Tough journeys: When cancer strikes people living with dementia

March 3 2023, by Dennis Thompson

America's aging population means that more families are soon going to

be grappling with a heartbreaking issue—a loved one living with dementia who then develops cancer.

These families will have to work their way through a series of tough decisions regarding screening, treatment and end-of-life care, a new report warns.

People with dementia already start out at a disadvantage as far as cancer is concerned, researchers say.

They are more likely to have their cancer reach an advanced stage before it's diagnosed, and they also tend to receive less extensive treatment, according to the report recently published in CA: A Cancer Journal for Clinicians.

"It's diagnosed much later in patients who have dementia, so their symptoms are worse and they're having a hard time articulating what some of those symptoms are. So they're coming to the doctors with much more severe cancer, which then makes the dilemma of treatment even more hard for the patient and for their family," said co-researcher Nicole Fowler, associate director for the Indiana University Center for Aging Research at Regenstrief Institute.

Cancer doctors need to be prepared to help guide patients and their families through a knotty set of choices, Fowler and her colleagues warn.

"Oncologists oftentimes don't have at their ready the full ability to identify people who maybe don't have the capacity to make their own decisions about cancer treatment," she said. "They also must understand what might be the appropriate course of treatment for somebody who has a limited life expectancy and limited functional status."

Cases rising three-fold by 2050

It's happening more and more, Fowler added. "And it's a really difficult decision for both patients, families and providers," she said.

More than 50 million people worldwide are living with dementia today, and that figure is projected to explode to 152 million by 2050, according to the study.

Dementia and cancer both grow more likely as people age, Fowler said. In fact, the prevalence of dementia increases steeply with age, doubling every five years after age 65.

"And so as we start to see population aging, that's when we're starting to notice more the co-occurrence both of these diseases together, as well as people being at risk for developing one or the other if they already have dementia or cancer," Fowler said.

Cancer rates among people with dementia range between 1% and 28% across 31 studies cited in the new report.

The largest high-quality study based on U.S. data estimated a preexisting dementia rate of 7% among more than 106,000 cancer patients aged 68 or older, the report says. But another U.S. study of nursing home residents with cancer found that 52% also had dementia.

"Dementia is an important comorbidity that not only affects the treatment of cancer, but also affects people's overall quality of life, the resilience of caregivers, overall cost of care and the logistics of getting cancer care," said Dr. Arif Kamal, chief patient officer for the American Cancer Society.

Cancer screening the first step

The decisions surrounding the intersection of dementia and cancer start with screening for the disease in these patients, Fowler said.

"For people who have early-stage cognitive impairment, which we might call mild cognitive impairment, identifying and detecting cancer may still be an important goal because their cognitive impairment and their functional capacity is still appropriate for them to be able to seek treatment," Fowler said.

But as dementia progresses, it lowers a person's life expectancy—eventually to the point where screening for cancer may cause more harm than good for the patient, she said.

People also become less likely to notice potential cancer symptoms or to communicate these symptoms to caregivers or doctors, researchers said.

"Maybe we need to start to think about how we tailor the screening better to match those persons who have dementia and who may not really benefit from screening anymore," Fowler said.

Cancer screening and treatment guidelines don't always take life expectancy into account, leaving families and doctors with hard decisions to make, she said.

"A woman who's maybe in her early 70s with dementia does not have the same life expectancy as a healthy woman without dementia in her 70s," Fowler said. "I think the importance is being able to not necessarily think about age specifically as a cutoff, but also take into account functional status and life expectancy, which is one of the things that the guidelines really have a hard time doing."

Frank talk needed

People diagnosed with cancer often face tough treatment regimens, and those with dementia are sometimes less able to understand or withstand chemotherapy, surgery, radiation therapy, immunotherapy or targeted therapies.

Recent studies have shown that about 1 in 3 people with dementia die within six months to a year of a cancer diagnosis, the study says.

"People who have moderate to severe dementia not only have a limited life expectancy, but really limited functional status and decisional capacity," Fowler said. "Are they even going to be able to handle the treatment?"

She recommends that families and caregivers have frank discussions about these sort of questions with dementia patients and their doctors sooner rather than later, preferably before a crisis emerges.

"The first thing to talk to that person's provider about is what's important to them, what's important to you as a family," Fowler said. "Have they always been somebody who, no matter what, is looking to find out if they have something? Maybe that continues to be their goal until the point where they're no longer receiving any benefit from that versus somebody who says, you know what, my goal is to really focus on things that help keep me comfortable, help keep me at home and safe. Then that would be different care trajectory."

Those discussions can be hard, she added.

"But what's nice about having them, at least in a non-acute setting—say, somebody visiting their primary care doctor—you can start that conversation and there isn't this sort of sense of emergency like it might be in the intensive care unit," Fowler said.

Dementia or cancer treatment side effect?

These discussions can also help cancer doctors, who often don't have the experience to fully appreciate how dementia affects treatment strategies, Kamal said.

This is particularly true when it comes to patients they've been seeing for a long time regarding a slow-developing cancer, who later develop dementia, he said.

"We haven't been taught to think through all those comorbidities that may pop up during the course of treatment because many of these patients are going to live years or even decades with the cancer," Kamal said.

Cancer doctors also have to keep in mind that, for some of these patients, what seems like the onset of dementia might actually be a side effect of medications they are taking to treat a tumor.

"For example, we give them high doses of steroids and that might make them confused and have some short-term memory difficulty," Kamal said. "I think it's important for oncologists to be able to discern between the two."

Asking for help

Caregivers should feel free to lean on a patient's cancer care team, both for everyday help and to craft solutions that fit the patient's needs, Kamal said.

"I would just remind caregivers that the oncology team has access to lots of resources that can be helpful in terms of the caregiver at home," he

said. "For example, home health aides or social workers or meal delivery, all those are well within the toolbox of oncology teams. Caregivers shouldn't feel shy to ask for that type of help, even if they think that help is not directly related to the cancer."

It also can be very difficult to get people with moderate or severe dementia to regular chemotherapy appointments, Kamal said—getting them bathed and dressed and fed, driving them to the clinic, dropping them off at the front, worrying as you park if they'll wander off.

In those cases, a chemotherapy pill taken at home might be preferable to intravenous chemotherapy provided at a clinic, Kamal said.

"The caregivers may not feel it's right to bring that up, because they might say, I want the best treatment for my loved ones," he said. "But what they don't know is that the oral is better or as good as the IV. There's this presumption that intensity and complexity is somehow related to benefit. That the more we undergo, the harder this process may be maybe means that we're doing all that we can."

Kamal said that should be a conversation involving the patient, the caregiver and the clinical team, "saying, 'look, here's what's challenging for us on a daily basis as it relates to my loved one's dementia. I still want the best treatment for him or her, but is there a way to be able to find something in the middle that allows the best possible treatment but at the same time, it's not too logistically complex?'"

Helping doctors prepare

The paper written by Fowler and colleagues offers a number of suggestions to help cancer doctors prepare for the oncoming wave of patients with both dementia and cancer. They include:

- Involving caregivers and supporting their emotional, financial and other needs.
- Reviewing decision-making capacity and legal decision-making powers, as well as verifying advance medical directives.
- Considering and making reasonable adjustments to cancer-related care and treatment.
- Minimizing the risk of poorly controlled pain and other symptoms and side effects, including mental decline.
- Reducing the risk of emergency presentation for medical care.
- Increasing dementia knowledge and training among cancer clinicians.
- Communicating with patients using simple language, pictures and warm, empathetic, nonverbal gestures.
- Allowing more visit time for patients with dementia, and making clinical environments more dementia-friendly.
- Minimizing and improving care-related travel for people with dementia, including remote and mobile care options and parking.

Fowler said she and other researchers continue to work on checklists and guides to help families navigate cancer care for dementia patients.

"We've got many tools that we're trying to develop specifically for older adults with dementia and their family members to support their decision-making," Fowler said. "They really help walk them through some reflective questions, along with some data about likelihood of treatment success, things like that, so they can feel more confident when they go into these conversations" with doctors.

More information: Alys Wyn Griffiths et al, Decision-making in cancer care for people living with dementia, *Psycho-Oncology* (2020). DOI: 10.1002/pon.5448