

# Nearly Half of Caregivers Are Not Asked if They Need Help With Tasks

Many of the 40 million unpaid family caregivers in the U.S. are not asked by health care workers if they need assistance managing an older adult's care, according to a study out of the Johns Hopkins Bloomberg School of Public Health (JHSPH).

The new report published in *JAMA Network Open* says that 45 percent of caregivers were never asked whether they needed support while handling a host of caregiving duties, which may include medication management, transportation and other activities of daily living.

The positive news: Family caregivers are being heard. Nine out of 10 caregivers (89 percent) say they are always or usually listened to by doctors and health care personnel about their loved one's care, and almost 3 in 4 (72 percent) are asked if they understand the medical treatments that the person getting care is receiving.

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The findings are the result of an analysis of 1,916 family and unpaid caregivers who provide regular care to 1,203 older adults who have activity limitations and live in private homes, apartment buildings or housing for older adults.

Study lead author Jennifer Wolff, Eugene and Mildred Lipitz Professor in the Department of Health Policy and Management and director of the Roger C. Lipitz Center for Integrated Health Care at the JHSPH, says the report highlights the issues caregivers face in navigating the health system on behalf of those with a serious illness.

"One of the challenges I know from qualitative studies is that family caregivers are concerned about speaking up for their needs for help, because if it's a short visit they [want] the attention of the clinician focused on the patient," says Wolff. She also notes that caregiving is so multidimensional that there is no single solution to problems. "In some cases, the caregiver's need can be financial considerations related to work or employment. In other cases, it can be emotional support and counseling or respite care. It may be training to help with medically oriented activities. Part of the challenge for developing effective systems-based approaches is that they need to be flexible."

Meredith Greene, M.D., a geriatrician, internist and assistant professor in the Department of Medicine, Division of Geriatrics, at the University of California San Francisco, says that many health care providers may not ask struggling caregivers if they need support because they themselves don't know the resources that are available.

More coordinated team-based care by the health care system is one solution to improving care for older adults. “Even if the individual provider is not familiar with programs, a social worker or care manager could work with the care provider to help with referrals for other caregiving resources,” says Greene.

Greene says in her work she strives to “empower the caregiver to speak up — not only if they feel there are things they need help with — but just to give the insight into the person [they are caring for]. Has there been a change in function? How are they really managing their medications? The patient may say one thing and the caregiver may have a different perspective.”

She thinks it is a step in the right direction that many primary care providers are routinely asking their patients if they have caregiving responsibilities. “It's another opportunity to then assess how that person is doing and try to connect them to resources.”