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TOP STORY

Virginia Tech researchers seek to understand effects of caregiving on extended family

Luanne Rife

Feb 14, 2021

Two Virginia Tech researchers and a Carilion physician who specializes in treating patients with memory decline are teaming up to look at whether caregivers of people with dementia face additional challenges if they are extended family members rather than spouses or adult children.

Tech professors Karen Roberto and Tina Savla and Dr. Aubrey Knight think that grandchildren, nieces, nephews, siblings and stepchildren might encounter different barriers, but they are not sure since there hasn't been much research on the topic.

They have won a \$2.14 million, five-year grant from the National Institutes of Health's Institute on Aging to find out if these relatives have special needs.

Roberto and Savla, who are with Tech's Center for Gerontology, previously looked at the burden of caring for people with dementia on their spouses and children. They've delved into unique barriers encountered by Virginians living in rural areas. And, most recently, they looked at hardships created when the state went into lockdown in response to the COVID-19 pandemic.

This time they plan to compare 240 extended family caregivers' experiences with those of 120 adult children and spouse caregivers to see what differences might emerge that could then be addressed through community resources.

Roberto said they aren't sure what they might uncover.

"In a way, it would be great if they looked just like spouses or adult children because we have programs that have been developed and are in place. Our hunch is they are not," she said. "So what we hope to be able to do at a higher level is say these caregivers from extended families need support like all caregivers, but they may need particular types of supports."

That could lead to developing programs and information that would help the caregivers be more prepared.

"At the end of the day it is about maintaining the health and well-being of the caregiver, as well as the person with dementia, so that they continue on in this very important role," she said.

Knight, who sees patients through Carilion's Center for Healthy Aging and who has collaborated with the researchers on other studies, said it's important to not lose sight of caregivers' health.

"When I see patients, I see them for an hour-ish, and then they leave and I think, well, that was a challenging hour. Well, the caregiver has a challenging 24 hours, and 24 hours the next day, and the next day after that. The health of the caregivers is sometimes affected by that," Knight said. "While I knew that, these previous studies just brought it home about how difficult this job really is."

Virginia's Alzheimer's Disease and Related Disorders Commission in 2019 estimated 150,000 Virginians were living with Alzheimer's or another form of dementia. That number is expected to rise to about 190,000 by 2025.

While others look at the types of care and services the people with dementia need, Roberto and Savla look at what the people who care for them might need in order to stay healthy and to keep doing the work.

Knight said the research has prompted him to advocate more for services, resources and support groups for caregivers.

Most support groups are for spouses or adult children. Having ones for extended family, or even younger caregivers, might be beneficial. It depends on what the researchers learn.

"Some of the challenges come from the individuals themselves, the caregiver, because oftentimes they are from different generations and are at different stages of their lives," Roberto said. She had a student once who was juggling work, school and caring for an elderly uncle.

Outsiders might not have appreciated that the young woman was a primary caregiver.

Knight said that extended family members might come to the role without the same type of relationship that was built over decades with spouses and children.

"Telling someone they can no longer live independently, or drive anymore — all of those are losses of sense of self. It's one thing for your child to say that. It's another thing altogether for your niece or nephew or grandchild," Knight said.

"I am anxious to see what kind of things we find," Knight said. "We are finding more and more non-traditional family caregivers. Families are different. Sometimes our older patients have outlived their children, so it's grandchildren or nieces or nephews. It's stepchildren from people with multiple marriages. Are there unique challenges? I would suggest there probably are."

Savla said the study is designed to capture the relationship, with the first part consisting of an open-ended interview to find the history of the relationship and how well they knew each other and how the relative came to be the caregiver.

“After that, we will have structured questions on background, and on help from other family members, services they are using,” she said. “Following this interview, we will schedule them for eight consecutive days of daily diaries.”

Toward the end of each day, the interviewer will call to talk with them about what happened that day.

“As you can imagine, today would be a day where people would be saying, ‘Oh, because of the snow I had to change my plans and couldn’t take him or her out of the house, and he was unusually cranky because he couldn’t go out of the house,’” she said. “Those are the nuances we are trying to get.”

Over the eight days, they hope to pick up how days look when someone comes to help out, for example, or when someone brings a meal.

“We have done these daily interviews in our previous studies, and at the end of Day 8, they actually tell the interviewers that they are going to miss talking to them,” Savla said. “It’s always nice to hear from the caregiver that they enjoy these interviews.”

Finding the families could prove challenging. Knight said he will help to identify some.

The researchers are also working with Area Agencies on Aging and other groups across the state and are hoping to get a good mix of families living in urban, suburban and rural places, and to have a cross-section of race and ethnicity and gender, as they will seek to find men who are filling what has primarily been a woman’s role in caregiving.

Once the pandemic is over, Roberto and Savla plan to visit churches and community meetings across the state to recruit families.

They are calling the study CareEx and expect to enroll families for four years. For more information, email **CareEx@vt.edu**.

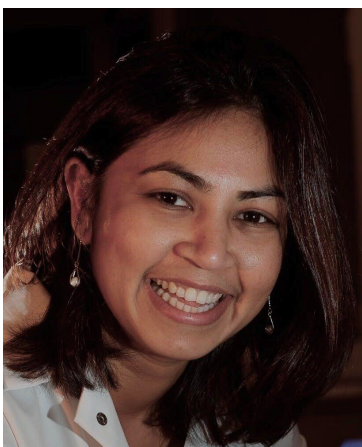
This article was written with the support of a journalism fellowship from The Gerontological Society of America, The Journalists Network on Generations and the Silver Century Foundation.





Virginia Tech professor Karen Roberto is researching whether extended family members face different challenges than adult children and spouses in caring for people with dementia.

Courtesy of Virginia Tech



Virginia Tech professor Tina Savla is researching whether extended family members have different challenges in caring for a person with dementia than more typical caregivers like spouses and adult children.

Courtesy of Virginia Tech



Dr. Aubrey Knight, senior dean for

student affairs at the Virginia Tech Carilion School of Medicine, specializes in caring for older residents and sees patients at the Carilion's Center for Healthy Aging.

Courtesy Virginia Tech Carilion School of Medicine

Luanne Rife

Luanne Rife writes about the businesses, policies, discoveries and inventions that affect the health of people living in southwestern Virginia.
