

Palliative Care at the End of Life



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.

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.

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.

Scientific Contributions

Health Quality Ontario would like to acknowledge the scientific contributions of:

Hsien Seow, PhD

Associate Professor, Department of Oncology, McMaster University

Canada Research Chair in Palliative Care, Cancer and Health System Innovation Member, Centre for Health Economics and Policy Analysis

Scientist, Escarpment Cancer Research Institute

Peter Tanuseputro, MD, MHS, CCFP, FRCPC

Investigator, Bruyère Research Institute

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

ISBN 978-1-4606-8333-0 (Print)

ISBN 978-1-4606-8334-7 (PDF)

Suggested citation: Health Quality Ontario. *Palliative Care at the End of Life*. Toronto: Queen's Printer for Ontario; 2016.

On the cover: Karen Nicole, courtesy of Healthy Debate: Faces of Health Care (<http://healthydebate.ca/faces-health-care>). Photo by Seema Marwaha.

Table of Contents

| | |
|---|-----------|
| Foreword | 2 |
| Executive Summary | 4 |
| Key findings | 4 |
| Introduction | 6 |
| 1. Services at Home at the End of Life | 11 |
| 2. Hospital Care at the End of Life | 22 |
| 3. Conversations and Caregivers | 32 |
| The Road Ahead | 40 |
| Methods Notes | 43 |
| Acknowledgments | 47 |
| References | 49 |



Photo by Roger Yip

Foreword



Dr. Joshua Tepper
President and Chief
Executive Officer

Everyone in Ontario who requires it should have access to palliative care, providing comfort and dignity for patients and families who are living with a life-threatening illness. Palliative care helps people with the physical, psychological, social, spiritual and practical issues as well as coping with loss and grief during the illness and bereavement.

At Health Quality Ontario, palliative care is one of three areas of emerging focus in our new strategic plan (along with mental health and addictions care and primary care). This report bolsters our understanding of the palliative care services that Ontarians receive at the end of their life – such as those in hospital, in the home (including home visits from doctors) and unplanned visits to the emergency department.

Palliative Care at the End of Life also reveals some of the health system's challenges and opportunities to improve palliative care so that patients can begin to receive palliative care as needed throughout their illness, and die in the location of their choice.

To ensure that people receive the highest-quality palliative care, we need to learn what we do well in the province, and what steps we need to take to make the palliative care system better. The current national discussion on medical assistance in dying in Canada provides a potential choice for some patients who are facing intolerable suffering. But it does not change the need for access to the best possible palliative care for all terminally ill patients when and where they need it, so they feel comfortable and supported.

A lot of work is already underway to build a better palliative care system in Ontario. The Ontario Palliative Care Network, a newly established partnership between patients, caregivers and providers, will continue to plan and connect care in all regions of the province. The Ministry of Health and Long-Term Care also highlights palliative care in its Patients First action plan, and the Ontario government's 2016 Budget includes an investment of \$75 million over three years to provide patients with more options and access to community-based palliative care.

Palliative Care at the End of Life provides insights so we can learn how to make palliative care better for people in Ontario.

Sincerely,



Dr. Joshua Tepper
President and CEO

Executive Summary

The last weeks of someone's life can be some of the most difficult for them, those close to them and their caregivers. When the health system performs well during this time, patients receive care that reflects their values and wishes so they can live with the highest quality of life possible and ultimately, die comfortably where they choose.

Currently, we are not always achieving best-quality care. In surveys of patients and caregivers in Ontario, most people say they would prefer to die at home.[1,2] With high-quality home care and home visits from doctors who provide palliative care, research has shown that more people would likely be able to die at home.[2,3] The reality, though, is that most patients in Ontario died in hospital, even among those who received palliative care.

In this report, we look at the care and services patients received during the last month of life, a potentially challenging time for patients and families, as they fully shift their focus from treatment, to ensuring comfort and managing symptoms. There are many services available in Ontario for patients at the end of their life, but with limited coordination in place to navigate the system, patients can receive fragmented care, especially as they move from one setting to another, such as going from their home to the hospital.[4]

Key findings about care at the end of life in Ontario

Based on the data we use in this report, more than 54,000 people in Ontario were determined to have received palliative care services between April 2014 and the end of March 2015. Of these patients who received palliative care, we found that:

- About half (47.9%) began receiving palliative care in their last month of life.
- Nearly two-thirds (64.9%) died in hospital.
- About one-quarter (25.8%) spent half or more of their last month of life in hospital.
- Nearly two-thirds (62.7%) had unplanned emergency department visits in their last month of life.
- Less than half (43.3%) received palliative home care services in their last month of life.
- About one-third (34.4%) received a home visit from a doctor in their last month of life.

One limitation of this analysis: If some patients received palliative care that was not captured in medical health records data as being palliative or end-of-life care, we are unable to report on their care.

We also include results of a survey of caregivers for patients who died in a select group of residential hospices (home-like buildings or apartments that provide palliative care). The survey results may not reflect the broader picture of palliative caregiving in Ontario, but it nevertheless provides valuable insights into the point of view of some caregivers. Among caregivers of patients who died at a residential hospice:

- About three-quarters (76.7%) rated emotional support in their last week of life as excellent.
- Less than half (45.7%) said health care providers “definitely” helped them understand what to expect or how to prepare for the patient’s death.

Based on the 2014 Commonwealth Fund Survey of Older Adults, we also report conversations about care at the end of life (which are not necessarily related to the formal process of Advance Care Planning):

- Nearly two-thirds (64.0%) of older adults surveyed in Ontario say they have had discussions with family, friends or health care professionals about the health care treatment in the event they become ill and cannot make decisions for themselves.

Laying the groundwork

Efforts underway in the province to improve palliative care will require engaging with the public and teaching people to understand the role of palliative care, which does not mean that nothing else can be done. In fact, palliative care is often offered alongside care that is intended to prolong survival. Patients, caregivers and providers share their experiences throughout this report, revealing aspects of palliative care that the numbers cannot tell us. These stories show what the health system means to people who are receiving palliative care and for their caregivers.

This report lays the groundwork for future reporting by showing what we do know about palliative care for patients in Ontario at the end of their life, and what other data are needed to learn more about this important area. We know about the types of services that are available for people at the end of their life and where people die, but little as yet about the quality of those services, whether they met the needs of patients and caregivers. In the future, we will work to find out more about the quality of palliative care.

Introduction



A new approach to palliative care

There is common misconception that if someone is receiving palliative care, it means that treatments to slow the progress of their disease would be stopped. Research has shown the opposite to be true: earlier palliative care can lead to better quality of life throughout the entire process from the time of being diagnosed with a life-threatening illness.[5]

We know patients should receive palliative care much earlier than they often do. In the past, the approach to palliative care was that it wouldn't begin until the very latest stages of the illness or often not at all. The newer approach to palliative care (sometimes also called "hospice palliative care," regardless of where it takes place) is that it can begin immediately after the patient is diagnosed with a life-threatening condition. Under this approach, palliative care is an undercurrent throughout the patient's care.

Palliative care at the end of life

Ontario, like many other jurisdictions, is in the process of determining the best ways and locations to provide care for people who are at the end of their life. This report looks at care in the last month of life for patients in Ontario, an important timeframe within the broader scope of palliative care, since currently nearly half (47.9%) of those patients began to receive palliative care during this last month. This is typically the time when people who are dying need the most involved care, and the weeks that will shape their experiences and those of their loved ones.

One limitation of this analysis is that we are unable to report on patients who may have received palliative care, but whose care was not captured in medical records data as being palliative or end-of-life care.

Where possible, we look at the care and experiences for different subgroups of people in Ontario in their last month of life by reporting results based on Local Health Integration Network (LHIN) regions, neighbourhood income, and whether they live in a rural or urban setting.

Dying at home

When surveyed, the majority of people in Ontario have said that they would prefer to die at home rather than in the hospital.[6] However, once someone becomes very ill, the reality of a home death may not be easy to achieve. In some cases, medical interventions and procedures may be better performed in hospital, but given enough supports – especially nursing care – most people should be able to die at home or elsewhere in the community (such as in a long-term care home or a residential hospice) if they choose. While most people might express a preference to dying at home when asked as part of a survey, in some cases the home death might be more challenging than people originally thought – the home might need to be transformed into a hospital-like setting. [7,8] Additionally, patients might not have the family or private caregiver supports they need or the financial means to cover the costs of dying at home.[9]

What is palliative care?

Palliative care – also known as “hospice palliative care” – is the broad approach to providing comfort and dignity for patients and families who are living with, or at risk of developing a life-threatening illness.

According to the report *Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action* (2011),^[10] palliative care aims to help people and families to:

- Address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears
- Prepare for and manage self-determined end-of-life and the dying process
- Cope with loss and grief during the illness and bereavement

- Treat all active issues and prevent new issues from occurring
- Promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization

Public consultations across Ontario for the *Palliative and End-Of-Life Care Provincial Roundtable Report* (2016) revealed that too often, people think palliative care means the system has given up on them or their loved ones. The report said education efforts should focus on teaching people that palliative care is a holistic approach to meet the needs of those with life-threatening illnesses. This includes helping them live longer with the best quality of life possible, and to die comfortably.^[11]

Where is palliative care at the end of life delivered and by whom?

People in Ontario who are receiving palliative care at the end of life receive services in many forms, such as caregiving from family members, home care and doctor services, and in several types of locations, including homes, long-term care homes, residential hospices (buildings or apartments where palliative care is provided in a home-like setting,) [12] and hospitals, both within and outside formally designated palliative care units.

Home and community care services for patients receiving palliative care include:

- Home care services, which can include nursing care, psychological counselling, personal care, as well as access to equipment such as hospital-style beds or oxygen
- Visits from doctors and nurse practitioners to their home (although the data reported here do not include nurse practitioner visits)
- Long-term care homes providing palliative care within the facility for patients at the end of their life

- About two dozen residential hospices in Ontario, which are partially funded by the province, provide palliative care services to patients at the end of their life.
- Visiting hospice care programs that provide counselling, and family support for grief and bereavement
- Volunteer palliative care services, including grassroots community support, palliative day programs, home and residential hospice supports
- Caregiver support

Hospital care for patients receiving palliative care includes:

- Hospital emergency departments provide care for patients who are receiving palliative care (some patients return home after a visit to the emergency department, while others are admitted to hospital)
- Hospital admissions for patients who need symptom and pain management in the hospital (some hospitals also have a small number of specifically designated palliative care unit beds, but most patients are admitted to the hospital's regular acute care beds)
- Many hospitals have palliative care consultation teams for patients, as well as other patient and caregiver programs and supports



Palliative care beds in hospices and hospitals, 2015

Data sources: For number of palliative care beds: Ontario Healthcare Financial and Statistical (OHFS) Database, provided by the Ontario Ministry of Health and Long-Term Care. For number of beds in residential hospices: provided by Hospice Palliative Care Ontario [email], May 16, 2016.

Note: Palliative care may be provided in acute care beds as well.

Focus on patients who received palliative care

A total of more than 95,000 people died in Ontario in 2014/15, over 54,000 of whom (57.0%) had a record of receiving at least one palliative care service in their last year of life across all health sectors (such as home care, hospital care and long-term care).

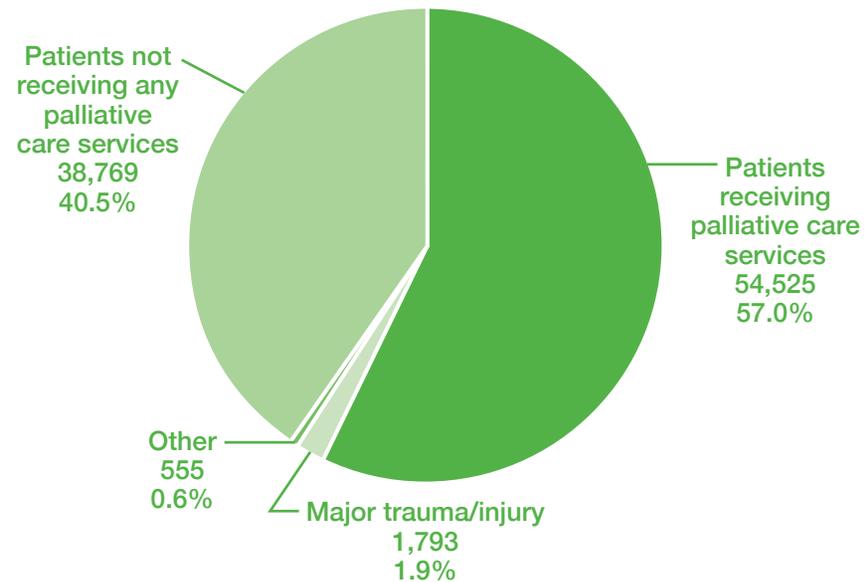
For this report, patients who received palliative care were identified based on receiving a palliative care service or end-of-life designation in their medical records in the last year of life, between the beginning of April 2014 and the end of March 2015.

For the sake of clarity throughout the report, we refer to this group of 54,000 patients who received palliative care as “palliative care patients.” “Palliative” describes the type of care, not the patient.

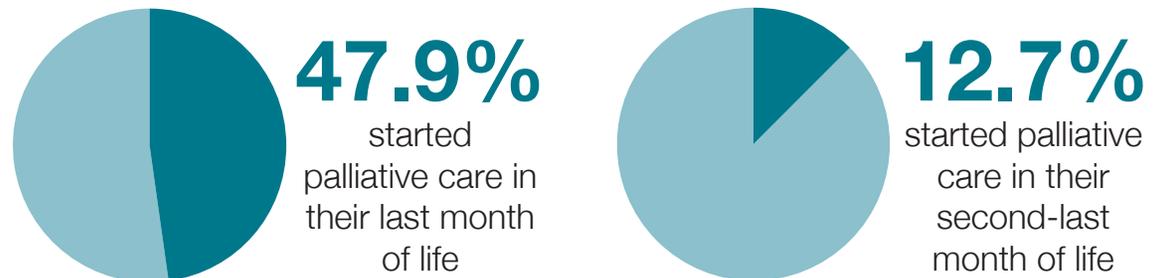
The first two chapters focus on the palliative care services that this group of palliative care patients received (or did not receive) in their last month of life, a time they are often most in need of health system supports.

For more information on the analysis, see the Methods Notes at the end of the report.

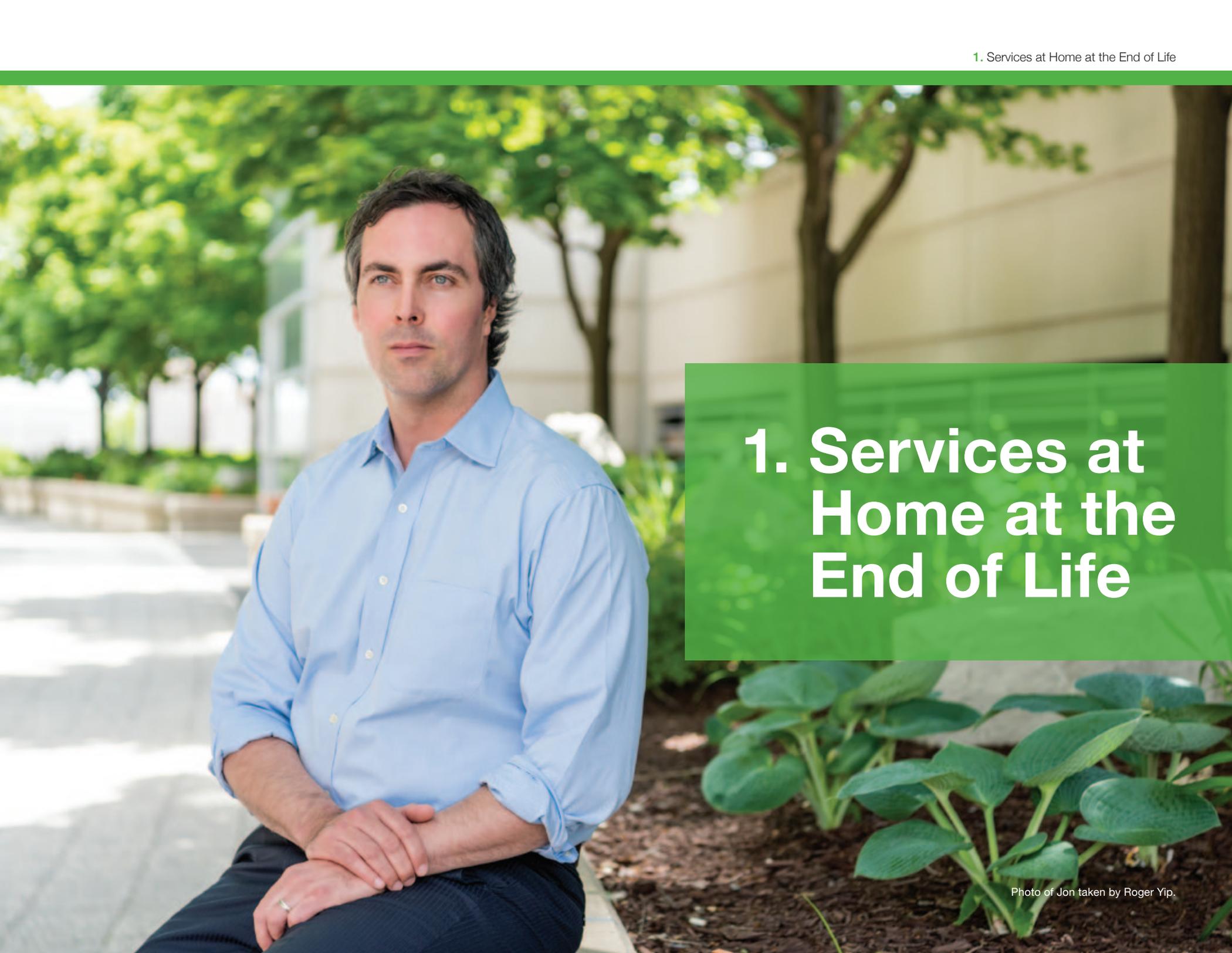
Description of the patients who received palliative care services as a proportion of all people who died in Ontario, 2014/15



Among the approximately 54,000 palliative care patients who died:



Data source: Continuing Care Reporting System (CCRS), Discharge Abstract Database (DAD), Home Care Database (HCD), National Ambulatory Care Reporting System (NACRS), Ontario Health Insurance Plan (OHIP), Registered Persons Data Base (RPDB), provided by the Institute for Clinical Evaluative Sciences (ICES)

A man with dark hair and blue eyes, wearing a light blue button-down shirt and dark trousers, is sitting on a stone ledge outdoors. He is looking directly at the camera with a neutral expression. His hands are clasped in his lap. The background is a lush garden with green trees and a light-colored building. A green semi-transparent box is overlaid on the right side of the image, containing the section header.

1. Services at Home at the End of Life

Dying is really hard

Pat's son Jon reflects on his mother's outlook on life, the care that she received at the end of her life, and the decision to die at home.

On dying

Wow, dying is really hard, on so many different levels. There's the physical aspect of actually dying and the emotional and the existential aspects. My mom handled herself with incredible dignity and grace, but she also had horrible days where she was feeling selfish and mean and bored. Humans are messy – we can't be neatly tied up into perfect little packages, and certainly she was no different.

Living in the moment

My mother didn't try to pretend like she had all the answers. She was in some ways comforting and in another way fatalistic about things. The diagnosis is the diagnosis, and you deal with it the best way that you can, she would say. One of the things that resonated with me with my mom's attitude was living in the moment. It's a bit of a cliché but we don't do that very well in this world right now. We do a lot of things to not be in the moment, in fact, and that's something that her disease forced her to do. And that, as my mom says in a video documentary she recorded, is where all the good stuff resides.

No rulebook

My dad, my brother and I felt like we could write a book to guide people through this; what to expect, the highs and the lows and where to go for help, because there is no rulebook. There is Murphy's Law: whatever can go wrong, does. There are so many important parts and every important part has the opportunity to go well or wrong. From the diagnosis all the way through to the advice you get to third parties who rent you hospital beds to dealing with the nurses who come to your house, it's an incredibly complex process. It's really hard to navigate, and you're under tremendous stress as it is.



Photo of Jon taken by Roger Yip.

The doctor meeting

In the early days, my mom wanted to make sure that my brother and I, and maybe also my dad, were OK and understood the diagnosis and all that stuff. And Dr. Nina Horvath, the palliative care doctor, said let's all come into my office and have a chat. With no regard for timing or kicking us out of the office, she met with us, all of us, and that was very powerful.

Staying home

My mom, being the selfless person that she was, didn't want to die in her house, because she didn't want it to be thrust upon my dad and family. As death got closer, I think she thought, 'Why would I want to be in an institution versus my home?' So she and my dad made the decision for her to die there, and I think it was the right one. It wasn't easy, though.

Stress

Little things can and do happen that end up being big deals. One day, towards the end of her life, my mom was in incredible pain in her midsection, and we thought, what could it possibly be? We could give her morphine but only at certain intervals. We didn't know what to do. The stress we were under was insane. The one thing that you commit to your mom or your partner is that you will not suffer on our watch. Finally, the nurse arrived five hours later. It turned out it was because her catheter was twisted – that's it.

A full-time job

In the last months of her life, my mom needed 24-hour care. She needed help doing everything and that is a lot of coordinating. The government-funded home care does six hours a day and you have to do private for the rest of the time. You have to coordinate with the agency, and then there are the drugs, getting them filled and delivered, and renting the hospital bed. You would do anything for your family, but it is a massive undertaking. People should definitely have their eyes wide open. It's a full-time job.

For more on Pat's story, see "Joy in my days" on the next page.



Photo of Jon taken by Roger Yip.

Joy in my days

Diagnosed with terminal cancer, Pat offered her views on palliative care, life and death in a video with a hospital in North York in the months before she died in 2014. These are Pat's words, excerpted from that video.

On life and death

We're all going to die, and if we're very very lucky, we're going to have friends and family around us, and no discomfort. When you're going through cancer, it can't be an everyday thing. You just can't immerse yourself in the illness.

Out of control

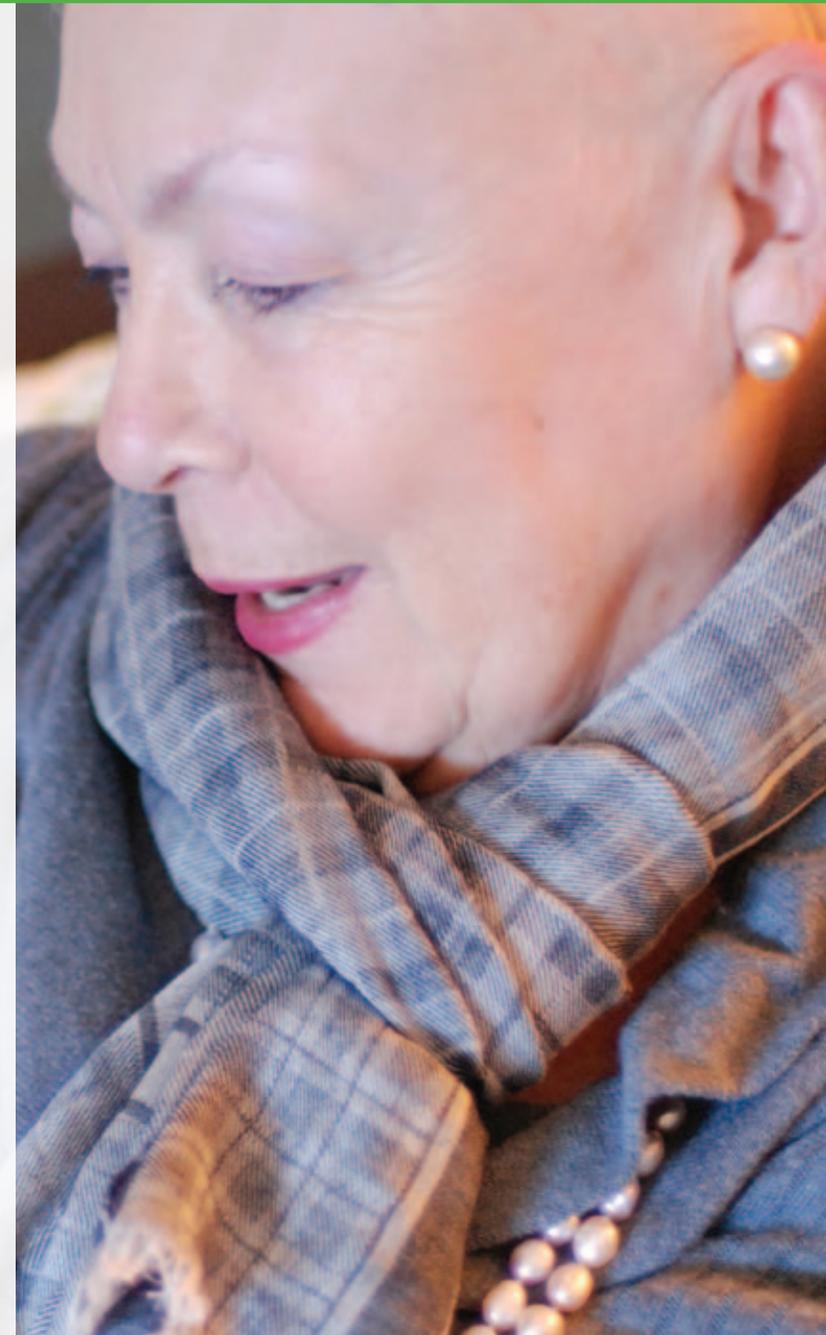
In 2009, I had a bilateral mastectomy and there was no lymph node involvement, so when you hear that, you automatically think, 'OK, I am winning this one.' So it was very shocking to discover this January that it actually had metastasized to the lungs and the brain. You know, everyone's diagnosis is so different, and the way they handle it is so different. And the first little part of it, you just feel so completely out of control, I think. I think a lot of people feel just completely out of control.

After the initial diagnosis, that's sort of shattering, and then you regroup. And I guess the most precious thing was my experience with the family during that initial shattering diagnosis because that sense of being surrounded with their love was huge. That was the most important thing.

Struggling with the future

I think many of us, including me, always felt that palliative meant you are on the end run. You were here and now you're falling off the cliff, and that palliative care is end-of-life care.

They know that the tumours that are in the brain are the problematic ones ... You can't help but want to know, when I fall off this cliff, cognitively, what is it going to look like? Is it going to affect my speech, my cognitive functioning, or am I going to become this crazy lady who's screaming obscenities at her family? That part is the part that's difficult.



We've got you covered

We all left [palliative care doctor] Dr. [Nina] Horvath's office feeling very comforted, knowing that we were going to manage. As Dr. Horvath said, "Birth is a mystery. We go into that not knowing what it's going to feel like, how we're going to manage it." She said death is the same. It's a mystery. We don't know. We don't know how much pain is going to be involved or how long and protected it is, but we will deal with it and help you ... She said, we can deal with physiological pain, we can deal with emotional pain and we can deal with existential pain. So in other words, we've got you covered.

Quality of life

It sounds like a hackneyed phrase, but it's really about the quality of life. You want to hang around but not at the expense of the quality of your life. My plan was that I would die in hospice. I would not impose the dying in my house because I felt that the house was a sanctuary for the family and that was something I was depriving [my husband] Mike and the kids of. And things changed. Dr. Horvath said to me, "You don't have to make up your mind right now. This is a process and it's something you can think about long-term." So funnily enough, Mike and I have been measuring for a hospital bed and the sofa will fit here, and I can see my birds in the trees. And he said that would be my choice, not only for me but for himself.

Living in the moment

Somehow or other you have to get yourself in the headspace of living in the moment because when you have a terminal diagnosis, living in the moment is the only place to be, because that's where all the good things reside – your friends, your family, your love, your humour, the things you like to do, and that is probably the key.

The whole palliative thing for me, it's really about giving me energy to my days, joy in my days to do what I need to do, and I don't really focus a lot on the illness.

Pat died at home in February 2014, surrounded by family.

For a doctor's perspective on Pat's story, see page 19.



Patients in Ontario can receive publicly funded palliative care services in their home. These include home care visits for nursing care, personal support care, occupational and physical therapy, counselling and other services, and home visits from doctors and nurse practitioners. The amount and type of care that someone receives may vary depending on the severity and nature of the illness.

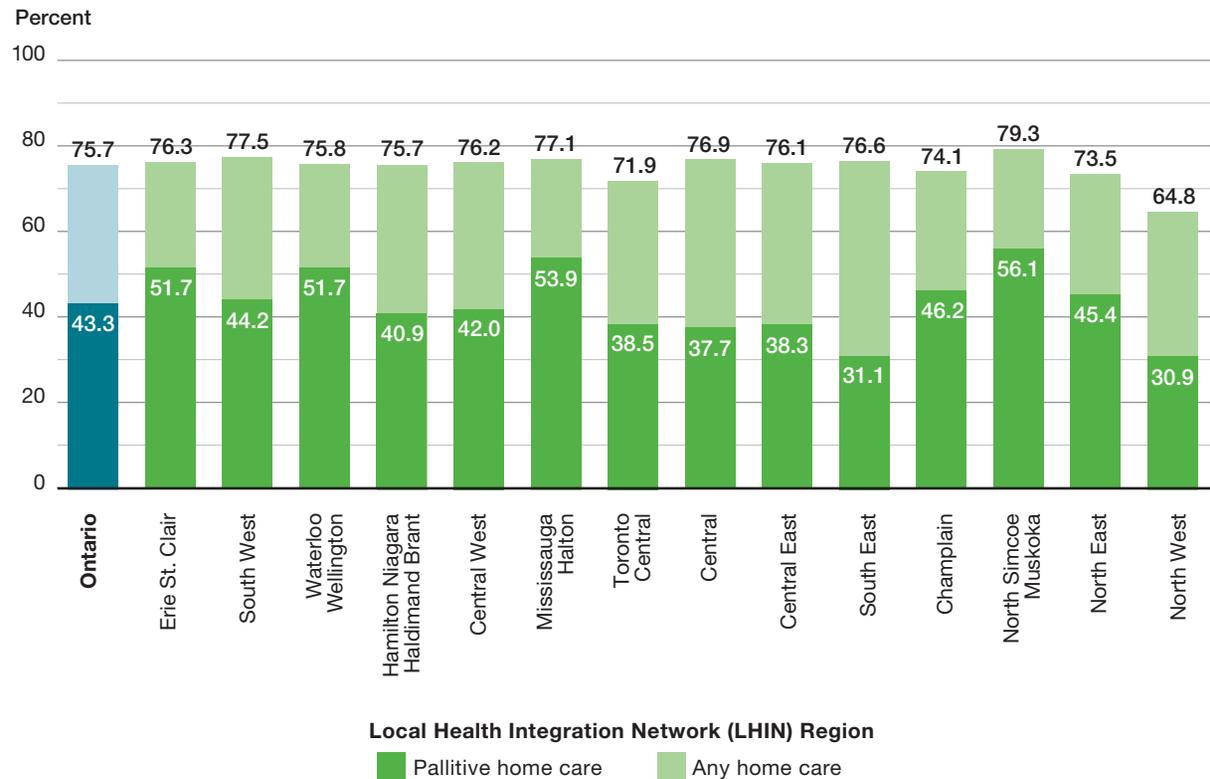
Home care visits

When patients are nearing the end of their life, publicly funded home care services can help to ease the burden on family and provide care that could increase the opportunity for patients to die at home if they wish. Receiving palliative home care has been associated with a 50% reduction in the likelihood of dying in hospital.[13]

About three-quarters (75.7%) of palliative care patients in Ontario who were in the community in the last month of life received at least one home care service in that period. Less than half (43.3%) received palliative-specific home care services, which typically involve more hours of care per week. (Figure 1.1)

FIGURE 1.1

Percentage of palliative care patients who received home care (any or palliative) in their last 30 days of life, in Ontario, by LHIN region, 2014/15



Data source: Continuing Care Reporting System (CCRS), Discharge Abstract Database (DAD), Home Care Database (HCD), National Ambulatory Care Reporting System (NACRS), National Rehabilitation Reporting System (NRS), Ontario Health Insurance Plan (OHIP), Registered Persons Data Base (RPDB), provided by the Institute for Clinical Evaluative Sciences (ICES)

By LHIN region, there was variation in the proportion of palliative care patients who received palliative home care services, ranging from 30.9% in the North West LHIN region to 56.1% in the North Simcoe Muskoka LHIN region. (Figure 1.2)

By income, the palliative care patients living in the poorest neighbourhoods were less likely to receive palliative home care services in their last month of life (39.0%), compared with 46.3% of palliative care patients in the richest neighbourhoods. However, there was no difference in the proportion of palliative care patients receiving home care services based on whether they live in an urban or rural area.

The true costs associated with a home death include those that are absorbed by the patient and family. According to a study that detailed total costs of caring for patients receiving palliative care services at home through a palliative care centre in Toronto, caregivers absorbed an average of \$17,500 per month in lost wages and leisure time and another \$700 per month in out-of-pocket expenses for the patient and family.[14]

The cost of home-based palliative care



Total cost of home-care palliative care

That total includes:

- + **\$17,500/month**
 Lost wages and leisure time for caregivers
- + **\$6,400/month**
 Health care system costs
- + **\$700/month**
 Out-of-pocket expenses for patient and family
- + **\$170**
 Third-party insurer costs

Data Source: Guerriere DN, Zagorski B, Fassbender K, Masucci L, Librach L, Coyte PC. Cost variations in ambulatory and home-based palliative care. *Palliative Medicine*. 2010 Jul 1;24(5):523-32.

Home visits by a doctor

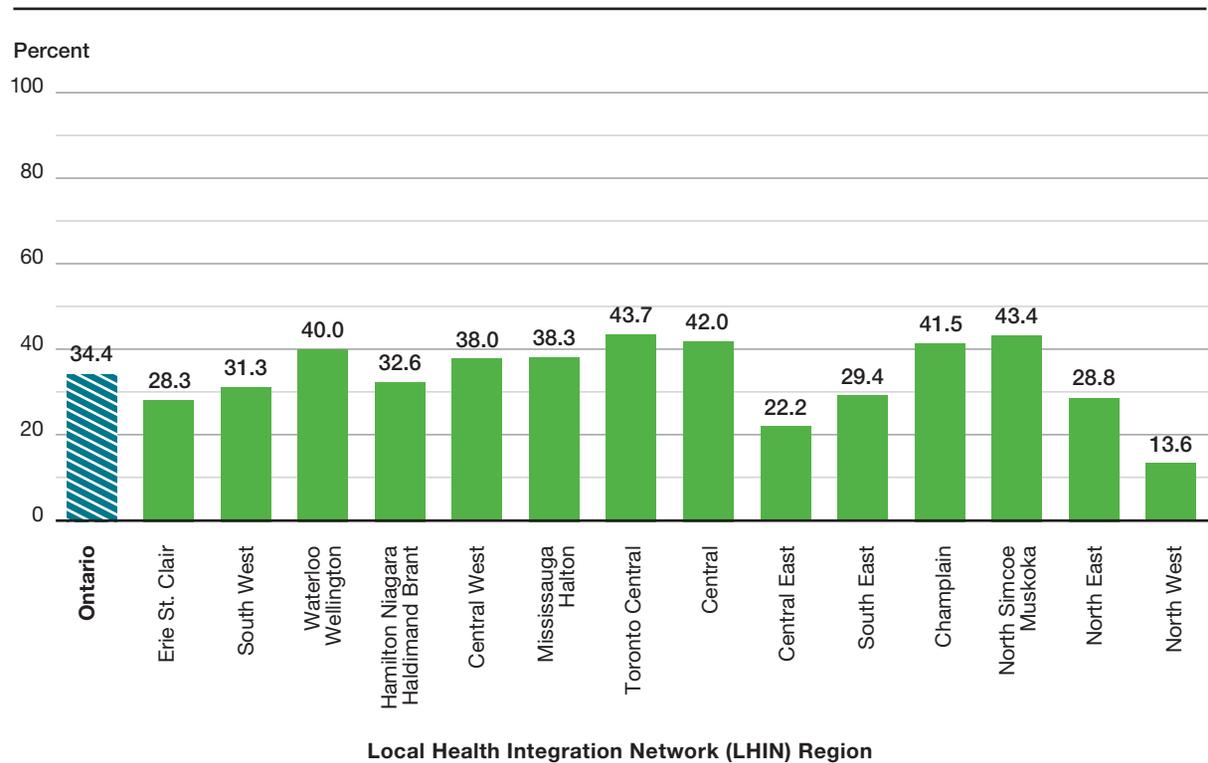
Patients in Ontario who receive palliative care sometimes receive visits to their home from primary care providers, including doctors, as part of their care. There is some evidence that home visits by doctors can lead to fewer unplanned trips to the emergency department for patients nearing the end of their life.[15] People who receive home visits by a doctor may also be less likely to die in hospital.[15]

We do not have any data or evidence showing the appropriate number of home visits by a doctor for the most benefit to patients, but we do know that just over one-third (34.4%) of palliative care patients in Ontario who were in the community in the last month of life received at least one home visit by a doctor during that time.

The rate of home visits by a doctor varied by region in Ontario, ranging from 13.6% in the North West LHIN region to 43.7% in the Toronto Central LHIN region (Figure 1.2). Some of this variation could be related to differences in geographical areas or numbers of palliative care doctors. Also, we do not have data on home visits by nurse practitioners, who may play a larger role in primary care for patients receiving palliative care in some LHIN regions.

FIGURE 1.2

Percentage of palliative care patients who had at least one home visit from a doctor in their last 30 days of life, in Ontario, by LHIN region, 2014/15



Data source: Continuing Care Reporting System (CCRS), Discharge Abstract Database (DAD), Home Care Database (HCD), National Ambulatory Care Reporting System (NACRS), National Rehabilitation Reporting System (NRS), Ontario Health Insurance Plan (OHIP), Registered Persons Data Base (RPDB), provided by the Institute for Clinical Evaluative Sciences (ICES)

“If a person is in pain or struggling, instead of going to the emergency department, a doctor or palliative care nurse can come to the home, assess the need, and order medications for symptom relief. A person nearing the end of life wouldn’t be able to come in the doctor’s office for a regular visit, so if they don’t get care in the home, they often have no recourse but to go to the hospital.”

“One common scenario is that many people close to the end of life will lose the ability to swallow and to take medications by mouth. A doctor who comes in the home can order injected or intravenous medications to provide symptom relief at home, and this very often prevents an emergency department visit.”

–Dr. Peter Tanuseputro, family doctor and palliative care researcher



Photo of Peter by Roger Yip.

Focus on equity

By income, palliative care patients living in the poorest neighbourhoods in Ontario were the least likely to receive home visits from a doctor (29.4%), compared with patients in the richest neighbourhoods (40.2%). Some 35.1% of palliative care patients living in urban areas received home visits from a doctor, compared with 30.4% of palliative care patients in rural areas. Some of the variation by region and across rural and urban areas could be attributed to larger geographical areas and a higher proportion of nurse practitioners – whose visits are not included in this data – providing primary care in rural areas.

“I think it’s helpful to have someone caring for you who can relate to your cultural background. It just makes things easier. For example, the nurse who cared for my father was from the Caribbean, from Jamaica, and he had lived in Trinidad for a period of time. So being able to talk about his experiences in Trinidad and what he remembered was an entry point for discussions with my father, who lived in Trinidad his whole life.”

–Runako helped care for his father, who died of complications from prostate cancer.



Photo of Runako taken by Roger Yip.

2. Hospital Care at the End of Life





Photo of Nina taken by Roger Yip.

To live until you die

Dr. Nina Horvath, a palliative care doctor at a hospital in North York, discusses the inspiration she gets from Pat and other patients, and the evolution of palliative care in Ontario.

Lifting the burden

When I ask my patients for their biggest fear, they don't say pain or suffocating, they tell me it's being a burden to their family. I learned within my first few years of working in palliative care that it's such a universal feeling and perception. We sometimes put too much responsibility on the informal caregivers. I tell every family that it's not their job to take care of their loved one. They have to be family first and caregiver after.

End of life at peace

My approach is, only after I take care of my patients' symptoms and their physical pain can they figure out how to live while they are dying. To manage pain, for most people I try to make them comfortable in a way that is not going to make them groggy, so that they can live their life without being burdened, to be able to say their goodbyes and finishing their relationships.

I'm learning from my patients all the time. It's absolutely amazing how some people have it all figured out. One of my patients, a 28-year-old girl who was dying from cervical cancer, had her parents and her husband sitting at her bedside, and she was the one taking care of them the whole time. I could not figure out how she had the strength to do that. She told me it was her spiritual life, and that she didn't have any sense of entitlement. My patient Pat also came to peace with the fact that she was dying.

What's in a name?

Palliative care is a four-letter word to a lot of people because it started originally as end-of-life care. So when somebody hears the words "palliative care," they think, "Huh!?! Am I dying?" The idea



Photo of Nina taken by Roger Yip.

of changing our name keeps resurfacing, but I think whatever way you change it, it would still be scary. It's about educating people. Lots of times when I see people in the clinic, they say the patient doesn't want palliative care, so I will come in and tell the patient that I'm the pain specialist, which I am. And then I explain to them: "We also take care of you at the end of life, but that's not why I am here today."

A shift in thinking

When I started working here as medical director eight years ago, we launched inpatient beds for palliative care at the hospital, as well as consulting services and clinics. We also increased the outreach programs in the community, working with nurse practitioners, family doctors and other care providers, with palliative care specialists providing backup or consults. Over the years, there has been a definite shift in thinking that palliative care is important. Hopefully that will translate into more accessibility to patients, because right now palliative care is still basically in its infancy.

Areas of need

There are two main areas where people need more access to palliative care: in their own homes, and, for people who have very complex needs or who don't have enough caregiver support, end-of-life palliative care units in hospitals or residential hospices. The basic problem with palliative care is that you have to provide it 24/7. And that's not the way it works these days.

Beautiful view

Some people feel safer in a hospital or a hospice environment and some people prefer to stay at home. And you can't tell ahead of time. When I first met my patient Pat, she said she didn't want to die at home because she wanted to protect her family. Once she realized that they were OK with it, she was OK. Pat always wanted to watch the flowers in the courtyard of her building. I remember coming to visit the night before she died, and seeing the beautiful view, I realized what she meant, that it was an almost spiritual experience for her to see those flowers when she was in the bed.

Patients who are receiving palliative care can obtain a wide range of services from Ontario hospitals, including emergency department care and admissions to the hospital for further treatment or palliative care services.

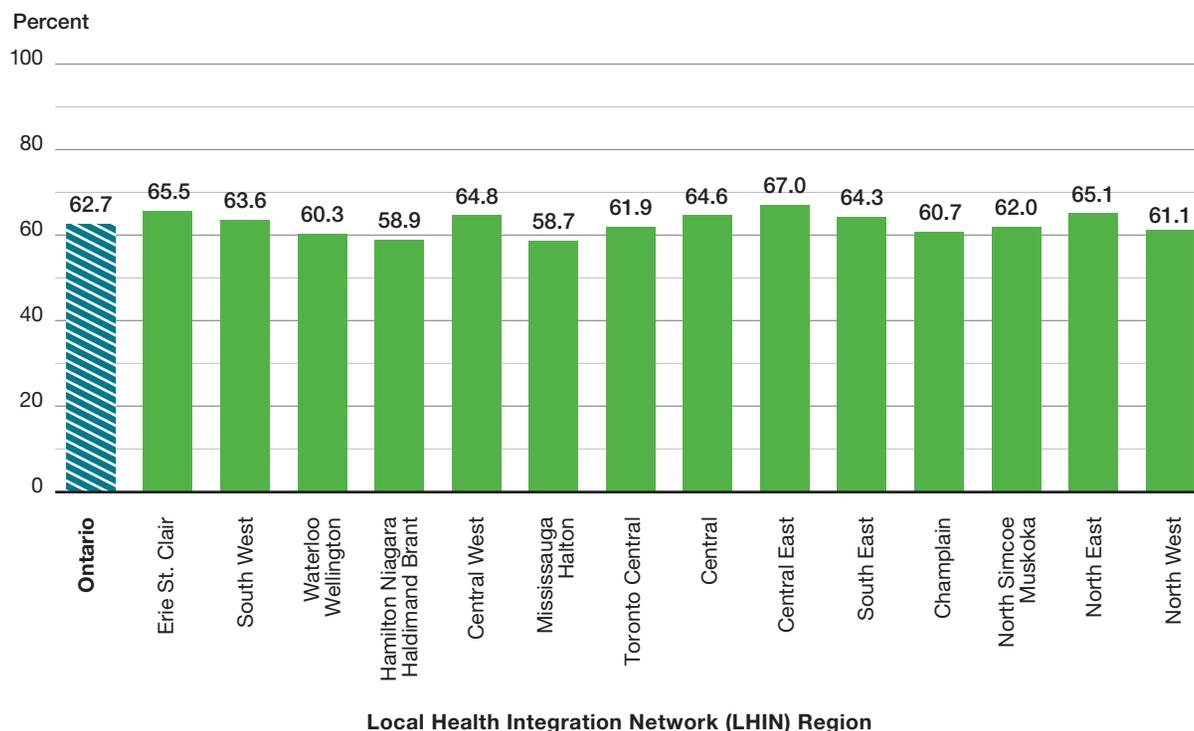
Unplanned emergency department visits

Unplanned visits to the emergency department by patients who are receiving palliative care can be an indicator that people did not receive the care they needed in the community.[16] Although there are also times when these visits may be appropriate or unavoidable, transitions can be very difficult for patients at this time of life. In addition to accessing needed care, another positive aspect of an emergency department visit may also be an opportunity for members of inter-professional teams at the hospital to talk to patients with chronic or terminal illnesses about a referral to palliative care services if that has not already occurred.[17]

Nearly two-thirds (62.7%) of palliative care patients in Ontario had unplanned visits to the emergency department in their last month of life. The rates of unplanned emergency department visits varied across LHIN regions, ranging from 58.7% in the Mississauga Halton LHIN region to 67.0% in the Central East LHIN region. (Figure 2.1)

FIGURE 2.1

Percentage of palliative care patients who had at least one unplanned emergency department visit in their last 30 days of life, in Ontario, by LHIN region, 2014/15



62.7%

of palliative care patients had at least one unplanned emergency department visit in their last 30 days of life.

Data source: Continuing Care Reporting System (CCRS), Discharge Abstract Database (DAD), Home Care Database (HCD), National Ambulatory Care Reporting System (NACRS), Ontario Health Insurance Plan (OHIP), Registered Persons Data Base (RPDB), provided by the Institute for Clinical Evaluative Sciences (ICES)

Palliative care patients living in the poorest neighbourhoods were more likely to have unplanned visits to the emergency department in their last month of life (65.4%), compared with palliative care patients living in the richest neighbourhoods (59.8%). However, there was no variation by rural and urban setting.

Being admitted to hospital

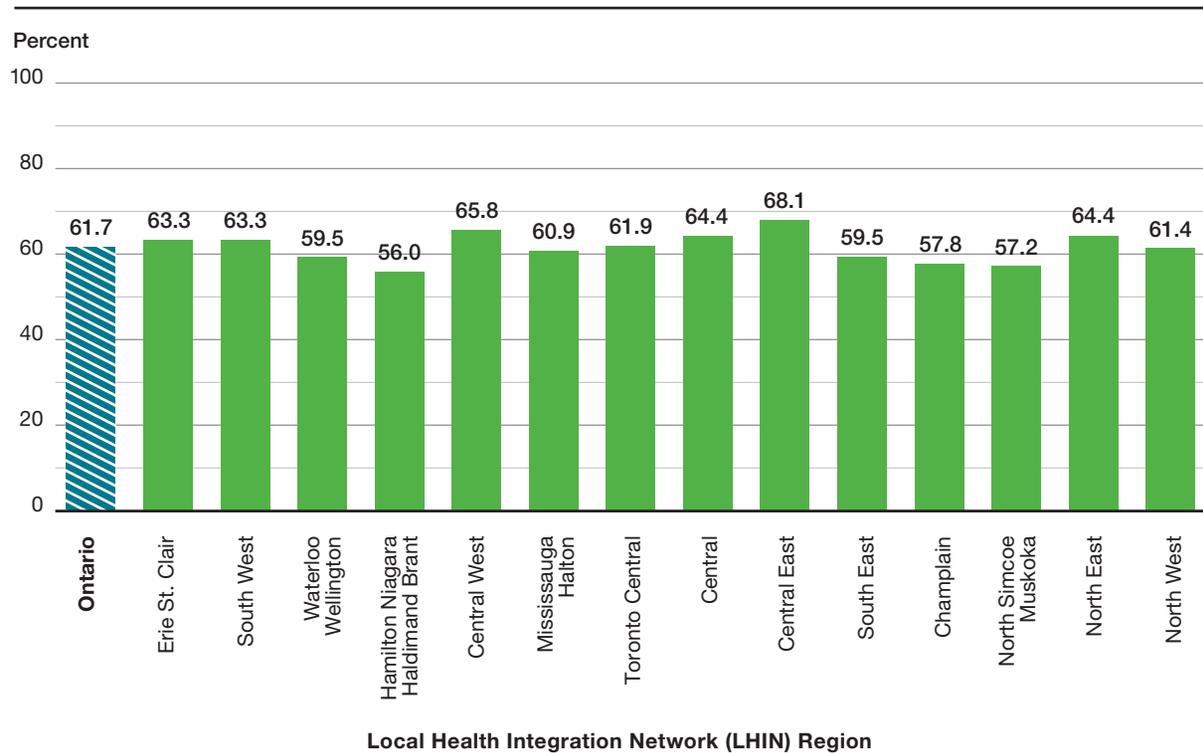
Sometimes patients who are receiving palliative care are admitted to hospital. Among palliative care patients in Ontario, 61.7% had at least one admission to hospital in their last month of life. The hospital admission rates for those patients varied by LHIN region, ranging from 56.0% in the Hamilton Niagara Haldimand Brant LHIN region to 68.1% in the Central East LHIN region. (Figure 2.2)

61.7%

of palliative care patients who had at least one hospital admission in their last 30 days of life.

FIGURE 2.2

Percentage of palliative care patients who had at least one hospital admission in their last 30 days of life, in Ontario, by LHIN region, 2014/15



Data source: Continuing Care Reporting System (CCRS), Discharge Abstract Database (DAD), Home Care Database (HCD), National Ambulatory Care Reporting System (NACRS), Ontario Health Insurance Plan (OHIP), Registered Persons Data Base (RPDB), provided by the Institute for Clinical Evaluative Sciences (ICES)

Palliative care patients living in the poorest neighbourhoods in Ontario are more likely to get admitted to hospital in their last 30 days of life than palliative care patients living in the richest neighbourhoods (64.5% compared with 58.9%). However, there was no difference in the hospital admission rates by rural or urban areas.

Time spent in hospital

Based on hospital data, we are able to look at the number of days that palliative care patients spent in hospital during their last month of life. More than half of palliative care patients (54.9%) in Ontario spent five days or longer in hospital during their last 30 days of life. About a quarter (25.8%) of palliative care patients spent half or more of their last month of life in the hospital (Figure 2.3).

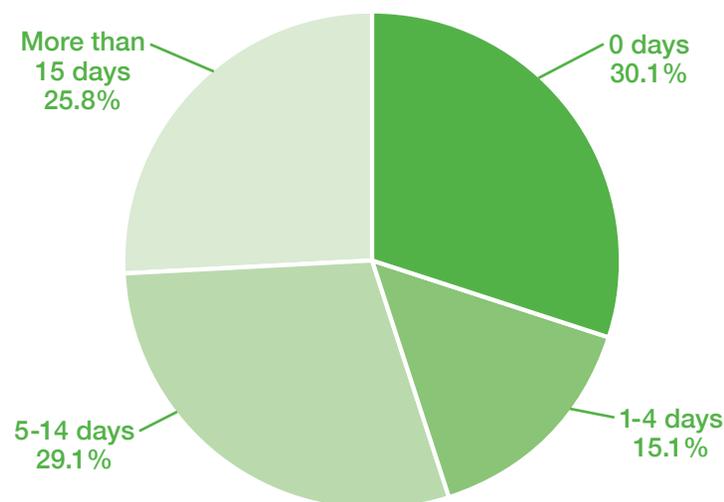
Among all neighbourhood income groups, as well as rural or urban settings, the average (median) number of days spent in hospital in the last month of life ranged from 5 to 6 days.

25.8%

More than a quarter (25.8%) of palliative care patients spent half or more of their last month of life in hospital.

FIGURE 2.3

Percentages of palliative care patients in Ontario, grouped by length of hospital stay in their last 30 days of life, 2014/15



Data source(s): Continuing Care Reporting System (CCRS), Discharge Abstract Database (DAD), Home Care Database (HCD), National Ambulatory Care Reporting System (NACRS), Ontario Health Insurance Plan (OHIP), Registered Persons Data Base (RPDB), provided by the Institute for Clinical Evaluative Sciences (ICES).

Among palliative care patients who spent time in hospital in their last 30 days of life, the average (median) number of days varied by region, ranging from 4 days in the Hamilton Niagara Haldimand Brant and South East LHIN regions to 8 days in the North West LHIN region.

Location of death

Most caregivers of patients receiving palliative care report that they and the patient had a preferred place of death. About two-thirds of people in Ontario (and across Canada) say they would prefer to die at home, but there is a mismatch between their preferences and the reality, which is that most people die in hospital.[18] A seven-country study of older patients who died of cancer found that palliative care at the end of life was most hospital-centric in Belgium and Canada, and less so in the Netherlands and the United States.[19] In some countries, such as the U.K., there are ongoing efforts to shift palliative care so that people who want their home to be the place where they die are able to do so.[20]

While there are ongoing discussions about appropriate locations of death,[21,22] the purpose of this report is to look at the current reality in Ontario for the types of services and locations of care that people can expect in the last month of life. There are many factors that affect the place of death, including patient preference and changes in preference over time, caregiver availability, community and family support, the nature of the illness and the level of disability at the end of life.

Karen's comfort

Karen Nicole has kidney disease, has had a kidney transplant, a cardiac arrest, and now has a rare cancer. She shared these thoughts on palliative care with the Faces of Health Care blog (facesofhealthcare.ca/karen-nicole).

“I definitely have my moments. I will be honest. Within the last two years I have called the social worker three times to say I'd like to sit down and discuss palliative care and discontinuing dialysis. Really dark moments. Maybe a few too many hours in that room doing dialysis by myself without a care partner. But I am surrounded by so much love. Every weekend during the last month I've had visitors – people flying in to spend time with me.”

“I'd put my hospital bed right here, with sunlight coming in, and I'd get to pass with dignity and in comfort, with help in my own home. At times that has been my comfort, my solace.”

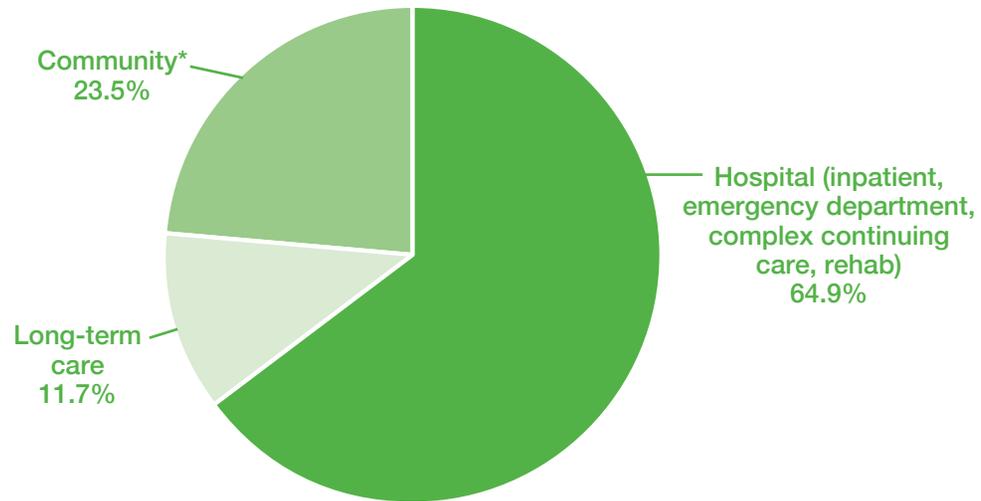


Photo of Karen Nicole taken by Seema Marwaha.

Among the palliative care patients in Ontario, 64.9% died in hospital, 23.5% died in the community (which includes home, residential hospices, retirement homes and assisted living homes), and 11.7% died in long-term care homes (Figure 2.4).

We provide the location of death for palliative care patients who died in Ontario, but focus on hospital deaths, as this is where we have the most accurate data. Deaths in hospital include palliative care patients who died in the emergency department, those who were admitted to hospital and complex continuing care (specialized medical services for people with complex illnesses).

FIGURE 2.4
Percentage of palliative care patient deaths, by location, in Ontario, 2014/15



Data source(s): Continuing Care Reporting System (CCRS), Discharge Abstract Database (DAD), Home Care Database (HCD), National Ambulatory Care Reporting System (NACRS), National Rehabilitation Reporting System (NRS), Ontario Health Insurance Plan (OHIP), Registered Persons Data Base (RPDB), provided by the Institute for Clinical Evaluative Sciences (ICES).

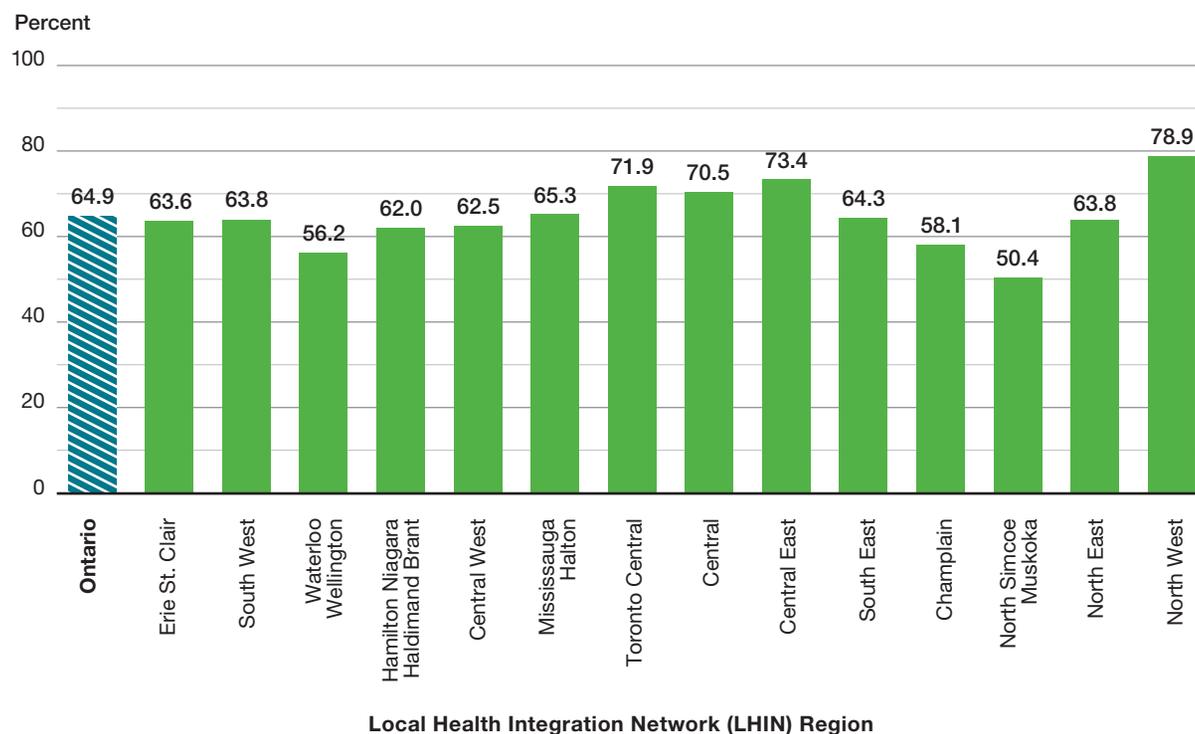
Notes: *May include places such as home, hospice, assisted living, retirement home

There is wide regional variation across Ontario in the location of death among palliative care patients. The rate of hospital deaths ranged from a high of 78.9% in the North West LHIN region to a low of 50.4% in North Simcoe Muskoka LHIN region. (Figure 2.5)

Palliative care patients living in the poorest neighbourhoods were more likely to die in hospital than those in the richest neighbourhoods (68.5% compared with 61.5%). People in urban areas are slightly more likely to die in hospital compared with those living in rural areas (65.3% compared with 61.9%).

FIGURE 2.5

Percentage of palliative care patients who died in hospital, in Ontario, by LHIN region, 2014/15



Data source: Continuing Care Reporting System (CCRS), Discharge Abstract Database (DAD), Home Care Database (HCD), National Ambulatory Care Reporting System (NACRS), Ontario Health Insurance Plan (OHIP), Registered Persons Data Base (RPDB), provided by the Institute for Clinical Evaluative Sciences (ICES)

3. Conversations and Caregivers



Every breath counts

Calvin, 61, explains his illness, waiting to get on a list for a double-lung transplant, and how he first found out that he was receiving palliative care.

Unable to breathe

Four years ago, I was getting ready to head out for a meeting on the weekend. I did a lot of volunteer work here in the community in Thunder Bay. I took a deep breath of fresh air and all of a sudden I couldn't breathe. My lungs just stopped. The first week or so of being in the hospital I had double pneumonia, so I still didn't really know how bad I was. The pneumonia was getting better, but I still wasn't able to breathe without oxygen. Life was getting pretty scary at that point. After a whole bunch of testing, they said that my lungs are burned from the inside out. They're still not sure what's causing my condition, but they decided I was eventually going to need a double lung transplant.

Shocked

I was sent home from the hospital and had a nurse come in several times during the week. One day she told me that I was under palliative care. I was a little shocked and didn't really quite understand. Palliative care to me at that point meant that I was dying. After talking to her and learning what her job actually was, I felt better and more at ease. I found out that palliative care doesn't just mean end-of-life, but it also means a better and higher quality of life for me and my family. It also helps us deal with all the problems of my life-threatening illness, whether they're physical or psychological.

The care team

Now in 2016, my lungs deteriorate a little bit more each year. There's nothing I can do to stop that, but they can slow it down with a variety of medications. I have a team and they work very well together, from my doctor, my nurse and two specialists to my rehab team and lung transplant team.



Photo of Calvin taken by Alan Dickson.

Lungs

I'm waiting and as soon as my lungs get bad enough, I will be put on the list for a double-lung transplant. Once I'm put on the list, we have to move to Toronto and live there. The maximum wait would be two years. When you get put on the waiting list, if the right sized lungs come in that are compatible to you, you could be there six weeks. Or you could wait two years.

The weight

Now I know when I'm getting a lung attack and what to expect. Put a 500-pound weight on your chest and try to breathe, upside down, that's what it feels like to have a lung attack. Or take a deep breath in, hold it for 10 seconds and then try to breathe in again without exhaling your air. You can get sweats, you can get cold, or you just pass out, which I have done many times.

Benefit of early palliative care

The palliative care approach with me improves life for me and my family. The goal is to keep me as healthy as possible until I need that double-lung operation. Double lungs last between five and 10 years and that's it. They're hoping they can hold me off on the lung transplant until I'm 65, that'll get me to possibly 70 or 75.

The future

We all joke at rehab that we get up in the morning, have our coffee and look at the back of the newspaper and if our names aren't listed in the obituaries, we get up, get dressed, have a shower and go on with our day. I started a support group here for people with lung problems called Every Breath Counts. My wife Lois helps run the meetings for us.

For the caregiver perspective from Calvin's wife, Lois, see "In good hands" on page 36



Photo of Calvin taken by Alan Dickson.

Research suggests that conversations about care that people would like to receive in the event that they become very sick are associated with improved quality of care, and patient and caregiver satisfaction with communication and decision-making.[23]

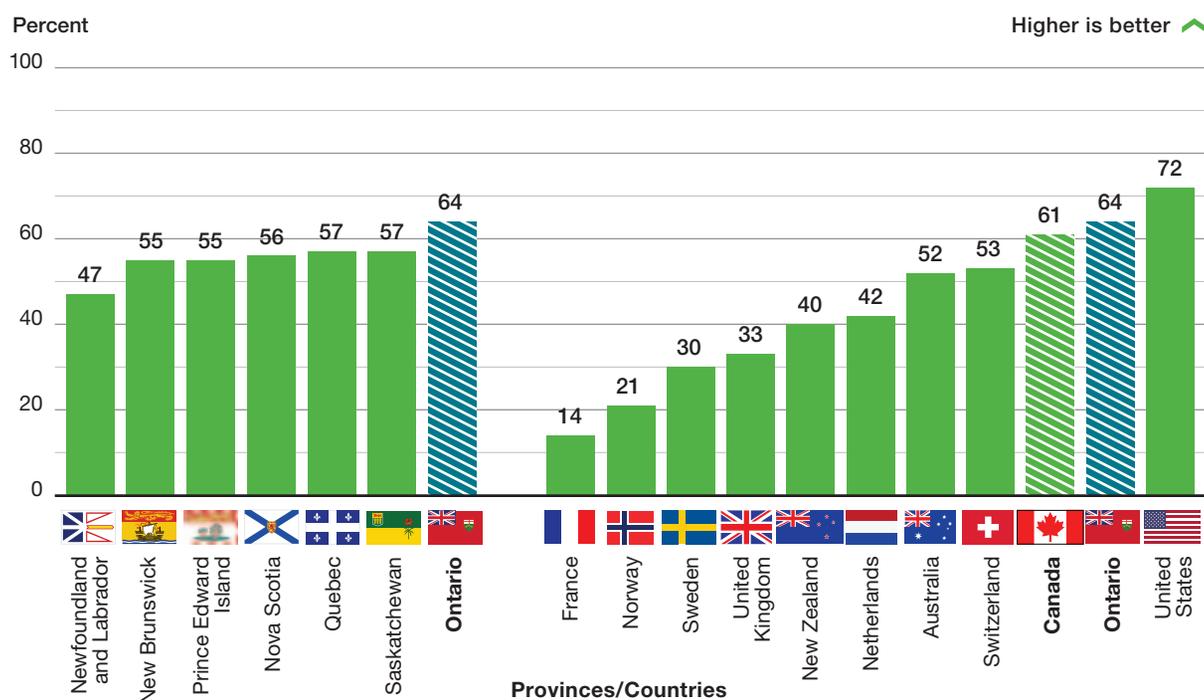
Discussions about wishes

Based on the results of the Commonwealth Fund Survey of Older Adults conducted in 2014, about two-thirds of people in Ontario aged 55 and older had discussions with a family member, a close friend, or with a health care professional about what health care treatment they want, or do not want, in the event they become very ill or injured and cannot make decisions for themselves. Ontario ranks among the highest in Canada and internationally when it comes to these conversations, comparable to Germany (65%), higher than the U.K. (33%) and lower only than the U.S. (72%), although the wide variation internationally may be affected by differences in legislation that might skew the numbers one way or another for some countries. (Figure 3.1)

Note that these types of conversations do not necessarily relate to the formal process of Advance Care Planning in Ontario (for more, see sidebar “Advance Care Planning in Ontario”).

FIGURE 3.1

Percentage of adults 55 and older who report that they had a discussion with family, a close friend, or with a health care professional about what health care treatment they want, or do not want in the event they become very ill or injured and cannot speak for themselves, in Canada and internationally, 2014



Data source(s): 2014 Commonwealth Fund International Health Policy Survey of Older Adults

Notes: Only statistically significantly different results from Ontario are shown.

See Methods Notes for a description of statistical significance.

In good hands

Calvin's wife Lois shares her views on her husband's diagnosis and what early palliative care means to them.

A weight lifted

Having a palliative care nurse come in takes a tremendous load off me. To know that there's somebody qualified who can predict what's going to be happening medical-wise, it's just a huge weight lifted. There would be no way for me to help him the way that she does.

Everything stopped cold

It's a huge adjustment. He was always so active. To see his world shrink from how huge it used to be to what it is now was really hard to watch. Everything stopped cold when he got sick. It took him about two years to just start back with the baby steps. For me, I don't volunteer to the extent I used to, I retired a year after Cal got sick. He got ill very suddenly.



The palliative care approach with me improves life for me and my family.



The signs

He's getting to be to recognize when his breathing is not doing well and knowing when he has to rest. He goes to rehab twice a week, and it's always good to know that he's in good medical hands when he's down there. That's two days out of the week that I know he's in a place where if anything went wrong, they'd be all over it.

Advice

It's just a way of rethinking what you can do now versus what you could do before, and getting over that initial shock of wow, what's going to happen now? You just think if I can't do this, I can do that. That's just the way you have to approach life, as far as I'm concerned. I would say to people, if you are in what they call palliative care, have that explained to you. What does palliative care mean? Where can I go with my life? What can I do? How can I help? Seek knowledge.

Primary care doctors' conversations with older or sicker patients

While the aforementioned survey is based on older adults' conversations with family, friends or health care professionals, another survey was focused specifically on primary care doctors. In that survey, the *2015 Commonwealth Fund Survey of Primary Care Doctors*, the doctors were asked whether they routinely, occasionally or never had conversations with their older or sicker patients about their care preferences should they become ill. In Ontario, 38% of primary care doctors reported that they routinely have conversations with older or sicker patients about the health care treatment they want. Of those who had any conversations (routinely or occasionally), about three-quarters (76%) of doctors routinely documented their patients' preferences in their medical records. (Table 3.1)

TABLE 3.1

Primary care doctors' conversations with older or sicker patients, in Ontario, 2015

| | Routinely | Occasionally | Routinely/ Occasionally |
|---|-----------|--------------|----------------------------|
| Having conversations (primary care doctor) | 38% | 47% | 86% |
| Recorded patient preferences (among those who mentioned routinely/occasionally) | 76% | 21% | 97% |

Data source: 2015 Commonwealth Fund International Health Policy Survey of Primary Care Doctors.

Advance Care Planning in Ontario

When people are not able to make decisions on their own, the process of Advance Care Planning can help people in Ontario reflect on their values, wishes and the kinds of health care and personal care they would like to receive should they become incapable of expressing their wishes on their own. We currently do not have data on Advance Care Planning in Ontario, but here is a brief guide on how to approach the process, based on information from Hospice Palliative Care Ontario.[24]

- **Think** about what's important to you. What makes life meaningful?
- **Learn** about relevant terms.
- **Decide** who will speak on your behalf as your substitute-decision maker and record this in a Power of Attorney for Personal Care. (If you don't decide, under the *Health Care Consent Act*, 1996, a default list of people will automatically be assigned as your substitute decision-maker.)
- **Talk** to your substitute decision-maker(s), family, friends and health care providers about your wishes, values and beliefs.
- **Record** your substitute decision-maker and communicate your wishes, values and beliefs.
- **Review** your wishes, values and beliefs regularly with the substitute decision-maker as your decisions may change.
- **Consent:** In Ontario, health care providers are required to get informed consent before giving you any treatment or care. That consent must come from you, if you are mentally capable of doing so. If not, consent must come from your substitute decision-maker.

Perspectives from caregivers

Family members or other informal caregivers play an integral role in the overall care for people receiving palliative care. There are as yet no system-level data on caregiver experiences in the province, but we can still gain valuable perspective from a sample of caregivers for patients who died in some residential hospices. Because this November 2014 to October 2015 survey was conducted with caregivers for patients who were in residential hospices, their experiences may not be reflective of caregivers for patients who were not in the residential hospice settling.

TABLE 3.2

Experiences of caregivers for patients who received palliative care and died in residential hospices, 2014/2015 CaregiverVoice Survey [25]



Data source: CaregiverVoice Survey, provided by McMaster University, 2015.

Notes: Survey conducted in select Ontario residential hospices (N=534 caregivers).

The Road Ahead



Our results show how people in Ontario who have been identified as having palliative care needs are using palliative care services in their last year of life. We know that palliative care started in the last month of life for half of palliative care patients in Ontario, nearly two-thirds had unplanned visits to the emergency department in their last month of life, a quarter spent half of their last month of life or longer in hospital, and the majority of all palliative care patients died in hospital. Less than half of palliative care patients received palliative home care services and one-third received one or more home visits from a doctor (we do not have data about home visits from other health care providers).

The bigger picture

These results give us a sense of the care received by palliative care patients in Ontario and what types of health care services they are receiving in their last month of life. As important as the last month of life is, it is only a narrow part of the palliative care experience. There are opportunities to provide palliative care earlier in the process and to plan and connect the care and supports for patients receiving palliative care and their families and caregivers. We need to learn more about the quality of palliative care in the province and to broaden the system's ability to measure the bigger picture of palliative care beyond the end-of-life stage in the last month.

Progress toward better palliative care in Ontario

Efforts have been underway for several years in Ontario to improve palliative and end-of-life care. In 2011, more than 80 partners across Ontario came together to identify the key components of the quality of palliative and end-of-life care, resulting in a declaration of partnership, *Advancing High Quality, High Value Palliative Care in the Ontario*.^[26] The partnership's vision was to help people with life-threatening illness live as they choose and have the best quality of life, comfort, dignity and security.

The Ministry of Health and Long-Term Care's *Patients First* action plan in 2015 identified palliative care as a strategic priority for the province's health system. The *Bringing Care Home 2015* report included recommendations that would help palliative care, including more resources to help family caregivers and respite services (that is, to provide much-needed breaks for overburdened family caregivers),^[27]

In 2016, as a follow-up to this action plan, the *Palliative and End-of-Life Care Provincial Roundtable Report* by Parliamentary Assistant John Fraser outlined the important steps to achieve the goals set out in *Patients First*. Recognizing that palliative care should start sooner in people's

illness, the Fraser report established a clear path of shared accountability and performance measurement to ensure high-quality palliative care. When developing performance measures, participants in the roundtable for the report suggested the system consider the following:

- The quality of the patient's dying experience
- Evidence that the patient received high-quality clinical care in an appropriate setting of their choice
- System performance in order to optimize care across settings
- Patient and caregiver experience
- Access to information about available resources, such as palliative care beds^[28]

Also in 2016, the Ontario Palliative Care Network was established as a partnership between health care sector stakeholders, including providers, patients and caregivers. It aims to transform palliative care in Ontario and address the gaps within the current system to ensure people in Ontario have access to high-quality palliative care, and to better plan and connect that care regionally throughout the province.

Health Quality Ontario's work in palliative and end-of-life care

Health Quality Ontario made several recommendations to improve end-of-life care in a 2014 report. Recommendations included that all patients approaching the end of life have access to specialized, inter-professional, team-based, integrated care, that patients and informal caregivers be provided education about symptom management and coping strategies, and that health care professionals receive education in end-of-life care, including training on providing care to informal caregivers.[29]

Health Quality Ontario provides support to Health Links, a provincial approach to improving outcomes and experiences of care for frail elderly people and those with complex chronic illnesses, including end-stage organ failure. Quality Improvement Specialists located across the province work closely with Local Health Integration Networks to implement palliative care best practices and to translate innovations into practices that can be implemented on a broader scale.

Building on this previous work and partnering with the Ontario Palliative Care Network, Health Quality Ontario has identified palliative and end-of-life care as an area of focus in its strategic plan.[30] Over the next few years, Health Quality Ontario will continue to work closely with patients, family members, caregivers, health care providers, system partners and health care organizations to expand evidence in quality of palliative and end of life care, improve performance measurement and support quality improvement efforts across Ontario.

Methods Notes

The following 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.

The findings presented in this report are based on analysis of administrative and survey data, as well as from stories from patients and caregivers with lived experience.

Administrative data

Indicators analyzed using administrative databases for palliative care patients at the end of life:

- Home care visits
- Home visits by a doctor
- Unplanned emergency department visits
- Being admitted to hospital
- Time spent in hospital
- Location of death

Defining the 'palliative care patient' population

The analysis used is based on published methodology.^[31] administrative databases, we identified 95,642 people who died in 2014/15.

Of these people, 54,525 (57.0%) had at least one palliative care service or end-of-life designation in their last year of life that they received across the health care sectors. This subset of the population is referred as palliative care patients in the report.

Deaths in 2014/15 were identified using the enhanced version of the Ontario Registered Persons Database (RPDB). Patients who died of major trauma and injury were excluded from the analysis as they likely did not have an opportunity to receive any palliative care due to sudden death. However, we may have not excluded all sudden deaths (i.e. the sudden deaths from heart attacks and strokes) as some of these patients may have received some palliative care services.

Using unique identifiers, the records of people who died were linked to administrative databases including Ontario Health Insurance Plan (OHIP) claims database, Discharge Abstract Database (DAD), National Ambulatory Care Reporting System (NACRS), Continuing Care Reporting System (CCRS), and Home Care Database (HCD), to identify people who had received at least one palliative care service or had an end-of-life designation in the last year of life. This population served as the denominator (with additional exclusions for some indicators) for looking at the services received in the last 30 days of life.

Limitations of administrative data

Limitations pertaining to the selected palliative care patient population:

- The number of palliative care patients in the selected population may be underestimated for several reasons including coding practices. In some cases, palliative care may be delivered but not coded as such. It is more

pronounced for the long-term care sector. A large proportion of long-term care residents likely receive palliative care in the long-term care home, however it may not be coded as palliative.

- The services that qualified palliative care patients for inclusion in the selected population were subsequently used to measure the indicators (i.e., emergency department visits, hospital admissions, etc.) which may bias the results.
- Some palliative care patients included in the selected population may not have been eligible for any other palliative care services in the community as they may have received their first and only palliative care service during the hospitalization at their last month of life, and died during that admission.

Limitations related to interpretation of results:

- The results should be interpreted with caution as regional variation in the observed rates of services could potentially be affected by availability of resources for providing palliative care (i.e. palliative designation in home care, SRC-95).
- In some sectors, administrative databases do not capture care provided by non-doctors such as nurses and nurse practitioners who may be providing a substantial portion of palliative care (i.e. OHIP).

- Administrative data has a limited capacity to capture clinical details, quality of care received or appropriateness of health service utilization.
- The presented results do not capture the number and frequency of palliative care services received by each palliative care patient. Also, there is no evidence on the appropriate number of palliative care services and whether receiving one service is sufficient. It is hard to interpret the results as there are no benchmarks or targets on the acceptable rates of care.

Significance testing for administrative data

Statistical significance was determined by comparing the 95% confidence intervals for each value. Confidence intervals were used to compare results at the regional level and at the neighbourhood income level. A value is said to be significantly different from another if the confidence intervals for the two values do not overlap. The report states an increase/decrease or higher/lower result only when results are statistically significant based on this method of testing.

Survey data

Indicators analyzed using the Commonwealth Fund survey data:

- Percentage of adults aged 55 and older who report that they had a discussion with family, a close friend, or with a health care professional about what health care treatment they want, or do not want, in the event they become very ill or injured and cannot make decisions for themselves, in Canada and internationally
- Percentage of primary care doctors who report that they routinely have conversations with older or sicker patients about the health care treatment they want or do not want in the event they become very ill, injured, or cannot make decisions for themselves, in Canada and internationally
- Percentage of primary care doctors who document their patients' preferences in their medical records after having conversations (routinely or occasionally) with their older or sicker patients about the health care treatment they want or do not want in the event they become very ill, injured, or cannot make decisions for themselves

Commonwealth Fund survey overview

As part of its mandate, the Commonwealth Fund (CMWF) has been conducting the International Health Policy Survey in 11 countries (Australia,

Canada, France, Germany, Netherlands, New Zealand, Norway, Sweden, Switzerland, United Kingdom and United States) for more than a decade.

In a triennial cycle, the IHP survey targets different populations, including doctors, older adults, and the general adult population. Data for this report are taken from the 2014 and 2015 years of the survey. The 2014 CMWF survey reflects the perceptions of a random sample of adults aged 55 or older who were surveyed via telephone between March and May 2014.

The 2014 CMWF data were weighted to represent the Canadian and Ontario population aged 55 and older. Parameters used for weighting were age-by-gender, education and knowledge of either English or French, all based on information from the 2011 census by Statistics Canada. The 2015 CMWF survey reflects the perceptions of a random sample of primary care doctors who were surveyed online, by mail, and telephone between March and November 2015.

The data were weighted to account for the over-representation of primary care doctors in some provinces, the availability of the email addresses, and the differential non-response along known geographic and demographic parameters. The weighting adjustment was conducted in 2 stages: design weight and stratification weight.

Data were weighted by age and gender within Ontario, Quebec and the rest of Canada.

Additionally, it was subsequently weighted to reflect Canada's distribution of primary care doctors by province. All benchmarks were derived from the January 2015 Canadian Medical Association Masterfile. In this report, we compare Ontario data to the international survey results where possible.

Commonwealth Fund Survey limitations:

- Small sample sizes and wider margins of errors make statistical testing difficult for some provincial comparisons.
- The survey provides self-reported data, which relies on respondents to recall aspects of their health care or the health care they provided in the case of doctor surveys over the previous one to two years. There may be some gaps or errors in their memory of events, and the survey is not able to verify information.
- The variation of the results internationally and provincially may be related to differences in care practices in each country or province.

Significance testing for Commonwealth Fund survey data

Social Sciences Research Solutions conducted statistical analyses to compare responses across countries and provinces within Canada. For

provincial comparisons, statistical tests were conducted to compare each province's response to every other province and to Canada as a whole.

Ontario's results were also compared to other countries. Significance was assessed based on a P-value of less than 0.05, meaning that there was less than a 5% probability that the difference was due to chance rather than real differences in respondents' experiences.

CaregiverVoice Survey

The CaregiverVoice (CV) survey reflects the perceptions of a small sample of caregivers for patients who died in some of Ontario's residential hospices. The survey was conducted between November 2014 and October 2015.

The results from the CV survey that are reflected in this report include:

- Percentage of caregivers who stated that, in their last 3 months of life, services the patient received at home worked well together (definitely and to some extent)
- Percentage of caregivers who thought they and their family got as much help and support from

health and supportive services as they wanted when the patient was at home in the last 3 months of his or her life

- Proportion of caregivers who stated the patient they cared for definitely experienced smooth transitions between settings of care in their last 3 months of life
- Percentage of caregivers who rated overall care of the patient they cared for in their last 3 months of life as outstanding or excellent
- Percentage of caregivers who rated pain management for the patient they cared for in their last week of life as excellent
- Percentage of caregivers who rated emotional support for the patient they cared for in their last week of life as excellent
- Percentage of caregivers who knew where the patient wanted to die
- Percentage of caregivers who knew where the patient wanted to die, reported that this information was recorded by a health care provider
- Percentage of caregivers who thought the health care providers definitely helped them understand what to expect and how to prepare for the patient's death
- Percentage of caregivers who thought the

discussion between the patients they cared for and the health care providers regarding advance care planning came at the right time

CaregiverVoice survey limitations:

- The experiences of these caregivers may not be reflective of the experiences of caregivers who cared for patients not residing in residential hospices.
- Most, though not all, residential hospices participated in this roll-out.

For details on additional indicator-specific details and limitations, please see the individual indicator templates in the online Technical Appendix.

Acknowledgments

This study was also supported by the Institute for Clinical Evaluative Sciences (ICES), which is funded by an annual grant from the Ontario Ministry of Health and Long-Term Care (MOHLTC). The opinions, results and conclusions reported in this paper are those of the authors and are independent from the funding sources. No endorsement by ICES or the Ontario MOHLTC is intended or should be inferred.

Some of the indicators in this report were derived using health administrative datasets from Ontario. These datasets were linked using unique encoded identifiers and analyzed at the Institute for Clinical Evaluative Sciences (ICES).

Health Quality Ontario acknowledges and thanks Nina Horvath, Calvin, Lois, and the Mackay family, as well as Runako and Karen Nicole, for sharing their stories and insights in this report. In addition we thank Corey Bernard and Isra Khalil for helping to seek out these stories.

This report was developed by a multi-disciplinary team from Health Quality Ontario, including: Susan Brien, Naushaba Degani, Gail Dobell, Ryan Emond, Louise Grenier, Michal Kapral, Sandra Kerr, Isra Khalil, Reena Kudhail, Ivana McVety, Amira Salama, and Naira Yeritsyan.

Health Quality Ontario also acknowledges and thanks the review panel including:

Anne Bell, Heather Binkle, Darren Cargill, Julie Darnay, the Executive Oversight Committee of the Ontario Palliative Care Network, Enza Ferro, Rob Fowler, Russell Goldman, Doris Grinspun, Kathy Kastner, Andreas Laupacis, Barb Leblanc, Nancy Lefebvre, Kathryn McCulloch, Josephine Mo, Jeff Myers, Dipti Purbhoo, Hsien Seow, Shirley Sharkee, Peter Tanuseputro, Sara Urowitz, Lilly Witham, and Georgina White.

Scientific Contributions

Health Quality Ontario would like to acknowledge the scientific contributions of:

Hsien Seow, PhD

Associate Professor, Department of Oncology,
McMaster University

Canada Research Chair in Palliative Care, Cancer and Health System Innovation
Member, Centre for Health Economics and Policy Analysis

Scientist, Escarpment Cancer Research Institute,
who provided results from CaregiverVoice Survey,
McMaster University, 2015.

Peter Tanuseputro, MD, MHSc, CCFP, FRCPC

Investigator, Bruyère Research Institute,
who provided methodological insights in the
development and analysis of the indicators
based on his work funded by the Health System
Performance Research Network (HSPRN).

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

References

- ¹ Brazil K, Howell D, Bedard M, Krueger P, Heidebrecht C. Preferences for place of care and place of death among informal caregivers of the terminally ill. *Palliative Medicine*. 2005;19(6):492-9.
- ² Bainbridge D, Hsien S, Sussman J, Pond G. Factors associated with acute care use among nursing home residents dying of cancer: a population-based study. *International Journal of Palliative Nursing*. 2015;21(7):349-56 8p.
- ³ Brumley R, Enguidanos S, Jamison P, Seitz R, Morgenstern N, Saito S, et al. Increased satisfaction with care and lower costs: results of a randomized trial of in-home palliative care. *Journal of the American Geriatrics Society*. 2007;55(7):993-1000 8p.
- ⁴ Fowler R, Hammer M. End-of-life care in Canada. *Clinical And Investigative Medicine Médecine Clinique Et Experimentale*. 2013;36(3):E127-E32.
- ⁵ Zimmermann C, Swami N, Krzyzanowska M, Hannon B, Leighl N, Oza A, et al. Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial. *The Lancet*. 2014;383:1721-30.
- ⁶ Brazil K, Howell D, Bedard M, Krueger P, Heidebrecht C. Preferences for place of care and place of death among informal caregivers of the terminally ill. *Palliative Medicine*. 2005;19(6):492-9.
- ⁷ Dudgeon DJ, Kristjanson L. Home versus hospital death: assessment of preferences and clinical challenges. *CMAJ: Canadian Medical Association Journal = Journal De L'association Medicale Canadienne*. 1995;152(3):337-40.
- ⁸ Steneke S, Streeter L. Considerations for a home death [Internet]. Winnipeg (MB): Canadian Virtual Hospice; Copyright 2003-2015 [updated 2015 Jul 15; cited 2016 Jun 4]. Available from: http://virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Decisions/Considerations+for+a+Home+Death.aspx
- ⁹ Hospice Palliative Care Association. Cost-effectiveness of palliative care: A review of the literature [Internet]: The Way Forward Initiative: an Integrated Palliative Approach to Care; 2012 [cited 2016 Jun 6]. Available from: <http://www.hpcintegration.ca/media/36290/TWF-Economics-report-Eng-final-webmar7.pdf>
- ¹⁰ Local Health Integration Networks, Ontario. QHPCCo. Advancing high quality, high value palliative care in Ontario: A declaration of partnership and commitment to action [Internet]. Toronto (ON): Ministry of Health and Long-Term Care; 2011 [cited 2016 Jun 6]. Available from: http://health.gov.on.ca/en/public/programs/lhc/docs/palliative%20care_report.pdf
- ¹¹ Parliamentary Assistant John Fraser to the Minister of Health and Long-Term Care. Palliative and end-of-life care provincial roundtable report [Internet]. Toronto (ON): Ministry of Health and Long-Term Care; 2016 [cited 2016 Jun 6]. Available from: http://www.health.gov.on.ca/en/public/programs/palliative/pdf/palliative_report.pdf
- ¹² FAQs [Internet]. Ottawa (ON): Canadian Hospice Palliative Care Association; Copyright 2016 [cited 2016 Jun 4]. Available from: http://virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Decisions/Considerations+for+a+Home+Death.aspx

- ¹³ Tanuseputro P, Beach S, Chalifoux M, Wodchis W, Hsu A, Seow H, et al. Effect of physician home visits for the dying on place of death. Under publication 2016.
- ¹⁴ Guerriere DN, Zagorski B, Fassbender K, Masucci L, Librach L, Coyte PC. Cost variations in ambulatory and home-based palliative care. *Palliative Medicine*. 2010;24(5):523-32.
- ¹⁵ Bainbridge D, Seow H, Sussman J, Pond G, Barbera L. Factors associated with not receiving homecare, end-of-life homecare, or early homecare referral among cancer decedents: A population-based cohort study. *Health policy*. 2015;119:831-9.
- ¹⁶ Lawrenson R, Waetford J, Gibbons V, Kirk P, Haggart S, Reddy R. Palliative care patients' use of emergency departments. *The New Zealand Medical Journal*. 2013;126(1372):80-8.
- ¹⁷ American College of Emergency Physicians Choosing Wisely: Don't delay engaging available palliative and hospice care services in the emergency department for patients likely to benefit. [Internet]. Philadelphia (PA): ABIM Foundation; © 2016 [updated 2013 Oct 14; cited 2016 Jun 6]. Available from: <http://www.choosingwisely.org/clinician-lists/american-college-emergency-physicians-delaying-palliative-and-hospice-care-services-in-emergency-department/>
- ¹⁸ Fowler R, Hammer M. End-of-life care in Canada. *Clinical And Investigative Medicine Médecine Clinique Et Experimentale*. 2013;36(3):E127-E32.
- ¹⁹ Bekelman JE, Halpern SD, Blankart CR, Bynum JP, Cohen J, Fowler R, et al. Comparison of Site of Death, Health Care Utilization, and Hospital Expenditures for Patients Dying With Cancer in 7 Developed Countries. *JAMA*. 2016;315(3):272-83.
- ²⁰ National Health Services (NHS). Commissioning person centred end of life care: A toolkit for health and social care [Internet]. England: NHS; 2016 [cited 2016 13 JUN]. Available from: <https://www.england.nhs.uk/wp-content/uploads/2016/04/nhsiq-comms-eolc-tlkit-.pdf>
- ²¹ Wilson DM, Truman CD, Thomas R, Fainsinger R, Kovacs-Burns K, Froggatt K, et al. The rapidly changing location of death in Canada, 1994–2004. *Social Science & Medicine*. 2009;68:1752-8.
- ²² Higginson IJ, Sarmiento VP, Calanzani N, Benalia H, Gomes B. Dying at home--is it better: a narrative appraisal of the state of the science. *Palliative Medicine*. 2013;27(10):918-24.
- ²³ Ontario Health Technology Advisory Committee. End-of-life health care in Ontario: OHTAC recommendation [Internet]. Toronto (ON): Queen's Printer for Ontario; 2014 [cited 2016 Jun 4]. Available from: <http://www.hqontario.ca/Portals/0/Documents/evidence/reports/recommendation-eol-1411-en.pdf>
- ²⁴ Canadian Hospice Palliative Care Association. Advance care planning quick guide. Ontario Edition. [Internet]: © Hospice Palliative Care Ontario; © 2016 [cited 2016 Jun 6]. Available from: http://www.advancecareplanning.ca/wp-content/uploads/2015/09/ACP-Ontario-Quick-Guide-03.2015_colour_FINAL-web.pdf

- ²⁵ CaregiverVoice Survey, provided by McMaster University, 2015.
- ²⁶ Local Health Integration Networks, Ontario.. QHPCCo. Advancing high quality, high value palliative care in Ontario: A declaration of partnership and commitment to action [Internet]. Toronto (ON): Ministry of Health and Long-Term Care; 2011 [cited 2016 Jun 6]. Available from: http://health.gov.on.ca/en/public/programs/lhc/docs/palliative%20care_report.pdf
- ²⁷ Expert Group on Home & Community Care. Bringing care home: Report of the Expert Group on Home & Community Care [Internet]2015 [cited 2016 Jun 4]. Available from: http://health.gov.on.ca/en/public/programs/ccac/docs/hcc_report.pdf
- ²⁸ Parliamentary Assistant John Fraser to the Minister of Health and Long-Term Care. Palliative and end-of-life care provincial roundtable report [Internet]. Toronto (ON): Ministry of Health and Long-Term Care; 2016 [cited 2016 Jun 6]. Available from: http://www.health.gov.on.ca/en/public/programs/palliative/pdf/palliative_report.pdf
- ²⁹ Ontario Health Technology Advisory Committee. End-of-life health care in Ontario: OHTAC recommendation [Internet]. Toronto (ON): Queen's Printer for Ontario; 2014 [cited 2016 Jun 4]. Available from: <http://www.hqontario.ca/Portals/0/Documents/evidence/reports/recommendation-eol-1411-en.pdf>
- ³⁰ Health Quality Ontario. Better has no limit: Partnering for a quality health system [Internet]. Toronto (ON): Queen's Printer for Ontario; 2016 [cited 2016 Jun 4]. Available from: <http://www.hqontario.ca/Portals/0/documents/about/strategic-plan-2016-en.pdf>
- ³¹ Tanuseputro P, Budhwani S, Yu Qing B, Wodchis W. Palliative care delivery across health sectors: A population-level observational study. *Palliative Medicine*. 2016;1-11.

Let's make our health system healthier

Health Quality Ontario
130 Bloor Street West
10th Floor
Toronto, ON M5S 1N5

Telephone: 416-323-6868
Toll-free: 1-866-623-6868
Email: info@hqontario.ca
www.hqontario.ca