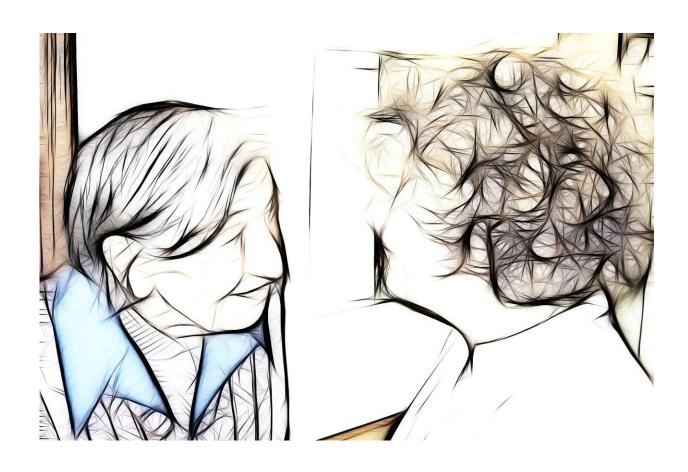


Caregivers have it tough—and the COVID-19 pandemic made things worse

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When Floria Foote first became a caregiver for her sister, she didn't anticipate just how much work she would eventually take on during her sister's decline. "It was so not like her," said Foote. "She was the go-



getter, raising two adoptive kids and taking care of our aging father at the same time. She went from that level of activity to not wanting to do anything. I had to help her wash up in the morning, keep her on a schedule, manage her bills, everything."

Foote's experience as a <u>caregiver</u> is surprisingly common. One in five U.S. adults provided unpaid care for another adult in 2020. This invisible group provides essential support to our society, particularly as the population ages, but faces numerous challenges and a dearth of resources in the course of their work. New research at the University of Chicago Medicine only further underscores the issue.

A new study has found that, before the COVID-19 pandemic, women caregivers had significantly higher odds of experiencing health-related socioeconomic vulnerabilities such as <u>food insecurity</u>, financial strain and transportation difficulties compared to non-caregivers, with 63% of caregivers reporting at least one vulnerability compared to 47% of non-caregivers. During the early days of the COVID-19 pandemic, things got even worse—caregivers had higher odds of experiencing new or worsening financial strain, as well as new interpersonal violence, food insecurity, transportation difficulties and housing insecurity. The results were published September 26 in the *Annals of Family Medicine*.

"Many adults provide care to other adults; one in five U.S. adults and one in three women are providing care to someone who is a parent, sibling or friend, who needs assistance on a daily basis," said Jennifer Makelarski, Ph.D., MPH, Senior Epidemiologist at the University of Chicago and senior author on the study. "These caregivers fill a critical role in healthcare. If caregivers suddenly weren't able to provide care for whatever reason, we'd have a problem. Our system couldn't handle the sudden influx of support needs."

Caregivers must balance their own lives and needs with those of their



dependents, finding ways to care for themselves while dedicating much of their time toward caring for their loved ones. "When you're in caregiving mode, there's a pull," said Foote. "You end up neglecting yourself for the person you're caring for, but it's always a struggle, because you have to maintain your own health as well. You can't get sick or out of shape or anything that would bring you down, because you have to be able to function, for yourself and for the person you're taking care of."

Caregivers are already at higher risk for experiencing health-related socioeconomic risks, and anything that jeopardizes their ability to care for themselves and their dependents—for example, a global pandemic—places additional strain on this unseen, unpaid workforce. Those who experience financial instability or housing insecurity may find themselves unable to provide adequate care to their loved ones, and for themselves. All of these risk factors can directly impact a person's health.

"People think my job as a gynecologist is about diagnosing and treating problems related to female sex organs," said Stacy Tessler Lindau, MD, MA, Professor of Obstetrics and Gynecology and Medicine-Geriatrics at UChicago Medicine. "When I identify and appreciate my patients as whole people, including their role as caregivers, I can adjust my medical recommendations around that reality. If I don't, my best medical care may be futile. This study is a call to action for healthcare systems to systematically and proactively identify people who are caregivers so we can provide care that works for them in the context of the critically important care they give to others. Caregivers are an overlooked extension of our healthcare system."

The researchers stress that while caregivers face additional challenges, these challenges are modifiable. "Something can be done to support caregivers," said Makelarski. "Things got worse for everyone during the



pandemic, but even more so for women caregivers. And these are things that we can work toward intervening on, to better support this essential component of our healthcare system."

They hope that these results will help further efforts by the <u>federal</u> government to formalize support resources for caregivers; they also plan to share the results with <u>community organizations</u> and representatives who can help raise awareness on this issue and advocate for systemic change.

"Traditionally, medical care has been primarily focused on what happens within the boundaries of the body and the four walls of a clinic or hospital," said Lindau. "But there are drivers outside the walls, such as access to food and transportation and a safe community, that affect a person's health. How can women caregivers provide care for their loved ones if they don't have enough food to eat themselves, or are subject to violence in their home or community? Women caregivers are bridging the great big gap between the healthcare system and home for our rapidly aging population and it's in all of our best interests to support them."

For Foote, whose sister passed in 2020, being able to support her sister was exhausting, but she was grateful for the opportunity to be there. "I always said that if she needed me, I would come help take care of her," said Foote. "The COVID-19 pandemic made everything a lot more work, but it was nice to be living with my sister again, to be there for the day to day."

The study, "Caregiving in a Pandemic: Health-Related Socioeconomic Vulnerabilities Among Women Caregivers Early in the COVID-19 Pandemic," was supported by the NIH (5R01AG064949, 5R01MD012630, R21CA226726 and 1R01DK127961. Additional authors include Kelly Boyd and Victoria Winslow of the University of



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More information: Kelly Boyd et al, Caregiving in a Pandemic: Health-Related Socioeconomic Vulnerabilities Among Women Caregivers Early in the COVID-19 Pandemic, *The Annals of Family Medicine* (2022). DOI: 10.1370/afm.2845

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