Study investigates aggression toward caregivers in Parkinson's disease patients
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Caregivers already dealing with the stress of looking after a loved one diagnosed with Parkinson's disease often have another concern to contend with—aggressive behavior directed toward them from the Parkinson's patient.

A new study led by Zachary Macchi, MD, assistant professor of neurology in the University of Colorado School of Medicine, reveals the extent of the problem and some of the factors that lead to the aggressive behavior.

Macchi's recent work on a clinical trial of outpatient palliative care for patients and caregivers with Parkinson's disease and related disorders helped to initiate this study.

"We noticed, as we were talking to caregivers, that they were reporting a fairly high prevalence of aggression toward them on behalf of patients," Macchi says. "This is something that really hadn't been explored in Parkinson's disease and similar disorders. That gave us a lot of pause, and it was a prompt to investigate this further."

A mixed-methods study

Macchi devised a study using a combination of quantitative data from the palliative care clinical trial and qualitative data gathered from interviews with trial participants. After looking at the data from the clinical trial, he went back to talk with caregivers who reported any type of aggression as part of their caregiving experience.

"We did interviews with these caregivers, letting them share their experiences, and we were able to begin to understand the triggers, or what we call predecessors to aggression," Macchi says. "The things that were leading up to aggression, as well as the behaviors themselves."

The qualitative research identified aggressive behaviors ranging from verbal abuse to threats of physical violence, largely attributable to the difficulty patients experience in coping with disease progression and related losses. Those triggers were evident in the quantitative data as well, which found that contributing factors to aggression included grief, loss of motor symptoms, confusion, change in functional status, and even the cognitive fluctuations that characterize Parkinson's disease.

"Going into this research, we hypothesized about the other factors that could be contributing to patients exhibiting aggressive behavior—things like cognitive impairment or specific types of medications that were being used—and interestingly enough, those things that we expected to see: patients having dementia, being of male sex, being older, having longer disease duration, those variables were not associated with aggression," Macchi adds.

"It's interesting to see some of the things play out that we weren't expecting to be associated with these types of behavioral issues."
Creating an intervention to help

Additionally, Macchi’s study found that caregivers’ stress and mental health are worsened by aggressive behaviors, that aggressive behaviors negatively affect patient-caregiver relationships, and that caregivers are ill-prepared to manage aggressive behaviors and cope with the consequences on their own. He is now starting work to develop an intervention to help caregivers identify and deal with aggressive behaviors.

"The next step would be to build what we call a psychoeducation intervention, where we work with caregivers on identifying these behaviors, and then identifying triggers—or potential precursors to these behaviors, and then understanding the consequences of them," Macchi says. "We want to give caregiver the tools and skillset to be able to manage those, and to foster an ongoing relationship between the caregiver and the clinician."

Since aggressive behavior is an underrecognized issue in Parkinson’s, Macchi says, it will be important to understand how clinicians are currently working with caregivers on the topic, as well as to work directly with caregivers to create an intervention that best captures their concerns and offers help they would find useful.

Raising awareness

Macchi is currently developing a nationwide survey querying neurologists on this topic, specifically on the state of current practice for managing aggression. He plans to take this work further to support ongoing work to develop the intervention.

"This is an issue that we think is very much underrecognized, and I'm hoping to create more awareness toward it, even among clinicians who work directly with people living with Parkinson's disease," he says.

"Just knowing that this is a factor likely driving caregiver burden for some people and may be picked up on in outpatient appointments, I want them to realize it's worthwhile to investigate for these behavioral problems. That's what I hope people take away from this study."

The research was published in Movement Disorders Clinical Practice.


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