

Gender Affects Caregiver Support

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Women with Parkinson's disease (PD) have a tougher time getting support for their PD issues than men, according to new research from the National Parkinson Foundation's (NPF) Parkinson's Outcomes Project.

In a study presented at the American Academy of Neurology Annual Meeting in April, NPF researchers reported that women with PD have fewer informal caregiving resources to rely on and are more likely to use formal, paid caregiving than men.

"We are looking at how important the informal caregiving role is. For instance, if you put a monetary value to it—the number of hours spent helping with activities of daily living, administering medicine and going to doctor's appointments—it's substantial," said study co-author Nabila Dahodwala, MD, Director of the Parkinson's Disease and Movement Disorders Center at the University of Pennsylvania in Philadelphia. "And the fact that women don't have as much access to it as men is a major concern that we need to think about on a societal level."

For the study, NPF researchers analyzed data on more than 7,000 men and women receiving care at NPF Centers of Excellence. They looked at whether patients were accompanied by a caregiver for



a doctor's visit and at the relationship between caregiver and patient. Here are the findings:

- Compared with women, men were significantly more likely to have a regular care partner (88.3 percent vs. 80.1 percent), and less likely to have a paid caregiver when they first enrolled in the study (2.2 percent vs. 4.9 percent).
- Women were 26 percent less likely to have a caregiver accompany them to a regular doctor's visit. And women were using a paid caregiver at a faster rate than men, which is significant because research suggests that health-related quality of life declines when a family caregiver is replaced by a paid caregiver.
- Caregiving is harder on women than men (20.2 vs. 16.9, respectively, as measured on the Multidimensional Caregiving Strain Index), even after adjusting for potential confounders.

"What was surprising is that even when the disease was more severe in women, caregivers of female patients still reported less burden than the caregivers of male patients," Dr. Dahodwala said. "One

hypothesis is that a male caregiver may be more open to inviting someone into the house to provide extra support whereas women may be more resistant to doing that, even when they need more help.”

Getting Support

Why aren't women caregivers getting adequate support, given its pivotal role in Parkinson's treatment? During the average 30-minute office visit, doctors are so focused on patient treatment that they often don't have time to address the needs of the caregiver, Dr. Dahodwala said. Often it's not even on their radar.

Women—whether stressed caregivers or PD patients with inadequate social support—need to talk to their doctors about these issues. Seeking information about caregiving and community resources might be helpful, explained Dr. Dahodwala.

“Most are really passionate about doing the best they can,” Dr. Dahodwala said. “But caregiver strain actually affects the caregiver's health. The caregivers are less likely to visit a doctor or take their medicine because they are caring for someone else.”

NPF regards caregiving education and support as a top priority. That's why NPF developed a new guide for caregivers called *Caring and Coping*. It includes a comprehensive set of recommendations and tips to help caregivers cope with daily activities and relationships.

Dr. Dahodwala's center recently introduced "Caregiver to Caregiver," a telehealth caregiver mentor program. “This is just another strategy to provide extra support,” she said. “It helps to know that you are not alone, that others have similar issues.”

Researchers will continue to study the support needs of women with PD. The aim is to better understand what drives these differences so that remedies can be developed and quality of care can be improved for men and women alike. “There are probably a lot of reasons underlying this lack of caregiver support for women with Parkinson's disease,” Dr. Dahodwala said. “Certainly, we know it affects many women, and it's a big problem.”

Signs a Caregiver Needs Help

Caregiver strain refers to a high level of stress experienced by a person caring for someone with a chronic illness or disability. A caregiver with any signs of strain should seek help.

Red flags include:

- Feeling burdened by stress
- Feeling depressed, anxious or irritable much of the day
- Being isolated, without much support from family or friends
- Being too busy to engage in daily activities to relieve stress

If you are experiencing caregiver strain, feel free to call our Helpline for assistance and support at 1-800-4PD-INFO, or e-mail helpline@parkinson.org.