

Parkinson's Outcomes Project Links Age to Increased Risk of Caregiver Strain

Caregiving for someone with Parkinson's disease (PD) can be an incredibly challenging task. When in a caregiver role over the course of many years, it can take a toll on even the healthiest of individuals.

In a study presented at the International Parkinson and Movement Disorders Society's Annual Congress in June, National Parkinson Foundation (NPF) researchers reported that older age is linked to an increased risk of caregiver strain.

The research stems from NPF's *Parkinson's Outcomes Project*, the largest-ever clinical study of Parkinson's. The study's goal is to improve care of people with PD by identifying and implementing best practices across NPF Centers of Excellence and beyond.



C. Kingsley Okoro, BS, and Jennifer G. Goldman MD, MS, present their study findings at the International Parkinson and Movement Disorders Society Annual Congress.

For the caregiver study, Jennifer G. Goldman, MD, MS, and colleagues at Rush University Medical Center in Chicago analyzed data from 8,078 patients receiving care at NPF centers. Researchers examined caregiver strain using the Multidimensional Caregiver Strain Index (MCSI), which is an 18-question index measuring caregiver strain in the following areas: physical, financial, interpersonal, social and time management.

Researchers conducted baseline comparisons between patients with and without MCSI data, and collected data again one year and two years later. Changes in MCSI scores were compared from the three time periods. The aim was to examine the predictors of change in caregiver strain variables over

time, such as: baseline demographics, stage of PD, other health conditions, mental health and cognitive functions.

Caregiver strain index data was available at all three visits for 1,574 patients who attended doctor's visits with caregivers. Data was received for 4,304 patients who attended the baseline appointment and either the year-one or year-two follow-up appointment with a caregiver.

According to study results, those with MCSI data were significantly more likely to be male, live at home, have longer PD duration and more advanced PD. Regular caregivers changed in 14.8 percent from baseline to year-one and 16 percent to year-two, with caregiver changes seen with older, female patients, with more advanced PD and higher MCSI scores. This is important because caregiver transition is associated with a change for the worse in health-related quality of life. MCSI scores increased significantly at year-one and year-two visits, with substantial increases in all caregiver burden domains with the exception of financial strain.

This study is an important step in understanding how caregiver strain increases over time in those caring for people with PD, who are at highest risk of caregiver strain, and in which specific areas strain is experienced. These findings can help us identify caregivers at risk for strain and design interventions to prevent and reduce caregiver strain in PD, said Goldman.

The study determined that age was the most common significant predictor of change in the caregiver strain index. Caregiver strain increases over time for those caring for people with PD in general and in specific areas. In addition, caregiver changes over time appear to affect older women who are experiencing the later stages of Parkinson's the most. The study underscores the importance that interventions to ease caregiver strain should address not only caring for older people with PD, but also physical, social, time management, interpersonal and family conflict issues.

For more information about the Parkinson's Outcomes Project visit www.parkinson.org/outcomes.