

Non-Motor Symptoms of Parkinson's Disease Are More Common Than Most Think

Christine Kilgore

Non-motor symptoms — and fluctuations in these symptoms — are a surprisingly common and often disabling part of life for residents with Parkinson's disease (PD), said Julie Gammack, MD, CMD, at the annual conference of AMDA — The Society for Post-Acute and Long-Term Care Medicine in Atlanta, GA.

Non-motor components of the disease such as dementia and psychosis are often a reason for long-term care placement, and the subsequent morbidity and mortality are significant: The limited body of research available on residents with PD in long-term care has shown a high prevalence of depression, hallucinations, and agitation, for instance, and a 3-year post-placement mortality of 50%.

More broadly, one-third of patients with PD who experience motor function fluctuations also have non-motor fluctuations. “What I didn't realize was how prevalent these symptoms can be,” said Dr. Gammack, a professor of medicine in the Division of Geriatric Medicine at Saint Louis University in Missouri. “There's a suggestion [from the literature] that after having PD for 5 or 10 years, almost everyone will have some non-motor component of the disease.”

Research indicates, moreover, that cognitive dysfunction and mood disorders, autonomic dysfunction, and other non-motor symptoms can actually precede motor symptoms by up to 10 years in some individuals with PD. “We should think about [such symptoms] as potential precursors, especially in those who are starting to develop some rigidity and gait instability,” she said.

Non-motor symptoms in patients with PD can be managed as they would in other clinical scenarios, such as managing insomnia with sleep hygiene or constipation with changes in diet and fluid intake. However, in addition, because “on-off phenomena can happen with non-motor symptoms just as with motor symptoms” and because these fluctuations appear to be connected, it is often important to optimize continuous dopaminergic prescribing, she said.

Increasing dopaminergic administration, optimizing dopaminergic agonists, and adding advanced therapies and non-dopaminergic treatment are all therapeutic options, Dr. Gammack explained. “So for non-motor fluctuations, optimizing the total management of their PD [is the goal].”

PD psychosis, which appears to increase mortality, involves hallucinations, illusions, or delusions that are continuous or recurrent for 1 month or more. “Their psychosis is often visually based,” Dr. Gammack said. “These individuals are clear in their thinking, they have insight and are not delirious, and they're adamant that what they're seeing is actually there.”

The risk of psychosis increases with the use of certain medications (such as

dopamine agonists, anticholinergics, amantadine, and serotonin) and in the presence of underlying visual processing deficits and ocular pathology, sleep disorders, and psychiatric conditions. Medication reduction can reduce the symptoms of psychosis, but unfortunately this often comes at the cost of worsened motor symptoms, Dr. Gammack said.

The antipsychotics clozapine and quetiapine “get the most attention” for PD psychosis (an off-label use), but both can potentially worsen motor symptoms. Clozapine may have more minimal motor side effects, but agranulocytosis is a concern. “And of course, we try to avoid antipsychotics as much as we can,” Dr. Gammack said.

The drug pimavanserin, a 5-HT_{2A} inverse agonist, was approved in 2016 by the U.S. Food and Drug Administration for PD psychosis. A 6-week randomized, double-blind, placebo-controlled study reported an approximately 3-point decrease in the PD adapted

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Florida). Over a six-month period, there was a 17% reduction in all-cause hospitalizations among all participating nursing homes and a 24% reduction among those who were most “engaged” in the program (*J Am Geriatr Soc* 2011;59:745–753).

A subsequent randomized trial of the program produced disappointing results, however. The 85 nursing homes that received remote training and support for implementing INTERACT had no significant reduction in overall hospital admissions compared with the nursing homes that received no training or support. They also had no significant differences in readmission rates or emergency department visits. The one positive result was a reduction in hospitalizations that were deemed potentially avoidable (although it wasn’t a statistically significant difference after correction for multiple comparisons). “The magnitude implied a nearly 15% reduction in potentially avoidable hospitalizations relative to the pre-intervention rate for intervention nursing homes,” the investigators led by Robert Kane, MD, reported (*JAMA Intern Med* 2017;177:1257–1264).

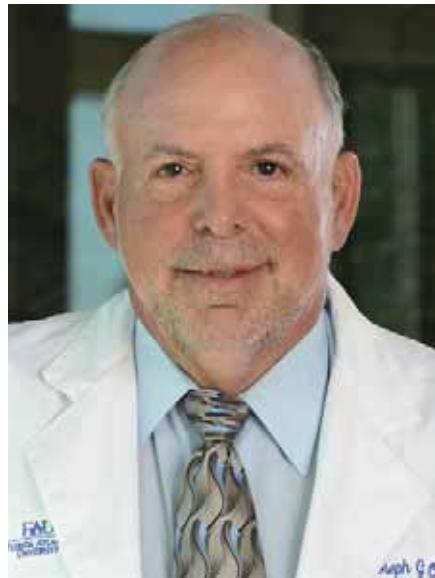
Dr. Ouslander said the latter study was affected by the passage of time and a change in the national policy climate shortly before it began. Medicare had implemented its policy of penalizing 30-day readmissions, and there was evidence that some of the nursing homes in the control group were using parts of the INTERACT program on their own. On the flipside, many of the nursing homes in the intervention group did not fully utilize or participate in the training curriculum. Both these issues muddied the evaluation, he said.

Since then, a handful of recently published secondary analyses supported by the National Institute for Nursing Research have validated INTERACT’s content and value, Dr. Ouslander said. One analysis combined the intervention and control groups and compared their outcomes according to the degree of INTERACT use. The SNFs that reported an increased use of the tools had significantly greater reductions in all-cause hospitalizations and potentially avoidable hospitalizations compared with those that stayed the same or decreased their use of the tools (*J Am Geriatr Soc* 2018;66:1830–1837).

Another secondary analysis of the randomized trial data looked at all the reported acute changes in condition (*J Am Geriatr Soc* 2018;66:2259–2266). Most changes were nonspecific and multifactorial (e.g., altered mental status or shortness of breath), and only 10% resulted in a hospital transfer between 72 hours and 7 days after the change. “Ninety percent of the [residents with changes in condition] stayed in the facility and were managed there,” Dr. Ouslander pointed out. According to another secondary analysis, the providers in the trial rated almost 25% of the transfers that did occur as

potentially avoidable (*J Am Med Dir Assn* 2016;17:256–262).

With respect to resident safety during the implementation of INTERACT, an analysis of the Minimum Data Set (MDS) data for eight different measures — including dehydration, pressure ulcers, changes in fall rates, and septicemia — found no significant differences in the percentage of residents with these outcomes when comparing the intervention and control SNFs in either the year preceding the intervention or during the intervention, and no differential change in these measures for intervention SNFs relative to controls (*J Am Med Dir Assn* 2018;19:907–913).



Joseph G. Ouslander, MD

“We were concerned that when staff try to manage sicker people in the facility, this could have an impact on quality measures,” Dr. Ouslander said. “Fortunately, this did not occur.”

What Experience Tells

In Dr. Lam’s SNF 2.0 program, a nurse practitioner trained in INTERACT and in key mentoring and teaching principles visits the SNF over a six-month period to conduct group training and work one-on-one with nurses and aides in order to understand their jobs and point out opportunities for integrating INTERACT tools into the daily workflow. “The goal is to pique curiosity,” Dr. Lam said. “To look for teachable moments.”

Dr. Lam, who chairs the Department of Geriatric Medicine at the Palo Alto Foundation Medical Group, built the program after talking with colleagues and realizing that many SNFs faced similar issues with changes in condition going unnoticed and unaddressed. He looked into INTERACT in 2012 and “saw that the program was powerful,” but he worried about the ability of SNFs to implement it.

“I realized that those who didn’t know about it might not even be equipped to do it, and that those who had started to do it weren’t really embracing the whole program,” he said. With initial funding from the California Health Care Foundation and subsequent funding

from the California Association of Long Term Care Medicine (CALTCM) — as well as funding from some of the SNFs that got involved — Dr. Lam built and tested SNF 2.0. He incorporated parts of various change-management and educational theories. And as facilities began to use the program, he documented significant reductions (33% to 66%) in their admissions and readmissions.

Today, over 50 facilities have implemented INTERACT using SNF 2.0, and the program has made a home at CALTCM, where Dr. Lam and colleagues have more recently created a broader “ecosystem” of hospitals, health plans, and medical groups that speak the INTERACT language and support quality improvement in SNFs. Facilities are now paying for the program themselves.

Outside California, in the SNFs of Lifespace Communities (or “health centers” as they are called there) INTERACT has empowered frontline staff — not only nursing aides but staff who work in the culinary, maintenance, and housekeeping departments as well — to have a voice in the well-being of residents, said Sara Elizabeth Hamm, DNP, RN, senior vice president of successful aging and health services at the West Des Moines, IA-based company. “Our frontline team members are the eyes and ears of our nurses,” she said. “This system gives them wings.”

Lifespace last year adopted PointClickCare for each of its 12 campuses, and as part of its EHR agreement it purchased the eINTERACT platform. Parts of INTERACT are being embedded into various EHR products, but PointClickCare’s eINTERACT was developed by the company in partnership with FAU.

Dr. Ouslander considers EHR integration to be the most significant milestone thus far in the history of the program, and Dr. Hamm said that for her facilities it will move the needle even further toward better SNF care and fewer hospitalizations. “Before we converted ... there were some INTERACT tools that were not being utilized simply because it was difficult,” she said. In the meantime, the “lessons we’ve learned using INTERACT in our health centers are really helping us in assisted living and residential living,” Dr. Hamm added. “We identify changes in condition when they’re early and subtle so residents won’t be prematurely admitted to the health center or sent to the hospital.”

Kevin W. O’Neil, MD, CMD, helped develop and test a modified version of INTERACT for assisted living and memory care while he was chief medical officer with Brookdale Senior Living. Today, as chief medical officer with Affinity Living Group of Hickory, NC, he is implementing it stepwise in Affinity’s assisted living communities. The Stop and Watch tool is basically the same, he noted, but the SBAR form has been changed to Appearance & Request.

“What gets us into the most trouble [in SNFs and throughout health care]

are usually communication gaps — things falling through the cracks,” said Dr. O’Neil. “The INTERACT program creates a discipline around the processes that are needed to reduce avoidable hospitalizations.”

Dr. Ouslander disclosed that he receives royalties and serves as a paid advisor to Pathway Health, which has a license agreement with FAU for use of INTERACT materials and training.

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scale for assessment of positive symptoms (SAPS-PD) — a 37% improvement — with use of the drug, although the rating scale used in the study had not been previously validated (*Lancet* 2014;383:533–540).

PD dementia is also common, especially with a longer duration of PD (>70% at 5 years), Dr. Gammack noted. Research has looked at stimulants, cholinesterase inhibitors, and memantine in patients with PD (all off-label), and thus far cholinesterase inhibitors have the “best evidence” for a small improvement.

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