

Why Unpaid Caregivers Need Our Care, Too

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Published Feb 16, 2016



A seminal new study published February 15, 2016, in [JAMA Internal Medicine](#) illuminates sobering facts that those of us who work in the caregiving arena have known for many years: **The life of the unpaid caregiver is incredibly difficult, and takes a toll on all aspects of his or her life.**

The new study also reveals a significant problem I encounter in my daily work with caregivers: In most cases, they don't self-identify as caregivers and don't ask for help.

A typical scenario: Mom and Dad are living at home doing pretty well, with their adult kids calling to check in on a regular basis. Slowly, the kids begin accompanying their parents to doctors' appointments so they can be more involved in their healthcare. Meanwhile, they're picking up groceries and making a few meals to put in Mom and Dad's freezer. And before they know it, they're paying their parents' bills, refilling pill boxes once a week, and helping Mom shower because she had [a little slip in the bathroom](#).

These adult children most often have the mindset that this is what they must or should do for their ailing parents. They've slowly morphed into caregivers, but they're not likely to think of themselves as someone needing supportive services.

Millions of Caregivers Hard at Work

[Jennifer Wolff, PhD](#), associate professor in the Center on Aging and Health at the Johns Hopkins Bloomberg School of Public Health, and her colleagues analyzed data from two large national studies that looked at 1,739 family and unpaid caregivers who were caring for 1,171 older adults who still reside in their communities.

The two areas of caregiving they reviewed were coordinating care (taking an [older adult](#) to doctor's appointments and speaking to or emailing medical professionals about their care) and managing medications (helping to keep track of and ensure that they take their medications).

Using this data, the researchers constructed categories to describe caregivers' level of involvement in the older person's healthcare:

- No help
- Some help: care coordination but not medication management, or medication management but not care coordination
- Substantial help: assisting with both care coordination and medication management

Then researchers extrapolated their data to the 14.7 million family and unpaid U.S. caregivers who care for 7.7 million older adults and estimated that:

- 6.5 million caregivers (44.1 percent) provided substantial help and worked an average of 28.1 hours per week on caregiving duties
- 4.4 million (29.8 percent) provided some help and worked an average of 15.1 hours
- 3.8 million (26.1 percent) provided no help and worked an average of 8.3 hours

Half of those providing a substantial level of help were caring for people who had dementia or a severe disability.

A Profile of the Typical Caregiver

Those in the "substantial help" group were more likely to be female and the child of the older adult they cared for. They were also older and less likely to rate their health as excellent or very good compared with caregivers providing less help.

Caregivers who were providing substantial help were also more likely to report fewer opportunities to visit friends, go out for enjoyment, go to religious services, or participate in clubs or group activities. They were more likely to have missed work because of caregiving responsibilities, and their work productivity had declined. But they were more apt to use support

services than caregivers who provided some or no help, though only one in four caregivers overall got any support services.

The authors conclude that “because the magnitude and scope of assistance to disabled older adults by family and unpaid caregivers far exceed those of paid caregivers, devising organizational strategies and healthcare practices to identify and more purposefully engage and support family caregivers merits greater attention by health system stakeholders seeking high value care.”

What I Know About Caregivers

Caregivers often don't ask for help, but they should.

As the authors of the new study note, “The lack of systematic identification and support of caregivers in mainstream care means that their information and support needs are not well understood and often remain unmet. Family caregivers providing substantial assistance with healthcare experience significant emotional difficulty and role-related effects, yet only one-quarter use supportive services.”

I hope this is a great stepping-off point to educate this army of unpaid workers that they are indeed caregivers who should avail themselves of existing information and support programs.

If you're a caregiver, here are some resources you can try:

- [Edlercare Locator](#)
- [National Alliance for Caregiving](#)
- [Family Caregiver Alliance](#)
- [Caregiver Action Network](#)
- [Generations United](#)