What's Hot in Parkinson's Disease?

Recognizing and Treating Caregiver Strain

Helen Keller's caregiver, Anne Sullivan, once said, "I cannot explain it, but when difficulties arise, I am not perplexed or doubtful. I know how to meet them." As a neurologist, I see a lot of Parkinson's patients, and I know that one of the keys to success is a fully engaged caregiver.

Findings from a new study from the National Parkinson Foundation (NPF) paint a picture of just how important the caregiver really is. NPF's Parkinson's Outcomes Project has assembled the largest group of Parkinson's disease patients being studied over time in a clinical setting. We have been using a measure called the multidimensional caregiver strain index (CSI) to collect data on caregiver strain. This scale reflects how spouses and caregivers feel about caring for their family members and loved ones.

To understand how vital the caregiver is to the person with Parkinson's as well as the dramatic impact caregiving has on a person thrust into this role, we looked at data in caregiving situations where the caregiver changed from spouse to another family member. We wanted to know how hard caregiving is on those thrust into this role.

As expected, we found that caregiver strain was higher for new caregivers. In addition, when a patient's caregiver changed from his or her spouse to another family member, the CSI increased 20 points from a year earlier when the spouse was the caregiver. When the spouse remained the caregiver, the increase was just five points. On this 72 point scale, where zero means you have little or no stress and 72 means you are experiencing a great deal of strain, this 15 point difference is 20 percent from no impact at all to intolerable strain, and is quite serious.

The study also showed other notable results. When a patient's caregiver went from spouse to another family member, the patient suffered worse health. They got sicker, reported worse health and experienced slower mobility. Not only do experienced caregivers have well developed coping skills, they also provide better care and help maintain the health of their loved ones.

Also using data from the Parkinson's Outcomes Project, Tanya Simuni, MD, a movement disorders specialist at the NPF Center of Excellence at Northwestern University, examined the impact of caregiver strain on patients. In this study, she found a correlation between the self-reported health of patients, and caregiver strain: the better the patient's health, the lower the strain. This is important because our research indicates that it is more the patient's perception of their own health than the clinical measurement of the impact of the disease that determines strain.

This new evidence has really shed light on how I look at the concerned spouse who accompanies my patients to their visits with me. Caregivers are an integral part of care, and we have found that a happy, knowledgeable caregiver is not only better able to cope with the stress of caregiving, but also an equally important member of the Parkinson's care team. With this new research, we have learned that recognizing and treating caregiver strain is critical.

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Read Dr. Okun's monthly column, "What's Hot in PD?" online at **www.parkinson.org/whatshot.**