

Poll: Adult caregivers overwhelmed and undertrained

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Adult caregivers looking after aging relatives and friends have little training for their stressful roles but still find the experience rewarding, according to a poll released Thursday.

The Associated Press-NORC Center for Public Affairs Research survey finds that long-term caregivers don't just provide rides to the doctor and run errands. Nearly half perform some kind of medical care, from changing bandages (30 percent) to inserting catheters or feeding tubes (6 percent).

Only 47 percent of those say they got most or all of the training needed for their often delicate tasks.

Despite all the challenges, more than 9 in 10 call their care-giving experience worthwhile, even if they also find it stressful (77 percent), and overwhelming (52 percent).

"It's a labor of love, but it can be stressful," said Cheryl Johnson, a factory supervisor from Bay Minette, Alabama, who along with other family members is caring for her elderly mother and stepfather.

"Nobody can ever be prepared for that." Her mother has liver disease.

The poll of people age 40 and over who have either provided or received long-term care offers a glimpse into homes across the United States where aging and disabled people are being cared for by an ad hoc army of relatives, neighbors and friends.

It highlights how long-term care remains a major unmet need for government programs and private health insurance.

The lack of training for caregivers is a shortcoming in the health system, said Judy Feder, a professor at Georgetown University McCourt School of Public Policy.

"Caregivers are taken for granted and they are invisible in the system," Feder said. "It's bad for them, it's bad for care recipients, and it's bad for the system because there's evidence that if you engage them, it improves the quality of care."

According to the poll, most caregivers are also trying to hold down jobs.

Johnson said her employer has been very supportive. "There have been times when they said, 'Cheryl's got to go home,'" she said.

Nearly half of caregivers say it's moderately or very difficult to balance work and caregiving. Men are more likely to report that their employers are not at all supportive.

Some switch to part-time jobs; others say they've endured serious repercussions. Eight percent say they were excluded from job growth opportunities, 7 percent had their roles or responsibilities changed, and in rare cases, some report being fired or asked to resign. (The federal Family and Medical Leave Act only applies to larger employers.)

In Hastings, Nebraska, a small city where the Kool-Aid powdered soft drink was invented, Anthony Wollen says self-employment allows him to balance caregiving with work. A landscaper in his late 40s, Wollen is helping an older friend who's recovering from knee surgery.

He's had to wrap and unwrap his friend's leg and change her dressings,

Wollen said. Caregivers also help with medications, doing blood-pressure checks and giving injections.

Just one-third of all caregivers and fewer than half of those who provide at least one type of medical care say they have any formal training, including from a medical professional, a class on senior care, or their own professional experience.

Wollen said he learned first aid years ago in the military, and that's about it.

"I've actually improved as a human being with her, which I like," said Wollen. "I thought I knew everything, and then she starts talking, and she knows a lot," he said of his friend, who once worked in the mental health field.

Alzheimer's and other conditions that affect mental status are more stressful for caregivers, according to the poll. Seventy percent of those helping someone with a loss of mental abilities say caregiving made them feel sad, as opposed to 52 percent of those helping someone with no such loss.

Cognitive symptoms and confusion can result from heart disease, or even temporary causes such as a urinary tract infection or a medication mix-up.

Johnson, the small-town Alabama caregiver, said cognitive changes that affect her mother now and then can be extremely unsettling.

"She'll be fine, and all of a sudden she won't be fine," said Johnson.

Experts said the poll has practical implications.

Congress is unlikely to consider a government program for long-term care any time soon, said Gail Wilensky, a former Medicare administrator. But that doesn't stop state and local governments, and private groups from helping caregivers.

"It's very much something that you don't need to wait for the federal government on," Wilensky said. "Because this is by its nature a large, informal system, providing some help and training for caregivers would be enormously helpful."

The long-term care poll was conducted June 27-July 31 by AP-NORC, with funding from the SCAN Foundation.

It involved interviews in English and Spanish with 1,004 people age 40 and older nationwide who have experience either giving or receiving long term care, including 772 long-term care providers. Interviews were conducted online or by phone among members of NORC's probability-based AmeriSpeak panel, which is designed to be representative of the U.S. population.

The margin of error for caregivers is plus or minus 4.2 percentage points.

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