

WHITE PAPER

Breaking Barriers to Advanced Parkinson's Disease Treatment



Parkinson's disease is a chronic, progressive neurological condition marked by both motor and non-motor symptoms that worsen over time.

[Christie Teigland, Ph.D.](#), worked with colleagues to uncover how social factors and geographic location impact access to advanced device-aided treatments. Their work reveals concerning disparities in who receives innovative therapies, and the resulting implications for healthcare equity and patient outcomes.

Understanding the Parkinson's Disease Landscape

Parkinson's disease is a lifelong condition affecting nearly 1 million people across the U.S., with numbers expected to reach 1.2 million by 2030.¹ Each year, approximately 90,000 new cases are diagnosed, with the average onset around 60 years of age. The disease impacts about 1% of people over 60 years and 5% of those over 85 years.²

However, Parkinson's disease does not affect all populations equally. For example, men are more likely to be diagnosed than women across all ages. Black patients face diagnostic disparities and have reduced access to neurologists and movement disorder specialists.³ And geographically, the highest prevalence rates are found within the 'Rust Belt' states.⁴

For patients with advanced Parkinson's disease (aPD), alternative non-oral treatments include surgical device-aided therapies (DATs). Two key DATs are carbidopa/levodopa enteral suspension (CLES) and deep brain stimulation (DBS). Clinical studies have demonstrated the efficacy of these treatments, showing improvements in quality of life and reductions in pill burden. CLES delivers levodopa continuously for up to 16 hours through a percutaneous endoscopic gastrostomy tube. DBS involves inserting electrodes into specific brain regions and sending electrical pulses via an implanted generator. Despite their availability and proven benefits, utilization of these advanced treatments remains surprisingly low among eligible patients.

A Nationwide Investigation of Treatment Disparities

Christie Teigland, Ph.D., and her colleagues designed a [retrospective study](#) using 100% Medicare Fee-for-Service medical and pharmacy claims data from January 2017 through December 2020, linked to [Inovalon's social drivers of health \(SDOH\)](#) data warehouse. This comprehensive approach allowed them to examine how demographic, clinical, social, and geographic factors influence which patients with aPD receive DATs.

The researchers identified adults with Parkinson's disease diagnosis who met the criteria for aPD based on several indicators: high medication doses, use of non-oral treatments, use of rescue medications, or presence of dyskinesia. They then determined which aPD patients received DAT, either CLES or DBS, and those who were eligible but did not receive DAT.

Revealing the treatment gap in aPD

Among 503,245 Medicare beneficiaries with Parkinson's disease:

- 22% (112,773) met the criteria for aPD
- Only 2% (2,450) of eligible aPD patients received DAT
- Of those who received DAT, 24% received CLES and 76% received DBS



Who Receives Advanced Treatments?

Significant disparities in who received DAT were identified. Compared to patients who did not receive these treatments, those who did were generally younger (average age 71 versus age 76) and more often male (65% versus 58%). Although most patients in both groups (those who received treatment and those who did not) were White (88-89%), fewer Black patients received advanced therapies (1% of Black patients versus 3% of White patients).

Patients with lower incomes were less likely to receive advanced treatments. Only 10% of patients who were dually eligible for Medicaid (a proxy for low income) received DAT compared to 19% of those who were not dual-eligible. Disabled Medicare beneficiaries (those under age 65 who qualify for Medicare due to disability) were more likely to receive DATs than those who qualified for Medicare at age 65 (29% versus 19%).

Patients receiving DAT were less likely to have dementia (4% versus 10%) but more likely to have drug-induced dyskinesias (7% versus 3%). DAT patients had fewer hospitalizations with shorter stays and more specialist visits, particularly to neurologists, neurosurgeons, gastroenterologists, psychiatrists, and nurse practitioners compared to those who did not receive DAT.



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SDOH: marital status, income, and education

Social factors also played a significant role in determining who received advanced therapies. Patients receiving DAT were more likely to be married (47% versus 46%) and had slightly higher annual household incomes (\$72,220 versus \$71,048). A smaller proportion of patients receiving advanced therapies had completed high school or less education (35% versus 36%), and they were more likely to own a vehicle (94% versus 93%).

While these differences appear small in percentage terms, they represent thousands of patients across the Medicare population and highlight how SDOH contribute to access and treatment disparities in Parkinson's disease.

Geographic patterns in disease prevalence and treatment

Distinct geographic patterns in both Parkinson's disease prevalence and treatment access were identified. States with more than 1,000 Parkinson's disease patients per 100,000 Medicare beneficiaries included New York, Iowa, Kansas, Connecticut, Nebraska, California, Illinois, New Jersey, and Missouri. The highest prevalence of aPD was found in states in the Northeast, Midwest, and West regions, particularly Iowa, North Dakota, Utah, Connecticut, Kansas, New York, Missouri, and California. States with the greatest proportion of aPD patients receiving DATs were concentrated in Mountain and South Central Census divisions, including Montana (4.2%), Idaho (3.5%), Arizona (3.3%), Oklahoma (3.2%), and Alabama (3.0%).

The researchers identified 413 facilities nationwide that provided DAT, averaging eight facilities per state. Three states (Alaska, North Dakota, and Wyoming) had no facilities offering either of these treatments, while six states had no facilities offering CLES specifically.

Patients receiving DAT traveled an average of 98 miles to reach a facility, with distances ranging from 11 to 255 miles. Patients in the Mountain division traveled the longest distances (averaging 172 miles), while those in Middle Atlantic states traveled the shortest distances (averaging 51 miles).

These geographic patterns reveal a concerning mismatch between disease prevalence and treatment access. Many states with a high prevalence of aPD have fewer facilities providing DAT and relatively low rates of DAT use, suggesting significant unmet needs in these regions.

Predictors of Receiving Advanced Treatments

Multivariate logistic regression models, a type of statistical analysis that examines the relationship between several factors and the likelihood of an outcome, were used to identify factors associated with a greater likelihood of receiving DATs. Younger patients were two to three times more likely to receive these treatments than those aged 75 to 84. Other factors associated with higher likelihood included Hispanic ethnicity, higher baseline medication doses, use of rescue therapies, visits with neurologists or nurse practitioners, and residence in states with more facilities providing DATs.

Conversely, patients less likely to receive advanced treatments were older (especially those age 85 and above), female, Black, low-income, and those with higher disease burden. For CLES specifically, being married was associated with a four times higher likelihood of receiving treatment. Disabled Medicare patients were 90% more likely to receive CLES.



Implications for Healthcare Equity

There are significant disparities in access to aPD treatments. Only 1.8% of females received DATs compared with 2.4% of males, and only 0.7% of Black patients received these treatments compared with 2.2% of White patients.

The researchers found that patients with neurologist visits were more likely to receive DATs. However, a 2019 study found that only 50% of Medicare Parkinson's disease patients received care from a neurologist and just 9% from a movement disorder specialist.

The study also highlighted the challenges of geographic access, with patients often traveling long distances to receive treatment. This suggests a potential barrier for patients without the physical or financial ability to travel. The research identifies states with high aPD prevalence yet low DAT utilization, representing an opportunity to screen patients for consideration of these treatments.

Additionally, the findings revealed that states with high aPD prevalence did not necessarily have more facilities providing DAT, indicating another potential access barrier. Identifying and mitigating patient-related challenges such as financial constraints, health literacy issues, and access and transportation difficulties could improve access to advanced therapies.



Future Interventions for Improved Care

This comprehensive analysis provides crucial insights into the disparities affecting Parkinson's disease treatment in the U.S., and the complex interplay of clinical, demographic, social, and geographic factors influencing who receives advanced therapies.

By identifying these barriers, this research lays the groundwork for interventions to improve access to effective treatments for all patients with aPD, regardless of their socio-demographic and economic background or geographic location.

Together, we can advance health equity and improve outcomes for underserved populations. Get the real-world clarity you need to understand treatment performance and outcome drivers.

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Sources

1. "Prevalence of Parkinson's disease across North America," Marras, C., Beck, J.C., Bower, J.H. et al., npj Parkinson's Disease 4, 21 (2018). <https://doi.org/10.1038/s41531-018-0058-0>
2. "Ageing and Parkinson's disease: Why is advancing age the biggest risk factor?" Reeve, A., Simcox, E., & Turnbull, D., Ageing Research Reviews 14, (2014): 19-30. <https://doi.org/10.1016/j.arr.2014.01.004>
3. "Incidence of Parkinson disease in North America," Willis, A. W., Roberts, E., Beck, J. C., Fiske, B., Ross, W., Savica, R., Van Den Eeden, S. K., Tanner, C. M., Marras, C., & Parkinson's Foundation P4 Group, NPJ Parkinson's disease 8, no. 1 (2022), 170: <https://doi.org/10.1038/s41531-022-00410-y>
4. "Access to device-aided therapies in advanced Parkinson's disease: navigating clinician biases, patient preference, and prognostic uncertainty," Auffret, M., Weiss, D., Stocchi, F., Vérin, M., & Jost, W. H., Journal of neural transmission (Vienna) 130, no. 11 (2023): 1411–1432. <https://doi.org/10.1007/s00702-023-02668-9>

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Christie Teigland leads the design and implementation of studies focused on quality measurement, health equity, and health economics and outcomes research. She works closely with health plans, providers, and life science organizations to develop actionable real-world data insights.

Dr. Teigland co-chaired the National Quality Forum (NQF) Scientific Methods Panel for four years and served on the Pharmacy Quality Alliance (PQA) Quality Measure Expert Panel and as co-chair of PQA's Health Equity Technical Expert Panel, as well as on many Centers for Medicare & Medicaid (CMS) expert panels. She has served as principal investigator on large foundation and government-funded projects over two decades focused on improving healthcare quality. Dr. Teigland earned her Ph.D. in Economics and Econometric Forecasting from the University of New York at Albany.