assessed using the RAI-HC tool approximately once per year, but possibly at longer intervals, so it is likely that several of these patients are missed from inclusion in this analysis, which only captures patients who had an assessment during the fiscal year.

Limitations

Distress, anger, depression, and ability to continue providing care are subjective measures. Results may under-report the true rate of distress if some caregivers do not want to admit that they feel burdened by having to care for a friend or family member. Similarly, cultural differences exist that can affect one's perception of distress caused by caring for a friend or family member, since it may be simply accepted as something that should be done, regardless of the stress it may cause.

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