

## The burden of Parkinson's disease (PD)

Parkinson's disease places a significant burden on patients, caregivers, payers, employers, healthcare systems, managed care organizations, and government programs. Currently, there are roughly 1 million people in the United States living with PD.<sup>1</sup> In July of 2019, the Michael J. Fox Foundation reported that the annual overall cost of the disease in the United States for 2017 was approximately \$52 billion.<sup>2</sup> A large claims analysis calculated that 89% (n=919,000) of people in the US with PD are eligible for Medicare.<sup>2</sup> In this study, 18% of Medicare patients reported claims for a nursing home.<sup>2</sup> In another retrospective analysis of a cohort of 469,055 patients with PD who received Medicare benefits in 2002, 25% were identified to live in a long-term care (LTC) facility/nursing home.<sup>3</sup> And there's no slowdown in sight—the number of affected patients in the United States is projected to rise to more than 1.2 million in the next decade.<sup>1,4</sup>

The LTC setting, which includes skilled nursing homes, rehabilitation and/or assisted living facilities, and residential memory care programs, will likely be forced to shoulder the burden of caring for many more PD patients in years to come. In 2017, managing PD in LTC settings\* annually cost approximately \$7 billion.<sup>21</sup> Management of residents with PD across these care facilities may present unique challenges to healthcare providers, family caregivers, skilled aides, and managed care decision-makers. Anticipating and resolving these challenges can help improve the quality of care while managing costs. This article explores some of the gaps and opportunities to improve the care of people with PD in LTC settings.

## How is PD characterized?

PD is the second most common neurodegenerative movement disorder.<sup>5</sup> It's typically defined by a progressive loss of dopaminergic neurons in the substantia nigra.<sup>5,6</sup> Before clinical features emerge, 50%-80% of dopaminergic neurons have already degenerated.<sup>7</sup> This neurodegeneration only continues as PD progresses, since the loss of dopaminergic terminals results in a decreased capacity to store dopamine.<sup>5</sup>

In 1817, Dr. James Parkinson first described a "shaking palsy" among other motor symptoms experienced by his patients.<sup>5</sup> Classic motor signs of PD include tremor, rigidity, akinesia/bradykinesia, and postural instability (TRAP).<sup>6,8,9</sup> A family history is reported by approximately 10%-20% of patients.<sup>10</sup> More commonly, PD is thought to develop through a combination of environmental and genetic factors.<sup>10</sup>

\*Nursing homes, skilled nursing facilities, and hospices.

<sup>1</sup>Source: Lewin analyses of PD prevalence using 2011-2015 Medical Expenditure Panel Survey (MEPS), 2015 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2017; combined with direct medical cost estimates using 2016 Optum claims, 2015 Medicare Standard Analytical File 5% sample claims, and 2015 Medicare Current Beneficiary Survey (MCBS).

## Addressing ON/OFF cycling in LTC facilities

Since the 1970s, orally administered medication has been used to manage the debilitating tremors and other symptoms of PD.<sup>11</sup> Regimens of medications may be used as Parkinson's progresses.<sup>11</sup>

Additionally, many patients with PD experience fluctuations in how effectively their symptoms are controlled, which is commonly referred to as "ON/OFF cycling."<sup>5</sup> The noticeable duration of beneficial impact of medication is referred to as an ON period, and the wearing off of the medication's benefit, and return or exacerbation of PD symptoms, is called an OFF period.<sup>5</sup> OFF periods can come on at any time and can be sudden, even for patients who receive their therapies as prescribed.<sup>5,12,13</sup> Together, these form ON/OFF cycles.

## OFF periods can result in recurring symptoms such as<sup>11</sup>:



- Rest tremor
- Bradykinesia
- Postural instability
- Fine motor-skill issues
- Hypophonia
- Muscular rigidity
- Shuffling gait

In general, PD tends to be underdiagnosed and under-treated in LTC settings.<sup>11,14</sup>

Thus, a combination of gaps and challenges are present in the effective management of LTC residents with PD. There may be opportunities for raising awareness and training of staff on the recognition of the entire ON/OFF cycle, as well as how individual residents with PD experience return of symptoms. Additionally, strategies that coordinate care among both LTC providers and neurologists may improve quality and prevent the costly burden of uncoordinated care.<sup>15</sup>

## Improving outcomes

Fortunately, there are measures that can be employed to improve PD patient outcomes in LTC settings. Better care coordination with specialists, education on OFF period signs and symptoms for LTC staff, and exercise programs, as appropriate, are strategies worth implementing.

For neurologists and other providers who specialize in treating people with PD or other neurological disorders, coordination with primary care providers is often second nature. People with PD have better outcomes, higher quality of care, and more effective management of symptoms when specialty providers are an integral part of the team.<sup>15,16</sup> In fact, in a 2011 study, newly diagnosed patients who saw a neurologist were less likely to need placement in a skilled nursing facility.<sup>16</sup>

Additionally, exercise programs have been found to improve symptoms in people with PD. Aerobic exercise in the form of walking and cycling may reduce neuromuscular decline.<sup>17,18</sup> In particular, a treadmill training program may help PD patients minimize gait impairment.<sup>18</sup> There is also evidence suggesting that dance programs and dance therapy may help PD patients to improve physical and mental health by increasing socialization and physical coordination.<sup>19,20</sup> Finally, strength training may be effective in increasing physical parameters of PD patients.<sup>21</sup>

Looking to the future, some emerging practices and therapies may yield improved patient outcomes. Preliminary data from a small randomized crossover pilot study indicated that cognitive stimulation was effective in enhancing cognition and certain non-cognitive symptoms like depression in LTC patients with PD dementia.<sup>22</sup>

Managing PD in LTC settings cost an estimated \$7 billion in 2017—an economic burden with significant room for improvement.<sup>2</sup> One such opportunity is the improved management of PD patient OFF periods in LTC facilities. By improving care coordination, educating LTC staff on OFF period signs and symptoms, and implementing exercise programs, patients can experience better outcomes.

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