Nursing home and end-of-life care in Parkinson disease

Delaram Safarpour, MD
Dylan P. Thibault, MS
Cori L. DeSanto, MD
Cynthia M. Boyd, MD,
PhD
E. Ray Dorsey, MD,
MBA
Brad A. Racette, MD
Allison W. Willis, MD,
MSCI

Correspondence to
Dr. Willis:
allison.willis@uphs.upenn.edu

ABSTRACT

Objective: To examine long-term care facility (LTCF or nursing home) use and end-of-life care for individuals with Parkinson disease (PD).

Methods: In this nationwide retrospective cohort study, we compared LTCF and hospice utilization among Medicare beneficiaries diagnosed with PD by demographic, clinical, and physician characteristics. We also examined the impact of outpatient neurologist care for institutionalized patients with PD on end-of-life care.

Results: We identified 469,055 individuals with PD who received Medicare benefits in 2002. Nearly 25% (more than 100,000 in total) resided in an LTCF. Women with PD had greater odds of nursing facility residence (adjusted odds ratio [AOR] 1.34, 95% confidence interval [CI] 1.30–1.38) compared with men. Black individuals with PD were 34% more likely than white individuals to reside in an LTCF (AOR 1.34, 95% CI 1.30–1.38), contrary to the race patterns typically observed for LTCF use. Hip fracture (AOR 2.10, 95% CI 2.04–2.15) and dementia (AOR 4.06, 95% CI 4.00–4.12) were the strongest clinical predictors of LTCF placement. Only 33% (n = 38,334) of nursing home residents with PD had outpatient neurologist care. Eighty-four percent (n = 80,877) of LTCF residents with PD died by December 31, 2005. Hospice utilization varied little by race and sex. LTCF residents who had outpatient neurologist care were twice as likely to utilize hospice services before death (AOR 2.35, 95% CI 2.24–2.47).

Conclusions and relevance: A large proportion of the Medicare PD population resides in an LTCF. There is substantial unmet need for palliative care in the PD population. Increased efforts to provide specialist care to dependent individuals with PD may improve end-of-life care.

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GLOSSARY

AOR = adjusted odds ratio; **CI** = confidence interval; **ICD-9** = *International Classification of Diseases, Ninth Revision*; **LTCF** = long-term care facility; **OR** = odds ratio; **PD** = Parkinson disease; **PR** = prevalence ratio.

Parkinson disease (PD) prevalence will rise sharply in the coming decades because of the aging of the population and improved survivorship. Current data on patients with PD in long-term care facilities (LTCFs), frequently referred to as nursing homes, focus on the PD symptoms (motor dysfunction, cognitive impairment, and psychosis) that predict nursing facility placement.^{1,2} Women and minorities with PD are at increased risk of being diagnosed with dementia, and are also least likely to receive guideline-adherent PD care.^{3,4} However, previous studies have not examined race and sex differences in nursing home placement, which may provide initial evidence of the long-term effects of these observed differences in disease course and treatment quality.

We have previously reported that Medicare beneficiaries with a new PD diagnosis who received regular neurologist care soon after diagnosis had a lower 1-year risk of hip fracture and greater 6-year survival,⁵ but the usefulness of specialist care for the highly disabled or those

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From the Departments of Neurology (D.S., D.P.T., A.W.W.) and Biostatistics and Epidemiology (A.W.W.), Center for Clinical Epidemiology and Biostatistics (D.S., A.W.W.), and Leonard Davis Institute of Health Economics (A.W.W.), University of Pennsylvania Perelman School of Medicine, Philadelphia; Department of Neurology (C.L.D., B.A.R.), Washington University School of Medicine, St. Louis, MO; Departments of Medicine (C.M.B.) and Health Policy and Management (C.M.B.), Johns Hopkins School of Medicine, Baltimore, MD; Department of Neurology (E.R.D.), Center of Human Experimental Therapeutics, University of Rochester Medical Center, NY; and School of Public Health (B.A.R.), Faculty of Health Sciences, University of the Witwatersrand, Parktown, South Africa.

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at later stages of PD is unclear. End-of-life care is an integral part of neurology training, and one possible benefit of neurologist care in end-stage PD is an out-of-hospital death via use of hospice services for palliative care.

In this study, we describe differences in LTCF utilization among Medicare beneficiaries with PD, decomposing those differences into race and sex disparities, and over- and underutilization predicted by clinical characteristics/events. We also examine neurologist and palliative care use by LTCF residents, providing initial data for updated PD clinical guidelines that improve outcomes at all stages of the disease.

METHODS **Standard protocol approvals, registrations, and patient consents.** This study was approved by the human studies research office of the University of Pennsylvania Perelman School of Medicine, and the Centers for Medicare & Medicaid Services.

Study design, patient, and clinical characteristics. This retrospective cohort study included 469,055 elderly Medicare beneficiaries with a diagnosis of PD identified in the year 2002 and followed through December 31, 2005. Medicare is a government-mandated insurance and prescription program used by 98% of adults aged 65 years and older, and a portion of the disabled population. Our PD case assessment methods are described elsewhere.⁶ Briefly, we identified prevalent PD diagnoses in the Carrier Research Identifiable Files using the *ICD-9* codes 332 and 332.0. Those beneficiaries who also had a diagnosis for a Parkinson-plus syndrome, or were younger than the age of standard Medicare eligibility (65 years), were excluded from further analysis.

PD cases were linked with the Beneficiary Annual Summary File, which contains demographic variables (race, age, and sex), data on health service utilization (including hospice, office visits, and hospitalizations), chronic/comorbid conditions, and vital status. Race or ethnicity was categorized using Medicare standard race codes. Beneficiary Annual Summary File Chronic Condition Warehouse⁷ data contain the initial diagnosis date for 21 common medical conditions, including the following: congestive heart failure, atherosclerotic heart disease, diabetes, chronic obstructive pulmonary disease, acute myocardial infarction, dementia/cognitive impairment, hip fracture, and chronic kidney

disease, and malignancy of the breast, colon/rectum, lung, or prostate, identified using validated *ICD-9*-based algorithms. These data were used to create an age-weighted Charlson comorbidity score for each patient, and also to examine the relative impact of these conditions on nursing facility placement and hospice utilization.

Provider characteristics. We used the physician specialty code variable in the carrier file to identify the specialties of the physician who provided outpatient PD care. These files allow us to distinguish between practicing neurology or a primary care specialty—internal medicine, family practice, or geriatrics. A patient with PD was determined to have “neurologist care” if they had at least 2 outpatient office visits for PD with a neurologist between 2002 and 2005, a minimum threshold for quality care of other chronic diseases.^{8,9}

Outcomes. There were 2 main outcomes: residential nursing facility care and hospice utilization. To determine place of care, we applied a previously validated algorithm (table 1) that utilizes billing claims and extracted variables describing (1) facility type, (2) place of service, and (3) *Current Procedural Terminology* codes suggestive of LTCF care/nursing home residence to claims data from the year 2002.¹⁰ We restricted the value for the place of service variable “nursing facility” in order to exclude individuals receiving nursing care in skilled nursing facilities and in the inpatient setting, as these were more likely to be acute care-related (e.g., postoperative skilled nursing facility care). We compared individuals with PD in a nursing facility with those residing in the community according to 3 groups of factors: (1) race, age, and sex; (2) dementia/cognitive impairment diagnosis (yes/no); and (3) presence of comorbid illness and total comorbidity burden.

To examine end-of-life care in PD, we identified all patients with PD who died between January 1, 2003, and December 31, 2005. Hospice enrollment (yes/no) before death was determined for the calendar year of death and compared across categories of neurologist care (yes/no), place of care (nursing home vs community), and demographic characteristics (race, age, sex).

Analytical methods. Logistic regression models were developed to determine the likelihood of nursing facility placement according to categories of race, sex, and age and whether a diagnosis of dementia, congestive heart failure, hip fracture, ischemic heart disease, diabetes, or malignancy was present, adjusting for covariates. A separate set of models examined the associations between demographic (race, sex), clinical, and outpatient PD physician specialty characteristics and hospice enrollment before death. Health care utilization has been shown in many diseases, including PD, to vary by individual socioeconomic status and across small geographical areas.⁴ To address potential confounding by location or socioeconomic status, our final models included a previously validated county-level socioeconomic deprivation score, which accounts for small area variation in specialty care access by Medicare beneficiaries driven by socioeconomic characteristics.¹¹ All models also included an age-weighted modified Charlson comorbidity score.

Statistical analyses. Prevalence ratios (PRs) were calculated to compare baseline characteristics between nursing facility and community-dwelling elderly Medicare beneficiaries with PD, and between those who utilized hospice services before death and those who did not. Continuous variables were compared via 2-sided *t* test, where appropriate; χ^2 tests compared categorical variables. Standard methods were used to produce odds ratios (ORs) with 95% confidence intervals (CIs). Statistical analyses were performed using SPSS Statistics version 21 (IBM Corp., Armonk, NY).

Table 1 CMS Chronic Condition Data Warehouse coding algorithm for dementia

Algorithm	Ref. time period, y	Valid ICD-9/CPT-4/HCPCS codes
Alzheimer disease	3	DX 331.0 (any DX on the claim)
Alzheimer disease and related disorders or senile dementia	3	DX 331.0, 331.1, 331.11, 331.19, 331.2, 331.7, 290.0, 290.10, 290.11, 290.12, 290.13, 290.20, 290.21, 290.3, 290.40, 290.41, 290.42, 290.43, 294.0, 294.1, 294.10, 294.11, 294.8, 797 (any DX on the claim)

Abbreviations: CMS = Centers for Medicare & Medicaid Services; CPT-4 = *Current Procedural Terminology, Fourth Edition*; DX = diagnosis; HCPCS = *Healthcare Common Procedure Coding System*; Ref. = reference.

RESULTS Burden and demographic disparities of LTNF in PD. We identified 469,055 Medicare beneficiaries aged 65 years and older who had a diagnosis of PD recorded in the year 2002. Twenty-four percent ($n = 113,668$) had claims consistent with residence in an LTCF. Compared with community-dwelling patients with PD, LTCF residents with PD were older (mean age = 82.3 ± 6.94 years vs mean age in the community = 78.7 ± 6.96 years, $p < 0.001$) and more often female (58.2% female patients with PD in LTCF vs 49.0% female patients with PD in the community, $p < 0.001$). These sex and age differences are similar to those found in the general LTCF population, which consists mostly of women (66.2%) and individuals aged 75 years and older (71.8%).^{12,13}

Studies have also reported that minorities are underrepresented in the general nursing home

population, with black persons having 25% to 50% lower LTCF utilization rates than white persons.^{14–16} We found that African Americans with a PD diagnosis were relatively overrepresented in the LTCF population (5.7% vs 4.8% in the community, $p < 0.001$). Hispanic individuals were more common in the community PD population (2.1% vs 1.3% in LTCFs, $p < 0.001$) (table 2).

Regression models used to investigate the likelihood of nursing home care according to demographic variables also indicated that race was a predictor of nursing home placement among elders with PD: black patients were 34% more likely than white patients to reside in an LTCF, even after adjusting for other sociodemographic characteristics and comorbid disease (adjusted OR [AOR] 1.34, 95% CI 1.30–1.38). This is in stark contrast to studies of institutionalization in the general population, which report that black individuals are up 50% less likely to utilize LTCF care compared with white individuals (AOR 0.50, 95% CI 0.35–0.72).¹⁴ Asian (AOR 0.85, 95% CI 0.77–0.95) and Hispanic (AOR 0.86, 95% CI 0.81–0.92) patients with PD were less likely to reside in a nursing facility (table 3).

Clinical predictors of nursing facility care in PD. Nursing facility residents had a greater burden of comorbid disease than those in the community, evidenced by higher proportions of congestive heart failure, chronic obstructive pulmonary disease, ischemic heart disease, chronic kidney disease, dementia, and cerebrovascular disease (table 2). Dementia was diagnosed in 65.9% of LTCF patients with PD (compared with 29.3% of community-dwelling patients with PD; PR 2.25, 95% CI 2.23–2.26). Hip fracture had recently occurred in 12.4% of nursing facility residents with PD compared with 5.1% of community dwellers (PR 2.42, 95% CI 2.37–2.47).

Dementia and hip fracture were predictive of nursing facility care, even after adjustment for potential confounders. Dementia was associated with a 4-fold increase in nursing facility placement (OR 4.69, 95% CI 4.62–4.77; AOR 4.06, 95% CI 4.00–4.12). Recent hip fracture was more than twice as likely among nursing home residents (OR 2.65, 95% CI 2.58–2.71; AOR 2.10, 95% CI 2.04–2.15). The sequelae of atherosclerotic vascular disease—stroke/TIA, ischemic heart disease, and congestive heart failure were associated with modestly increased risks of nursing home placement (table 2).

Outpatient neurologist care among nursing home residents. In clinical practice, a person with PD is often placed in a nursing home (for PD reasons) when PD nonmotor symptoms, such as hallucinations, psychosis, and dementia, occur or motor symptoms (slowness, stiffness, gait, and balance impairment)

Table 2 Demographic and clinical characteristics of LTCF and community-dwelling individuals with Parkinson disease^a

Characteristic	Community (n = 355,387)	LTCF (n = 113,668)
Race		
White	326,862 (92.0)	104,866 (92.3)
Black	17,013 (4.8)	6,433 (5.7)
Asian	3,918 (1.1)	839 (0.7)
Hispanic	7,594 (2.1)	1,530 (1.3)
Sex		
Male	181,190 (51.0)	47,472 (41.8)
Female	174,197 (49.0)	66,196 (58.2)
Age, y		
65–69	37,418 (10.5)	4,570 (4.0)
70–74	64,666 (18.2)	11,295 (9.9)
75–79	90,600 (25.5)	22,360 (19.7)
80–84	87,138 (24.5)	31,578 (27.8)
85+	75,565 (21.3)	43,865 (38.6)
Comorbid medical diagnosis^b		
Atrial fibrillation	47,551 (13.4)	16,923 (14.9)
Dementia	104,199 (29.3)	74,930 (65.9)
Myocardial infarction	12,140 (3.4)	3,872 (3.4)
Congestive heart failure	107,951 (30.4)	47,248 (41.6)
Colorectal cancer	7,343 (2.1)	2,375 (2.1)
COPD	59,225 (16.7)	24,228 (21.3)
Diabetes mellitus	85,819 (24.1)	28,352 (24.9)
Hip fracture	18,168 (5.1)	14,086 (12.4)
Ischemic heart disease	124,064 (34.9)	53,859 (47.4)
Stroke/TIA	74,709 (21.0)	34,466 (30.3)

Abbreviations: COPD = chronic obstructive pulmonary disease; LTCF = long-term care facility. Data are n (%).

^aAmong all fee-for-service Medicare beneficiaries older than 65 years (year = 2002).

^bAccording to the Centers for Medicare & Medicaid Services Chronic Condition Warehouse.

Table 3 Predictors of nursing facility care among Medicare beneficiaries with Parkinson disease

Characteristic	Model 1, OR (95% CI)	Model 2, AOR (95% CI)
Race		
White	Ref.	Ref.
Black	1.17 (1.13–1.20)	1.34 (1.30–1.38)
Asian	0.79 (0.71–0.87)	0.85 (0.77–0.95)
Hispanic	0.61 (0.58–0.65)	0.86 (0.81–0.92)
Sex		
Male	Ref.	Ref.
Female	1.46 (1.44–1.48)	1.34 (1.30–1.38)
Comorbid disease diagnosis^a		
Atrial fibrillation	1.14 (1.12–1.17)	1.05 (1.03–1.08)
Dementia	4.69 (4.62–4.77)	4.06 (4.00–4.12)
Myocardial infarction	1.00 (0.96–1.04)	1.04 (1.00–1.08)
Congestive heart failure	1.66 (1.63–1.68)	1.51 (1.49–1.53)
Colorectal cancer	1.01 (0.96–1.06)	0.96 (0.92–1.02)
COPD	1.22 (1.20–1.25)	1.28 (1.25–1.30)
Diabetes mellitus	1.04 (1.02–1.06)	1.19 (1.17–1.21)
Hip fracture	2.65 (2.58–2.71)	2.10 (2.04–2.15)
Ischemic heart disease	1.70 (1.67–1.76)	1.52 (1.49–1.54)
Stroke/TIA	1.65 (1.62–1.68)	1.59 (1.56–1.61)

Abbreviations: AOR = adjusted odds ratio; CI = confidence interval; COPD = chronic obstructive pulmonary disease; OR = odds ratio; Ref. = reference.

Model 1: each characteristic alone. Model 2: individual race, age, sex, age-weighted modified Charlson Comorbidity Index score; county-level socioeconomic deprivation score (socioeconomic status).

^a According to the Centers for Medicare & Medicaid Services Chronic Condition Warehouse.

have progressed to the point that an individual is no longer able to ambulate safely or receive dependent care at home.¹⁷ Nursing home placement for a patient with PD, therefore, does not preclude the need for continued disease management. Yet, only 33% (n = 38,334) of nursing home residents with PD had outpatient neurologist care in this study sample. Similar to our previous data on the overall PD population, neurologist-treated nursing home residents were most often white (94.2%). Neurologist-treated patients were also healthier: they had a lower odds of dementia (AOR 0.41, 95% CI 0.40–0.42), hip fracture (AOR 0.74, 95% CI 0.70–0.77), congestive heart failure (AOR 0.67, 95% CI 0.65–0.70), diabetes (AOR 0.68, 95% CI 0.65–0.70), ischemic heart disease (AOR 0.78, 95% CI 0.76–0.80), and stroke/TIA (AOR 0.69, 95% CI 0.67–0.72).

End-of-life care. Almost 85% (n = 80,877) of nursing home residents with PD died between January 1, 2003, and December 31, 2005. Hospice care was utilized by 54.2% (n = 43,805) of the decedents. Regression models that examined hospice use according to patient race and sex determined that black and

Hispanic patients were as likely as white patients to utilize hospice services, after adjusting for baseline differences in age, sex, and comorbid disease (black patients: AOR 0.98, 95% CI 0.89–1.09; Hispanic patients: AOR 1.09, 95% CI 0.87–1.35). Similarly, women had adjusted odds of hospice care that were similar to men (AOR 0.92, 95% CI 0.89–0.97). However, Asian nursing home residents with PD had a much lower likelihood of hospice use (AOR 0.44, 95% CI 0.33–0.58) before death (table 4).

The association of race and hospice use may reflect cultural and community influences in health beliefs and behaviors, and race disparities in quality care and patient-centered care, whereas provider-level disparities in end-of-life care may reflect differences in training and experience. Hospice services were provided to 80.7% of nursing home residents receiving neurologist care before death vs 59.8% of those who did not have outpatient neurologist care (χ^2 , $p < 0.001$). A logistic regression model determined that neurologist-treated patients were more than twice as likely to receive hospice care before death (AOR 2.35, 95% CI 2.24–2.47). This difference was robust to adjustment for race, age, sex, comorbidity, hip fracture, and dementia status in additional models (table 4).

DISCUSSION This nationwide study of 469,055 community and nursing home residents with PD examined key life transitions: nursing home placement and end-of-life care. We found that 25% of the Medicare PD population receives nursing home care. African Americans, who have a much lower risk of PD, constitute a relatively large proportion of the PD nursing home population. Dementia and hip fracture predispose to nursing home placement in PD, and the benefits of neurologist care extend to the end of life for patients with PD.

The large number of Medicare beneficiaries who have PD and reside in nursing homes (more than 100,000) has substantial implications for patients and their families, the neurology community, long-term care providers, state and federal budgets, and policymakers. Approximately one-third of expenditures from the Medicaid program, which is jointly funded by state and federal governments, go to funding institutional care for older Americans. Such care is expensive—up to \$80,000 per year¹²—and is far more expensive than care from a multidisciplinary team of providers led by a neurologist. For policymakers, the growing burden of PD and other neurodegenerative conditions, notably Alzheimer disease, will require new care models and reimbursement policies.¹⁸

The relatively large proportion of African Americans observed in the PD nursing home population is in

Table 4 Patient, provider, and clinical characteristics associated with hospice utilization among 80,877 decedent nursing home residents with PD^a

Characteristic	Model 1, OR (95% CI)	Model 2, AOR (95% CI)
Race		
White	Ref.	Ref.
Black	1.21 (1.11–1.33)	0.98 (0.89–1.09)
Asian	0.50 (0.38–0.65)	0.44 (0.33–0.58)
Hispanic	1.41 (1.15–1.74)	1.09 (0.87–1.35)
Sex		
Male	Ref.	Ref.
Female	0.74 (0.71–0.77)	0.92 (0.89–0.97)
Comorbid medical condition^b		
Atrial fibrillation	1.19 (1.12–1.25)	0.80 (0.75–0.85)
Dementia	0.53 (0.51–0.56)	0.67 (0.64–0.70)
Myocardial infarction	1.32 (1.18–1.48)	0.78 (0.69–0.88)
Congestive heart failure	1.04 (1.00–1.08)	0.77 (0.74–0.81)
Colorectal cancer	1.18 (1.02–1.36)	0.85 (0.73–0.98)
COPD	1.29 (1.23–1.36)	0.88 (0.83–0.93)
Diabetes mellitus	1.23 (1.17–1.23)	0.79 (0.75–0.83)
Hip fracture	0.82 (0.77–0.86)	0.76 (0.72–0.81)
Atrial fibrillation	1.26 (1.21–1.31)	0.87 (0.83–0.91)
Dementia	1.12 (1.07–1.16)	0.84 (0.80–0.88)
PD physician specialty^c		
Primary care	Ref.	Ref.
Neurologist	2.71 (2.58–2.84)	2.35 (2.24–2.47)

Abbreviations: AOR = adjusted odds ratio; CI = confidence interval; COPD = chronic obstructive pulmonary disease; OR = odds ratio; PD = Parkinson disease; Ref. = reference. Model 1: each characteristic alone. Model 2: individual race, age, sex, age-weighted modified Charlson Comorbidity Index score; county-level socioeconomic deprivation score (socioeconomic status).

^aPD cases identified among all fee-for-service Medicare beneficiaries in the year 2002; death and neurologist care were measured between January 1, 2003, and December 31, 2005.

^bAccording to the Centers for Medicare & Medicaid Services Chronic Condition Warehouse.

^cPD physician specialty designated to be neurologist if beneficiary had at least 2 outpatient office visits for PD with a neurologist between January 1, 2002, and death. Primary care physician = specialist in internal medicine, geriatrics, or family practice.

contrast to previous studies of the general population that demonstrate a lower incidence of nursing facility use by African Americans.¹⁴ Increased disability among African Americans may suggest accelerated disease progression and higher prevalence of disabling comorbidities. Dementia is more prevalent among older black compared with white individuals in both the PD and general populations,¹⁹ and dementia has been consistently shown to correlate highly with nursing facility care in all races.²⁰ Common comorbid diseases, such as diabetes mellitus, congestive heart failure, and hypertension, are frequently more severe and poorly managed in African Americans.²¹ Therefore, overall health and disability, rather than PD, may be the driving force behind nursing home placement in this population.

Factors contributing to a decreased risk of nursing facility placement in other minorities are less clear, particularly among Hispanics, who are also at greater risk of developing dementia. One study found that Hispanic elders with limited English comprehension were less likely to agree to LTCF placement than their English-speaking counterparts.²² Asian individuals with PD may be less prone to dementia or have a better baseline health status, although data to this effect are limited. Cultures that are family-focused are frequently nonwhite and often have a more negative view of extended care facilities.²³ A growing body of literature reports that minorities in US nursing homes receive worse care than their white counterparts, and families may opt to keep their loved ones at home for this reason.²⁴ Another possible explanation of greater LTCF use among African Americans and women with PD is that LTCF placement may be a measureable consequence of known race and sex disparities in the use of basic (physiotherapy or dopaminergic therapy)^{25,26} or advanced (deep brain stimulation surgery)⁴ therapies for PD. Studies that focus on disease course in understudied groups and on long-term outcomes associated with lower-quality PD care will quantify the proportion of nursing home placements of patients with PD that could be delayed or prevented.

We have previously reported that improved survival, fewer PD-related hospitalizations, lower health care costs, and greater patient satisfaction scores are associated with neurologist care for PD. However, a recent randomized study that tested the effectiveness of an integrated specialty care model found no benefit for PD-related outcomes after adjustment for PD stage.²⁷ The differences may lie in the balance of unobservable confounders, or more simply, in the choice of outcomes. A potential barrier to progress in patient care (treatment, services, and preventive interventions) and quality survivorship for PD is that previous clinical research in this population has focused on symptomatic therapies (such as medications for tremor, slowness, rigidity, shuffling gait) and disease-related outcomes (Unified Parkinson's Disease Rating Scale score, disease-related quality of life). Given that there is currently no cure or neuroprotective therapy for PD, it may be more appropriate and informative to take a broader, health services approach to PD care and outcomes, viewing disability and resultant outcomes as avoidable (falls with hip fracture, urosepsis after unrecognized urinary tract infection) or unavoidable (symptomatic Lewy body burden). Taking that perspective, dementia and hip fracture emerge as "tipping point" conditions in our study population—most strongly associated with nursing home placement. Hip fracture in PD may be more immediately responsive to a change in

processes of care. The contributors to fall with hip fracture in PD are understudied and complex, but may include avoidance of medications that impair balance and cognition (narcotics, benzodiazepines, hypnotics or sleeping agents, anticholinergic, muscle relaxants) and optimal management of PD motor symptoms. Moreover, that approach provides alternative evidence of the benefits of neurologist care by focusing on death, a universal event, finding neurologist care may improve the process of dying with PD. Future studies will define the extent to which complex care models improve outcomes vs promote overspending without benefit or place patients with PD at risk of harm.

Limitations. All studies that utilize administrative data may be subject to bias because of unknown random or nonrandom errors in coding, and the large sample size may not be sufficient to overcome these biases. We were not able to assess whether PD severity was a primary cause of nursing home placement as opposed to functional disability from other common illnesses (congestive heart failure, dementia, and stroke). The process of application for nursing home care can lead to greater recording of comorbidities, and may bias comorbid disease assessment in LTCF patients. Other unobservable factors in this dataset may influence LTCF or hospice utilization, such as marital status, social support, and market, physician, and institutional factors.²⁸ Our definition of neurologist care was lenient, based on minimum follow-up care thresholds for other chronic diseases of the elderly, such as chronic obstructive pulmonary disease, congestive heart failure, and preventive care.^{8,9,29} The dying process among individuals with very frequent neurologist care may differ. Despite these limitations, these data reveal the large-scale use of LTCFs by patients with PD, provide additional evidence of a disparate disease course among African Americans with PD, highlight the unmet need for palliative care in PD, and suggest that the benefit of specialty care for PD extends to the end of life. Future studies of these potential differences in care and outcomes may inform treatment and best practice guidelines for PD.

AUTHOR CONTRIBUTIONS

Dr. Delaram Safarpour performed primary authorship, secondary data analysis. Dr. Allison Willis provided study concept and design, acquisition of data, data analysis, and secondary authorship. Dr. Willis had full access to and takes full responsibility for the accuracy of the data. Dr. DeSanto provided secondary data analysis. Mr. Thibault provided primary and secondary data analysis. Dr. Cynthia Boyd provided critical revision of the manuscript for important intellectual content. Dr. E. Ray Dorsey provided critical revision of the manuscript for important intellectual content. Dr. Brad Racette provided critical revision of the manuscript for important intellectual content, assisted with data acquisition.

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