

New study to examine the role of extended family caregivers of people with dementia

Reviewed by Emily Henderson, B.Sc.

Jan 26 2021

Karen Roberto and Tina Savla, both core faculty members of Virginia Tech's Center for Gerontology, are leading a five-year, \$2.14 million study that will examine the role of extended family caregivers and their service use, needs, and challenges.

The National Institute on Aging -- part of the National Institutes of Health -- awarded the grant.

While most of the caregiving literature to date has focused on close kin, such as adult children and spouses, this new study will turn the spotlight on other family caregivers, such as grandchildren, siblings, nieces and nephews, and step-kin.

Little is known about these other family caregivers and how they came to be in this role. What is daily life like for them as dementia caregivers? Do they face unique challenges? How is the type and manner in which they provide for their relative different, if at all, than the care provided by spouse or adult child caregivers? Do these extended family caregivers need more support, education, or training?

These are just a few of the questions the Roberto and Savla will examine.

"There is increasingly a recognition that the definition of family has changed," said Roberto, University Distinguished Professor in the Department of Human Development and Family Science and executive director of the Institute for Society, Culture and Environment. A more nuanced definition of family stems from a number of factors, including changing demographics, serial marriages, non marital parenthood, and greater recognition of diverse family structures.

“ *With these changes, many families are turning to people other than a spouse or adult child to provide care for their loved one* ”

with dementia. In prior studies and surveys of caregivers, these extended family members were grouped together in an 'other' category and largely ignored. When this happens, their stories don't get told. We really know very little about them."

Karen Roberto, Faculty Member, Virginia Tech's Center for Gerontology

Given their previous research collaborations and expertise, both Roberto and Savla were curious about these other caregivers.

The research team will recruit 240 extended family caregivers for the study, which they have named "CareEx." They will also recruit 120 adult children and spouse caregivers to serve as a comparison group.

Following a mixed-methods study design, each participant will take part in an in-depth telephone interview. The first part of the interview will use open-ended questions to learn more about participants' family relationships and how they came to be a caregiver. The second part of the survey will be more structured, using standardized measures and questions to collect data in several domains, including each participant's background and demographic characteristics, psychological well-being, and service use and barriers, as well as the daily care needs of the person with dementia.

This initial interview will be followed by an eight-day daily diary interview. This approach, which Roberto and Savla have used successfully in prior studies, will enable them to understand how caregiving plays out in daily life.

"Daily diary interviews are a unique way to understand the caregiver's day-to-day life, said Savla, a professor in the Department of Human Development and Family Science and an expert in research methodology. "We often rely on 'big picture' questions about people's overall health or experience of caregiving, but these questions don't really help us understand their daily lives. While it's not feasible to do a full ethnographic study, these data will give us snapshot of the daily lives of these families."

One of the most challenging aspects of the CareEx project will be finding the extended family caregivers to participate in the study since they are a very

defined population. Although Roberto and Savla will be recruiting participants from across Virginia, they will begin their efforts at Carilion Clinic, where they are partnering with co-investigator Aubrey Knight, a geriatrician who serves as senior dean for student affairs and a professor of family and community medicine in the Virginia Tech Carilion School of Medicine.

The researchers will also work through local Area on Aging agencies, the Alzheimer's Association, and other programs serving older adults as well as local churches, community organizations, and social media to recruit caregivers for the CareEx project.

In addition, their research will provide a rich educational experience for students. They plan to hire several graduate students to help manage the data and undergraduates to serve as interviewers.

"We will involve the students from the very beginning, including them in conversations about measures we are using, providing hands-on training, and then having them conduct most of the daily diary interviews," said Savla.

Roberto and Savla anticipate the CareEx study findings will inform the development of tailored interventions for extended family caregivers to address their unique challenges. The research may also have policy implications, particularly if the study team finds that extended family caregivers encounter unique barriers to accessing care for relatives with dementia.

Source:

Virginia Tech
