FOR SUBSCRIBERS THE THIRD ACT

A new tool could help predict death sooner and improve care for the dying

Anew study found that many older adults do not receive palliative care at home and suggested that new ways of identifying those in their final six months of life, such as an evidence-based mortality calculator, can help send much-needed support their way.

Updated 3 hrs ago Feb. 26, 2024

Katrina Prescott, left, poses for a photo with her mother Kathryn Love in this undated handout photo before her mother's dementia worsened significantly.

By Moira Welsh Staff Reporter

In the final years of her mother’s dementia, marked by deep declines and unexpected recoveries, Katrina Prescott provided a kind of medical care, without the training.

Prescott lost count of the times that death had seemed near but in April of 2022, when it was clearly imminent, she sat alone in her Vancouver apartment, listening to her mother breathing, while reading the drug schedule left by a visiting palliative-care doctor. He placed a subcutaneous port in her mother's stomach and told Prescott how to inject pain medication to ease the pain of dying.

She wanted to say goodbye as a daughter but had to act as a nurse.

“My mom was dying and I had to do all this but the thing is, I was lucky because so many people probably don’t even have that kind of help,” said Prescott, 46, a producer of commercials and corporate films.

Everyone who has cared for a dying parent, relative or friend has a palliative-care story to tell.

Some had a good experience. Others had no help. Many, like Prescott, witnessed long periods of near death, then recovery, wondering how long a parent can last. Is it months? Or years? Caregiving, she said, was deeply meaningful but even with the palliative support she received, it was so exhausting she feels physically aged by years.

A new study, published today in the Canadian Medical Association Journal, found that many older adults do not receive palliative care at home and suggested that new ways of identifying those in their final six months of life, such as an evidence based mortality calculator, can help send much-needed support their way.

“Most physicians will be able to kind of tell when a person is in their final four to six weeks of life,” said Dr. Amy Hsu, an investigator with the Bruyère Research Institute and faculty in the Department of Family Medicine at the University of Ottawa that did the study. “The difficulty is, how do you move that timeline up further?”

In the study, Hsu and Bruyère researchers looked at data on standardized "interRai" home care assessments done on almost 250,000 "community-dwelling" older adults in Ontario between August 2018 and September 2019. Using a diagnostic tool developed to help identify the need for palliative care among frail, older adults, researchers predicted the risk of dying within six months of that home care assessment and noted what, if any, health services those people received.

Palliative support can offer different types of care depending on individual needs. It can include pain management, psychological, spiritual and practical support along with help for caregivers and grief counselling.

Researchers found that roughly half of those with an estimated life expectancy of less than 3 months were given formal palliative home care. Those who did get palliative care at home had been given a terminal diagnosis by a doctor, who alerted their needs to the home care system.

Using algorithms in tools such as mortality calculators, the study said, "may improve recognition of reduced life expectancies and palliative care needs of individuals in their final years of life."

Bruyère researchers used the algorithm in a diagnostic tool their team helped develop. Called RESPECT (Risk Evaluation for Support: Predictions for Elder-life in their Communities Tool,) it is part of "Project Big Life," led by researchers at the Ottawa Hospital, the Bruyère Research Institute, the University of Ottawa and ICES, a not-for-profit research institute previously called the Institute for Clinical Evaluative Sciences. Found at https://www.projectbiglife.ca, Hsu said the tool is part of ongoing projects with long-term care homes and grassroots community initiatives in Ottawa, Toronto and Windsor.

In their study, researchers used a long list of mortality predictors that include: worsening abilities in the activities of daily living; cognitive impairment; diseases such as cancer, congestive heart disease, or Parkinson's along with hospital admissions or emergency department visits in the previous 90 days.

Many Canadians get palliative support in their final weeks or days but, as the study noted, research has shown that starting palliative care in the months before death can lead to a more positive end-of-life experience, including improved quality of life, less anxiety, better pain management, and potentially, the need for less aggressive medical care. Estimates show that 15 per cent of Canadians receive palliative care at home in the last year of life, the Bruyère report said.

"The goal," said Hsu, "is to provide this as a way for patients and family members to leverage and advocate for their care if they are feeling like they're not getting the support that they need."

End-of-life care is an important discussion, Hsu said, from a policy position and a societal perspective.

"One of the difficulties in talking about palliative care is that we live in a death denying society, so I think most people kind of shy away from the conversation and only have a conversation when they have to."

According to Statistics Canada, 334,623 Canadians died in 2022, with cancer and heart disease accounting for 41.8 per cent of deaths.

Canadians also died from COVID-19, accidents, strokes, respiratory diseases, diabetes, influenza and pneumonia, Alzheimer's disease, and chronic liver disease and cirrhosis, among other forms of demise, Statistics Canada said.

With Canada's population reaching super-aged status in the early 2030s, when one in four will be over the age of 65, the Bruyère study adds to a wider discussion on the desire of many older adults who want to die at home.

Liv Mendelsohn, executive director of the Canadian Centre for Caregiving Excellence, said families are struggling from the lack of palliative home care services and are in desperate need of better supports such as work leave that acknowledges the fluctuating timeline for death.

"Caregiver mental health really, really suffers during this period," Mendelsohn said.

That stress increases at the very end, when caregivers have to perform hands-on tasks, which many are not trained to do, she said.
"Instead of being able to take those final moments to hear the stories and hold the hand and offer comfort, caregivers are thrust into being essentially, a personal support worker and taking on all sorts of clinical tasks. We want end-of-life to be a time of reflection, to give that person the time to be with family and have deep conversations. That, frequently, is not the experience," she said.

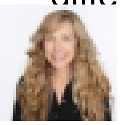
"They are also trying to figure out how they're going to pay for the time off work. There is tremendous anxiety."

In the end, Prescott did not have to give her mother the medication that the palliative doctor had left behind.

She held her hand as her breathing slowly stopped.

"Death is actually something that I talk about so much more now because my mom's death was so transformational for me," she said.

"It was the one thing that I was the most scared of. And I did it. And now my life is different because of that."



Moira Welsh is a Toronto Starjournalistleading The Third Act project, pushing for changes in the way older adults live. Follow her on Twitter: @moirawelsh.

Related Stories

'Grief’s trajectory is not a straight line': Why the death of a partner can hit in profound and unexpectedways