

Disease severity and quality of life in homebound people with advanced Parkinson disease

A pilot study

Jori E. Fleisher, MD, MSCE, Meghan M. Sweeney, LCSW, Sarah Oyler, RN, Talia Meisel, BS, Naomi Friede, BA, Alessandro Di Rocco, MD, and Joshua Chodosh, MD, MSHS

Correspondence

Dr. Fleisher
Jori_Fleisher@rush.edu

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Abstract

Background

As Parkinson disease (PD) progresses, symptoms increase, quality of life (QoL) declines, and individuals may become homebound, often losing access to neurologic care. We aimed to determine whether facilitating expert *in-home* care could improve our understanding of disease progression, treatment options, and unmet needs in this vulnerable population, and whether such a model could mitigate decline in QoL.

Methods

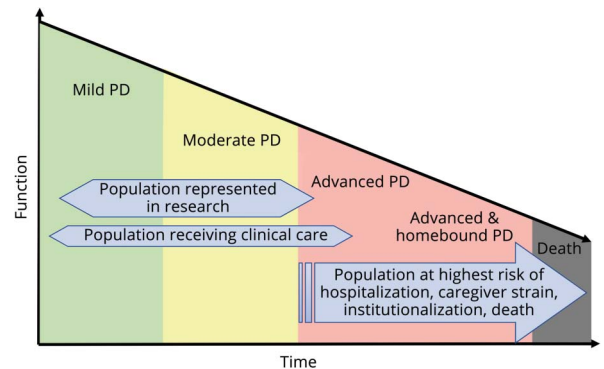
Patients with PD meeting Medicare homebound criteria were eligible for quarterly interdisciplinary home visits over 12 months. Each visit entailed an evaluation by a movement disorders neurologist, social worker, and nurse, including history, examination, medication reconciliation, psychosocial evaluation, pharmacologic and nonpharmacologic management, and service referrals. Disease severity, as measured by the Unified Parkinson's Disease Rating Scale (UPDRS), and QoL using the Neuro-QoL were measured at visits 1 and 4.

Results

Of 27 enrolled patients, 23 completed 4 visits, with high retention and high patient- and caregiver-reported satisfaction. The mean age at baseline was 80.9 years (SD 7.8) with a mean total UPDRS of 65.0 (SD 20.0). After one year of home visits, total UPDRS worsened by a mean of 11.8 points ($p < 0.01$) without a change in any of 8 QoL domains ($p = 0.19$ – 0.95).

Conclusions

Homebound individuals with advanced PD receiving interdisciplinary home visits experienced no significant decline in QoL over 1 year, despite disease progression. Our findings highlight the disease severity and impaired QoL of the advanced, homebound PD population, and the potential for novel approaches to foster continuity of care.

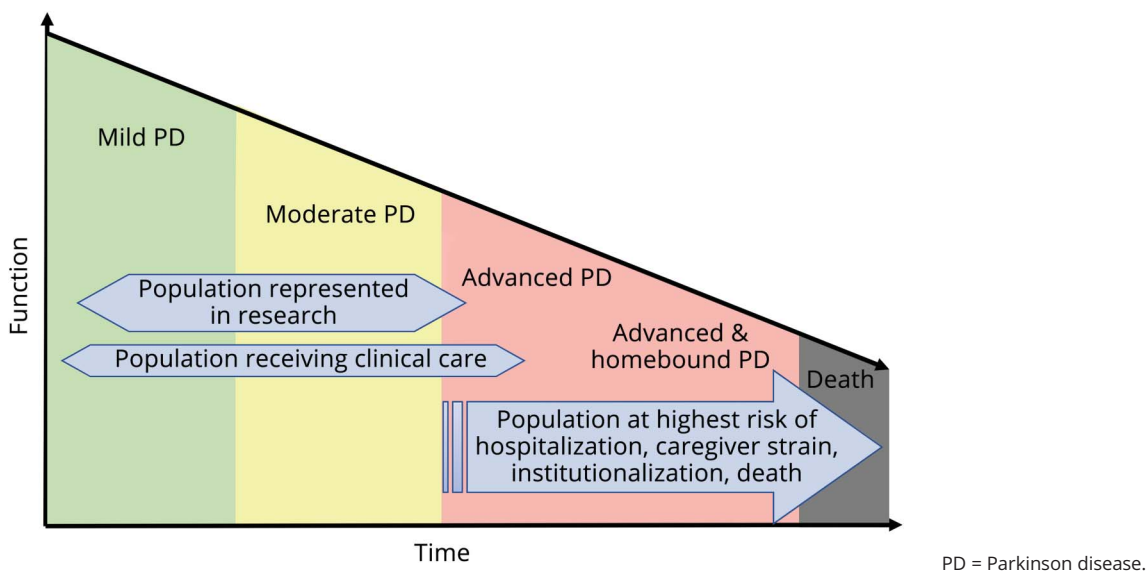


As Parkinson disease (PD) progresses, symptoms increase in number and severity.¹ Individuals with advanced PD have a symptom burden comparable to patients with metastatic cancer.² In both moderate and advanced PD, as motor and nonmotor symptoms worsen,

Rush University (JEF), Section of Movement Disorders, Department of Neurological Sciences, Chicago, IL; New York University Langone Health (JEF), Marlene and Paolo Fresco Institute for Parkinson's and Movement Disorders, Department of Neurology, NY; Kaiser Permanente (MMS), Department of Palliative Care, Lafayette, CO; Intermountain Medical Center (SO), Movement Disorders, Murray, UT; SUNY Downstate Medical Center College of Medicine (TM), Brooklyn, NY; Yale School of Nursing (NF), Orange, CT; Northwell Health and Donald and Barbara Zucker School of Medicine at Hofstra/Northwell (ADR), Long Island, NY; New York University School of Medicine (JC), Division of Geriatric Medicine and Palliative Care, Department of Medicine, New York, NY; and VA New York Harbor Healthcare System (JC), Medicine Service, New York, NY.

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Figure 1 Unmet need for care and research in the advanced, homebound PD population



quality of life (QoL) follows linearly along with worsening caregiver strain, both of which contribute to roughly 10–20,000 people becoming homebound each year in the US.^{3–5} Once homebound, this population loses access to expert care, leading to a surge in acute healthcare utilization, institutionalization, and excess morbidity.^{6,7} Simultaneously, this population is underrepresented in PD research (figure 1). In other complex elderly populations, modern adaptations of house calls have improved quality of care and limited functional decline.^{8,9} Most successful models have been interdisciplinary; however, PD implementations have been limited.^{10,11}

In 2014, we launched the Edmond J. Safra Interdisciplinary Home Visit Program for Advanced PD (HVP) to provide comprehensive care and outreach to homebound individuals with PD and related disorders. The HVP has been described elsewhere in detail.¹² Here, we report on a prospective one-year cohort study of a subset of HVP participants with PD. Our objectives were to describe: retention in and satisfaction with the HVP over one year; disease progression of advanced, homebound individuals over time; and whether the HVP can stabilize QoL despite expected functional decline. For this prospective study, individuals with significant cognitive impairment were excluded due to limitations with self-report assessments.

Methods

Standard protocol approvals, registrations, and patient consents

This study was approved by the New York University School of Medicine Institutional Review Board. Written informed consent was obtained from all participants.

Study participants and recruitment

Patients were recruited from the Marlene and Paolo Fresco Institute for Parkinson's and Movement Disorders at New York University. In addition to chart review to identify patients, movement disorders neurologists directly referred potential participants who were at least 21 years old, primarily English-speaking, diagnosed with idiopathic PD,¹³ and had missed >1 recent appointment or had been hospitalized or temporarily institutionalized in the preceding year. Using Medicare homebound criteria—leaving the home “required a considerable and taxing effort”, and was either contraindicated or required the use of assistive devices, assistive transportation, or the aide of another person¹⁴—we asked referring providers for their assessment of the individual's homebound status at the time of referral.

To identify individuals most at risk of hospitalization or institutionalization, we required patients to have ≥ 1 of the following criteria, as judged by their neurologist: motor fluctuations, multimorbidity, medication mismanagement, mild cognitive impairment, depression, anxiety, recent increased falls, or suspected elder abuse, neglect, or caregiver burnout. Patients with possible or probable atypical parkinsonism were excluded. Additionally, we excluded individuals scoring ≤ 20 on the Folstein Mini-Mental State Examination (MMSE) at screening to avoid impaired capacity to consent in the absence of a caregiver,¹⁵ and inability to complete study assessments. Cognitive impairment did not preclude HVP participation,¹² only prospective study participation. The catchment area included all 5 boroughs of New York City.

Once potential patients were referred or identified through chart review, the team contacted the patient or caregiver. If eligibility criteria were confirmed and the individual amenable, we scheduled the initial visit and sent the Unified

Parkinson's Disease Rating Scale parts I and II to be completed prior to the visit.¹⁶

Study visits

The team—comprised of a movement disorders neurologist, nurse, and social worker—traveled to the patient's home approximately every 4 months for a total of 4 visits over 1 year, becoming the patient's default care providers during that time and enacting clinical changes. Given its pilot nature, HVP funding supported the nurse and social worker's time and participants were not billed. The neurologist's time was supported by the institution. As the visit protocol is described elsewhere in detail,¹² we will briefly summarize the visits here. The nurse gathered orthostatic vital signs, given the prevalence of orthostatic hypotension and then identified fall risks and safety hazards throughout the home.¹⁷ The nurse reviewed the UPDRS I and II to identify impairments in activities of daily living. Next, she conducted a real-time medication reconciliation, comparing prescription and over-the-counter medications to those listed in the most recent outpatient encounter, and identifying signs of nonadherence.

The social worker reviewed the patient's living situation and healthcare utilization, and conducted a psychosocial needs assessment of the patient and caregiver, if applicable. The neurologist posed UPDRS follow-up questions and inquired about additional advanced PD concerns (e.g., constipation, unintentional weight loss), medication efficacy, adverse effects, and adherence, before examining the patient. The social worker and neurologist initiated a conversation regarding the patient's goals of care and advance directives. The team formulated a comprehensive assessment and plan, including medication, dietary, and home safety recommendations and referrals. These were reviewed, documented on a health literacy-friendly after-visit template, and confirmed with teach-back. Following each visit, we sent a comprehensive note to all of the patient's healthcare providers. Two weeks postvisit, we called to review the progress and identify the additional concerns. Patients and caregivers were provided with contact information for the HVP team for interim needs and questions.

Study assessments

We evaluated feasibility based on retention in the HVP, defined by the number of eligible patients enrolled and completing 4 visits. We assessed patient and caregiver satisfaction at visit 4 using the Client Satisfaction Inventory-Short Form (CSI-SF), scored 0–100, where 100 is perfect.¹⁸

To evaluate disease progression, we documented the UPDRS subjective and objective scores and Hoehn and Yahr (HY) stage at each visit.¹⁹ At visits 1 and 4, we administered 8 QoL domains from the Neuro-QoL item banks deemed to be of particular importance in advanced PD, namely *Stigma*, *Fatigue*, *Depression*, *Anxiety*, *Emotional and Behavioral Dyscontrol*, *Positive Affect and Well-being*, *Ability to Participate in Social Roles and Activities*, and *Satisfaction with Social Roles and Activities*.²⁰ Compared to PD-specific assessments in which a ceiling effect was anticipated, Neuro-QoL has been validated for use in PD populations,

demonstrates responsiveness to change, and includes more questions and a broader scoring range pertinent to advanced PD.²¹ We did not include motor-focused domains due to anticipated ceiling effects. Each queried domain is reported as a T score with a mean of 50 and standard deviation of 10. Lower scores indicate less of the quantity measured.

As exploratory outcomes, we measured caregiver burden using the Multidimensional Caregiver Strain Index (MCSI) at visits 1 and 4.²² The MCSI is scored from 0 to 72; 20–29 indicates moderate strain and ≥ 30 indicates severe strain. We evaluated cognitive change with MMSE at visits 1 and 4, and tracked acute healthcare utilization as the combined number of emergency room and hospital visits in the 12 months prior to vs 12 months enrolled in the HVP, as measured by patient and caregiver report at each of the 4 home visits, combined with review of the institutional electronic medical record.

Data collection and statistical analysis

We entered data into a HIPAA-secure electronic database, with data exported to STATA 14 for analysis.^{23,24} Demographic characteristics were analyzed for normality and reported as mean and standard deviation, or median and interquartile range, as appropriate. We calculated the changes in UPDRS motor and total scores, HY, Neuro-QoL domains, MMSE, and MCSI between visits 1 and 4 using paired *t* tests for normally distributed data and Wilcoxon signed-rank test for nonparametrically distributed data. We analyzed the change in utilization rate using generalized estimating equation modeling with a Poisson distribution for count data. For all analyses, we used a two-tailed α of 0.05.

Data availability

Anonymized data not published herein will be shared with qualified investigators pending request and approval by appropriate institutional review boards.

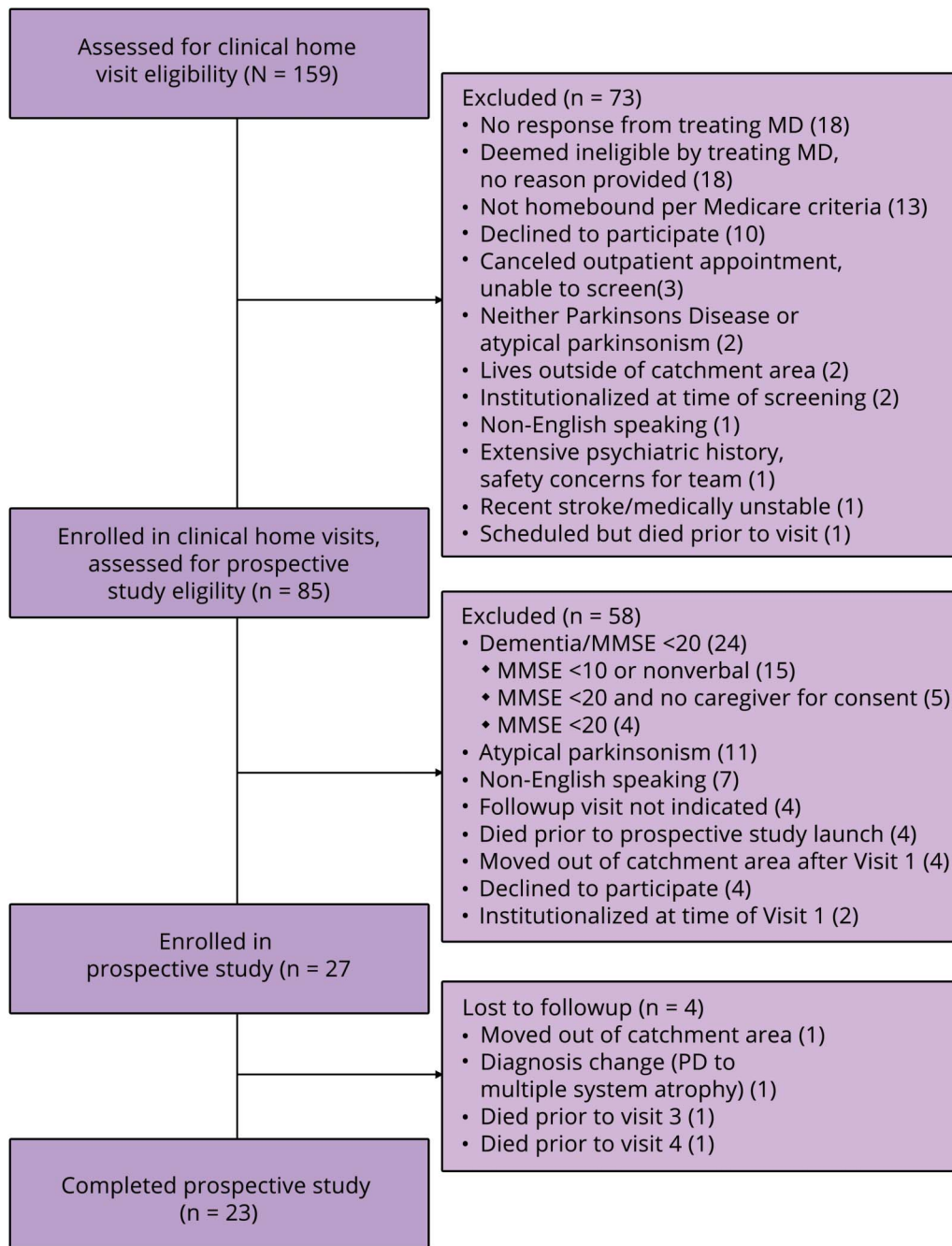
Results

Enrollment

We assessed 159 individuals for home visit eligibility; 65 were directly referred by their neurologist and 94 identified via chart review with subsequent neurologist review. Figure 2 shows participant flow. Among 73 people excluded, the main reasons were: no response from the neurologist to the screening query ($n = 18$); deemed ineligible by neurologist without reason provided ($n = 18$); not homebound per Medicare criteria ($n = 13$); and patient declined participation ($n = 10$).

Among the 85 individuals in the HVP, 58 were excluded from study participation. Eleven had atypical parkinsonism, 7 were non-English speakers, and 4 patients each: declined participation, planned to move following Visit 1, had no remaining needs after visit 1, or died prior to the prospective study launch. We excluded 24 individuals due to dementia. Although an MMSE ≤ 20 had been the a priori cutoff, 15 of the 24 had either an MMSE < 10 or were nonverbal, and 5 had an

Figure 2 Study flow of participants



MCSI = Multidimensional Caregiver Strain Index; PD = Parkinson disease.

MMSE below the cutoff, lacked capacity, and lacked a caregiver or proxy to consent. Four individuals were excluded solely for MMSE ≤ 20 .

Retention and satisfaction

We enrolled 27 patients and 23 completed all 4 visits (85% retention). All 23 opted to remain in the HVP post-study, and 18 completed the CSI-SF after visit 4 (78% response rate). The median satisfaction scores among patients and caregivers were 97

(interquartile range [IQR] 90–100) and 98 (n = 11, IQR 94–100), respectively.

Patient characteristics at baseline

Table 1 demonstrates the characteristics of patients at visit 1, with a mean age of 80.9 years (SD 7.8) and mean PD duration of 10.5 years (SD 5.9). Over 44% were HY 4 (severe disease but able to stand unassisted) and 11.1% were HY 5 (wheelchair- or bedbound). The mean UPDRS

Table 1 Baseline characteristics of home visit cohort

	N = 27
Age in y, mean (SD)	80.9 (7.8)
PD duration in y, mean (SD)	10.5 (5.9)
Male, %	44.4
Race, %	
Caucasian	81.5
African American	7.4
Education, %	
High school graduate or less	14.8
Some college or college graduate	48.1
Postcollege	37.0
Living situation at baseline, %	
Alone	40.7
Family/friends	59.3
Nursing home	3.7
Hoehn & Yahr stage, %	
2—bilateral disease without postural instability	3.7
3—bilateral disease with postural instability	40.7
4—severe disease, stands unassisted	44.4
5—wheelchair- or bed-bound unless assisted	11.1
UPDRS	
Motor subtotal, mean (SD)	37.5 (14.0)
Total score, mean (SD)	65.0 (20.0)
Neuro-QoL domain T scores ^a , mean (SD)	
Negative domains, >50 is worse	
Stigma ^b	53.1 (6.7)
Fatigue	51.4 (5.2)
Depression	51.6 (6.4)
Anxiety	55.0 (5.4)
Emotional and behavioral dyscontrol ^b	51.5 (7.6)
Positive domains, <50 is worse	
Positive affect and well-being ^b	47.4 (6.7)
Ability to participate in social roles and activities	42.6 (5.7)
Satisfaction with social roles and activities ^b	40.7 (4.6)
Hospitalization in past 12 months, %	55.6
Caregiver of any type completing MCSI, %	48.2

Abbreviations: MCSI = Multidimensional Caregiver Strain Index; PD = Parkinson disease; QoL = quality of life; UPDRS = Unified Parkinson's Disease Rating Scale. ^a Neuro-QoL: T scores are centered at mean of 50, SD 10. Higher scores indicate more of the concept being measured; e.g., mean 40.6 indicates nearly 1 SD below the mean for satisfaction with social roles and activities. ^b n = 26; one patient refused to complete multiple Neuro-QoL domains at Visit 1, withdrew after visit 1.

We identified a unique cohort typically lost to clinical care and research—homebound individuals with advanced PD—and followed them via interdisciplinary home visits.

motor score was 37.5 (SD 14.0), mean UPDRS total was 65.0 (SD 20.0), and mean MMSE was 26.8 (SD 2.5). Strikingly, 41% lived alone.

In all 8 domains of the Neuro-QoL, the cohort's mean was within 1 SD, or 10 points, of the standardized mean of 50. However, each domain was skewed toward poorer subjective performance (i.e., mean of 40.7 for satisfaction with social roles and activities, indicating nearly 1 SD below validation cohorts). Among 13 caregivers present for visit 1, the mean MCSI was 22.8 out of 72 (SD 16.5), indicating moderate strain.

Change in outcomes over 1 year

As shown in table 2, mean UPDRS mentation score worsened from 2.9 to 4.3 ($p = 0.02$), motor score from 34.4 to 42.5 ($p < 0.001$), and mean UPDRS total from 60.5 to 72.3 ($p < 0.001$). Despite disease progression, we found no significant changes in any QoL domains studied ($p = 0.19$ – 0.95).

Caregiver strain

Among the 10 caregivers completing the MCSI at visits 1 and 4, strain significantly increased from mild to moderate (17.1 vs 23.2, $p = 0.04$). Furthermore, among the 3 caregivers who withdrew from the study and as such, did not complete a visit 4 MCSI (2 due to death, one due to relocation), the median visit 1 MCSI was 42 (range 29–55), indicating that they were under severe strain, significantly skewing baseline results.

Healthcare utilization

Over 55% of patients had been hospitalized in the 12 months prior to enrolling in the HVP. Despite disease progression and isolation, healthcare utilization remained the same ($p = 0.15$) and none of the patients were institutionalized during the study.

Discussion

We identified a unique cohort typically lost to clinical care and research—homebound individuals with advanced PD—and followed them via interdisciplinary home visits. To our knowledge, this is one of the oldest and most disabled PD populations prospectively studied, with a mean age of nearly 81 years and UPDRS total of 65 at study entry. Home visits were met with high satisfaction and retention. The scores on NeuroQoL, however, indicate poor baseline QoL across all domains, but with disability progression over 1 year, denoted by clinically important differences on the UPDRS,²⁵ QoL did not significantly decline.

Table 2 Change in outcomes between visits 1 and 4 (n = 23)

	Mean	SD	95% confidence interval	p Value
UPDRS part 1—Mentation, behavior, mood				0.02
Visit 1	2.9	2.1	2.0–3.8	
Visit 4	4.3	2.6	3.2–5.5	
UPDRS part 2—Activities of daily living				0.17
Visit 1	19.5	8.1	16.0–23.0	
Visit 4	21.4	7.6	18.1–24.7	
UPDRS part 3—Motor examination				<0.01
Visit 1	34.4	12.2	29.2–39.7	
Visit 4	42.5	10.4	38.0–47.0	
UPDRS part 4—Complications of therapy				0.63
Visit 1	3.7	3.5	2.2–5.2	
Visit 4	4.0	3.6	2.5–5.6	
UPDRS total score				<0.01
Visit 1	60.5	17.0	53.2–67.9	
Visit 4	72.3	18.2	64.5–80.2	
HY stage				0.16
Visit 1	3.5	0.7	3.2–3.8	
Visit 4	3.7	0.8	3.3–4.0	
Mini mental state examination				0.43 ^a
Visit 1	26.9	2.6	25.8–28.0	
Visit 4	26.1	3.8	24.4–27.7	
MCSI^d				0.04
Visit 1	17.1	12.9	7.9–26.3	
Visit 4	23.2	16.7	11.3–35.1	
QoL/Neuro-QoL Domains: For each domain, range 0–100, mean = 50, SD = 10				
Negative domains, >50 is worse				
Stigma^b				0.34
Visit 1	53.2	6.8	50.1–56.3	
Visit 4	51.9	7.3	48.6–55.2	
Fatigue^c				0.39
Visit 1	52.0	4.4	50.0–53.9	
Visit 4	51.1	6.3	48.3–53.8	

Table 2 Change in outcomes between visits 1 and 4 (n = 23)
(continued)

	Mean	SD	95% confidence interval	p Value
Depression^c				0.95
Visit 1	51.4	6.4	48.5–54.2	
Visit 4	51.4	5.2	49.1–53.8	
Anxiety^c				0.93
Visit 1	54.6	5.8	52.1–57.2	
Visit 4	54.5	5.6	52.0–57.0	
Emotional and behavioral dyscontrol^b				0.31
Visit 1	51.6	7.9	48.0–55.2	
Visit 4	50.2	8.7	46.2–54.1	
Positive domains, <50 is worse				
Positive affect and well-being^b				0.19 ^a
Visit 1	48.4	6.3	45.5–51.3	
Visit 4	47.3	5.1	45.0–49.6	
Ability to participate in social roles and activities^c				0.55
Visit 1	43.1	5.5	40.6–45.5	
Visit 4	43.9	5.9	41.2–46.5	
Satisfaction with social roles and activities^b				0.29
Visit 1	41.5	4.0	39.7–43.3	
Visit 4	42.2	3.5	40.6–43.8	

Abbreviations: HY = Hoehn and Yahr; MCSI = Multidimensional Caregiver Strain Index; QoL = quality of life; UPDRS = Unified Parkinson's Disease Rating Scale.
UPDRS Total Score: 55 items, including motor items above, ranging from 0 = no disability, to 199 = total disability. HY Stage: Range 0 = no signs of disease, to 5 = wheelchair- or bedbound unless aided. Mini Mental State Examination: Range 0–30, where 30 = perfect. MCSI: Range 0–72, where 20–29 = moderate strain, >30 = severe strain.
P values based on paired t tests unless otherwise indicated; α = 0.05.
^a Nonparametrically distributed data, p value calculated using Wilcoxon signed-rank test. Bolded values indicate statistical significance.
^b n = 21.
^c n = 22.
^d n = 10 caregiver completing MCSI at both visits 1 & 4.

Our findings are noteworthy for 2 reasons: first, the progression in such an advanced PD population has not previously been reported, as these patients are typically lost to follow-up. A recent, cross-sectional study of 76 German patients with advanced PD (mean HY 4.0, SD 0.7, range 3–5) using the newer Movement Disorder Society (MDS)-UPDRS scale reported a mean MDS-UPDRS part 2 score of 31.4, and part 3 motor score of 60.8 in their population.³ Converting our patients' UPDRS to MDS-UPDRS scores based on published formulas

to facilitate comparison,²⁶ our population's mean MDS-UPDRS part 2 score increased from 24 to 25 across visits, and MDS-UPDRS part 3 score increased from 43 to 53, suggesting our populations were roughly comparable. In that population, baseline QoL was extremely poor; however, no longitudinal data were provided. Second, the observed decline in function would be predicted to accompany a proportionate decline in QoL on various PD-specific and general QoL assessments, as the latter is closely and linearly correlated with impairments in activities of daily living and mobility, as measured by the UPDRS and MDS-UPDRS parts 2 and 3.^{3,4,27} In an observational, longitudinal study of a heterogeneous population including advanced PD and atypical parkinsonism, Higginson et al.²⁸ demonstrated attrition of 36% and significant worsening of QoL and symptom burden over 1 year. However, differences in QoL assessments and the lack of UPDRS or MDS-UPDRS scores in that noninterventional study limit direct comparison with our population. Whether or not the decline the UK investigators and our team observed is the natural course of the disease or has been altered by observation—in the former case—or intervention—in the latter—requires future controlled studies. If either are true, our results may be biased toward the null, and progression in patients truly estranged from care may be worse.

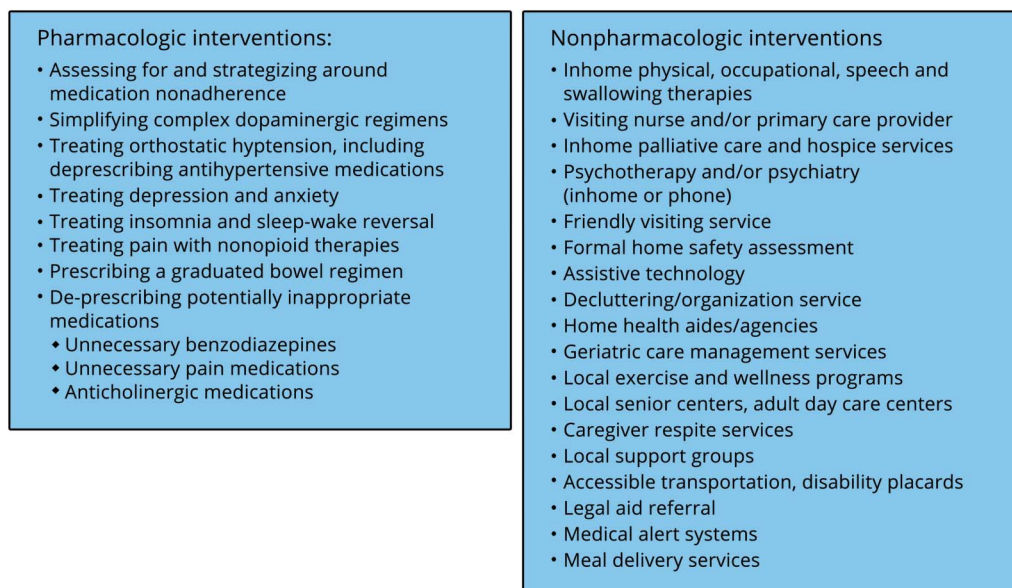
Prior home visit studies in PD have varied in implementation, population, and outcomes. A 6-month intervention in the UK involving 2 home visits from a nurse practitioner yielded referral provisions without change in function.²⁹ Three additional nurse- or physician-only interventions were limited by minimal description of the study population, intervention, or outcomes.^{11,30,31} Through the HVP described here, we demonstrate the feasibility of recruiting, describing, and

In-person, comprehensive medication reconciliation allowed our team to identify contraindications, interactions, and opportunities for improving adherence.

delivering multifaceted expertise to this underrepresented population. Furthermore, the stabilization of QoL in contrast to functional decline highlights a possible window of opportunity for impactful care despite advanced disease.

In addition to the proven benefits of neurologic and interdisciplinary care,^{10,32} we hypothesize that stabilization of QoL may be due to several features of this model. First, in-person, comprehensive medication reconciliation allowed our team to identify contraindications, interactions, and opportunities for improving adherence. For example, numerous patients reported frequent falls or lightheadedness, with objective orthostatic hypotension. Yet many were prescribed multi-antihypertensive regimens, possibly because their homebound status decreased contact with other physicians. Through identification of potentially inappropriate medications, regimens can be simplified, symptoms ameliorated, and adherence improved.^{33,34} Second, we employed common, practical interventions shown in figure 3, including frequent referrals to in-home therapies and community services, to

Figure 3 Common interventions used in the home visit program



proactively address issues before crises arose. In our retrospective analysis of the first 272 HVP visits, referrals were made at 92% of visits.¹² Third, our team focused on patient-centered, health literacy-friendly³⁵ counseling and resources. Despite progressive disability, the practical, palliative interventions may have buoyed patients' abilities to participate in and derive satisfaction from their social roles and activities, and likely contributed to satisfaction, retention, and QoL.

As the first iteration of this model, we recognize many limitations. This was intended as a *first-pass, proof-of-concept* model, with numerous resources and all team members attending each visit. We presupposed that *if* this population proved reachable by and amenable to such visits, and if the model demonstrated potential benefit, subsequent iterations would be honed for efficiency and cost-effectiveness. Second, this pilot study was small, lacked a control group, and was underpowered to detect significant changes in utilization and caregiver strain. A recent PD mortality study of over 17,000 patients used a 6 months timeframe, during which significant differences in mortality, utilization, and caregiver strain were detected.³⁶ Yet their survival curves support our concern that follow-up beyond 1 year may be biased by attrition and comorbidities, substantiating our 12-month duration. While the NeuroQoL queries multiple domains and has been used in PD and other advanced movement disorders,³⁷ it is both newer and not PD-specific, substantial drawbacks that limit comparisons with other interventions.

Whereas it might be assumed that community-dwelling individuals with PD have either minimal cognitive impairment *or* a caregiver, this was not always the case. By excluding individuals with significant cognitive impairment from this prospective study, we missed some of the most vulnerable, advanced patients otherwise enrolled in our HVP, limiting generalizability. We justified this trade-off as we sought to ensure that all participants had the capacity to consent, particularly those without proxy decision makers (41%). Furthermore, of 85 individuals assessed for study eligibility, only 5% were excluded due to MMSE ≤ 20 who might otherwise have been included.

The geographic location of New York City limits the generalizability of our findings given regional differences in the availability of movement disorders specialists, in-home therapies, services, and transportation. Finally, the absence of time and billing pressure cannot be discounted, and we lack detailed cost data on healthcare utilization and HVP team effort in this pilot. We are addressing all of the above with the next iteration of this model, with matched controls, validated and PD-specific patient- and caregiver-reported outcomes, and detailed utilization and team effort data, in a new cohort outside of New York *without* cognitive exclusion criteria. These iterations include strategically deployed telemedicine allowing the neurologist to join remotely. Additionally, we are piloting interventions to mitigate caregiver strain.

Despite the limitations, our results illuminate the feasibility of reaching these individuals, their satisfaction with the HVP, and the severity of symptoms, QoL, and level of unmet need

of homebound patients with advanced PD. By providing comprehensive expert care, we may intervene on the mean 12-point annual functional decline and stabilize the decline in QoL that otherwise have been a foregone conclusion. Current and future studies are necessary to create an efficient, patient-centered model primed for broader implementation that can improve access to and quality of care for this population. Consequently, such a model may facilitate research beyond the outpatient setting, allowing for enhanced retention and better representation of the PD spectrum. The onus is on healthcare and research teams to acknowledge, account for, and actively seek out this population.

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Disclosure

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TAKE-HOME POINTS

- Individuals with advanced PD are at risk of becoming homebound and losing access to neurologic care.
- Retention, patient satisfaction, and caregiver satisfaction were high in a pilot interdisciplinary HVP for people with advanced PD.
- In homebound patients with advanced PD, QoL did not parallel the downward trajectory of disability over 1 year.

Publication history

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Appendix Authors

Name	Location	Contribution
Jori Fleisher, MD MSCE	Rush University Medical Center, Chicago, IL	Conceptualization and design of study; acquisition of data; analysis and interpretation of data; drafting and revising the manuscript for intellectual content
Meghan Sweeney, LCSW	Kaiser Permanente, Lafayette, CO	Conceptualization and design of study; acquisition of patients and data; revising the manuscript for intellectual content
Sarah Oyler, RN	Intermountain Medical Center, Murray, UT	Acquisition of data; analysis and interpretation of data; preparation of manuscript
Talia Meisel	SUNY Downstate Medical Center College of Medicine, Brooklyn, NY	Acquisition of data; analysis and interpretation of data; revising the manuscript for intellectual content
Naomi Friede	Yale College of Nursing, Orange, CT	Analysis and interpretation of data; revising the manuscript for intellectual content
Alessandro Di Rocco, MD	Northwell Health, Long Island, NY	Conceptualization and design of study; acquisition of patients; revising the manuscript for intellectual content
Joshua Chodosh	New York University School of Medicine, New York, NY	Conceptualization and design of study; analysis and interpretation of data; revising the manuscript for intellectual content

References

1. Hely MA, Reid WG, Adena MA, Halliday GM, Morris JG. The Sydney multicenter study of Parkinson's disease: the inevitability of dementia at 20 years. *Mov Disord* 2008;23:837–844.
2. Miyasaki JM, Long J, Mancini D, et al. Palliative care for advanced Parkinson disease: an interdisciplinary clinic and new scale, the ESAS-PD. *Parkinsonism Relat Disord* 2012;18(suppl 3):S6–S9.
3. Klietz M, Tulke A, Müschen LH, et al. Impaired quality of life and need for palliative care in a German cohort of advanced Parkinson's disease patients. *Front Neurol* 2018; 9:120.
4. Martinez-Martin P, Rodriguez-Blazquez C, Forjaz MJ, et al. Relationship between the MDS-UPDRS domains and the health-related quality of life of Parkinson's disease patients. *Eur J Neurol* 2014;21:519–524.
5. Oguh O, Kwasny M, Carter J, Stell B, Simuni T. Caregiver strain in Parkinson's disease: National Parkinson Foundation Quality Initiative study. *Park Relat Disord* 2013;19:975–979.
6. Kaltenboeck A, Johnson SJ, Davis MR, et al. Direct costs and survival of medicare beneficiaries with early and advanced Parkinson's disease. *Park Relat Disord* 2012;18: 321–326.
7. Hassan A, Wu SS, Schmidt P, et al. High rates and the risk factors for emergency room visits and hospitalization in Parkinson's disease. *Parkinsonism Relat Disord* 2013;19: 949–954.
8. Edes T, Kinosian B, Vuckovic NH, Nichols LO, Becker MM, Hossain M. Better access, quality, and cost for clinically complex veterans with home-based primary care. *J Am Geriatr Soc* 2014;62:1954–1961.
9. Kono A, Izumi K, Yoshiyuki N, Kanaya Y, Rubenstein LZ. Effects of an updated preventive home visit program based on a systematic structured assessment of care needs for ambulatory frail older adults in Japan: a randomized controlled trial. *J Gerontol A Biol Sci Med Sci* 2016;71:1631–1637.
10. Boulton C, Green AF, Boulton LB, Pacala JT, Snyder C, Leff B. Successful models of comprehensive care for older adults with chronic conditions: evidence for the Institute of Medicine's "retooling for an aging America" report. *J Am Geriatr Soc* 2009; 57:2328–2337.
11. Vickers LF, O'Neill CM. An interdisciplinary home healthcare program for patients with Parkinson's disease. *Rehabil Nurs* 1998;23:286–289, 299.
12. Fleisher J, Barbosa W, Sweeney MM, et al. Interdisciplinary home visits for individuals with advanced Parkinson's disease and related disorders. *J Am Geriatr Soc* 2018, 66: 1226–1232.
13. Hughes AJ, Daniel SE, Kilford L, Lees AJ. Accuracy of clinical diagnosis of idiopathic Parkinson's disease: a clinico-pathological study of 100 cases. *J Neurol Neurosurg Psychiatry* 1992;55:181–184.
14. Pub 100-02 medicare benefit policy: clarification of the confined to the home definition in chapter 15, covered medical and other health services, of the medicare benefit policy manual. 2014. Available at: [cms.gov/Regulations-and-Guidance/Guidance/Transmittals/downloads/R192BP.pdf](https://www.cms.gov/Regulations-and-Guidance/Guidance/Transmittals/downloads/R192BP.pdf). Accessed August 15, 2015.
15. Folstein MF, Folstein SE, McHugh PR. "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* 1975;12: 189–198.
16. Fahn S, Elton RJ, Committee UD. The unified Parkinson's disease rating scale. In: Fahn S, Marsden CD, Calne DB, Goldstein M, editors. *Recent Developments in Parkinson's Disease*. vol 2. Florham Park, NJ: Macmillan Healthcare Information; 1987:153–163; 293–304.
17. Francois C, Biaggioni I, Shiao C, et al. Fall-related healthcare use and costs in neurogenic orthostatic hypotension with Parkinson's disease. *J Med Econ* 2017;20: 525–532.
18. McMurtry SL, Hudson WW. The client satisfaction inventory: results of an initial validation study. *Res Soc Work Pract* 2000;10:644–663.
19. Goetz CG, Poewe W, Rascol O, et al. Movement disorder society task force report on the Hoehn and Yahr staging scale: status and recommendations. *Mov Disord* 2004; 19:1020–1028.
20. Cella D, Lai J-S, Nowinski CJ, et al. Neuro-QOL: brief measures of health-related quality of life for clinical research in neurology. *Neurology* 2012;78:1860–1867.
21. Nowinski CJ, Siderowf A, Simuni T, Wortman C, Moy C, Cella D. Neuro-QoL health-related quality of life measurement system: validation in Parkinson's disease. *Mov Disord* 2016;31:725–733.
22. Stull DE. The multidimensional caregiver strain index (MCSI): its measurement and structure. *J Clin Geropsychology* 1996;2:175–196.
23. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inf* 2009;42:377–381. StataCorp. Stata Statistical Software: Release 14. College Station, TX: StataCorp LP; 2015.
24. Shulman LM, Gruber-Baldini AL, Anderson KE, Fishman PS, Reich SG, Weiner WJ. The clinically important difference on the unified Parkinson's disease rating scale. *Arch Neurol* 2010;67:64–70.
25. Goetz CG, Stebbins GT, Tilley BC. Calibration of unified Parkinson's disease rating scale scores to Movement Disorder Society-unified Parkinson's disease rating scale scores. *Mov Disord* 2012;27:1239–1242.
26. Rahman S, Griffin HJ, Quinn NP, Jahanshahi M. Quality of life in Parkinson's disease: the relative importance of the symptoms. *Mov Disord* 2008;23:1428–1434.
27. Higginson JJ, Gao W, Saleem TZ, et al. Symptoms and quality of life in late stage Parkinson syndromes: a longitudinal community study of predictive factors. *PLoS One* 2012;7:e46327.
28. Jahanshahi M, Brown RG, Whitehouse C, Quinn N, Marsden CD. Contact with a nurse practitioner: a short-term evaluation study in Parkinson's disease and dystonia. *Behav Neurol* 1994;7:189–196.
29. Hurwitz A. Home visiting by nursing students to patients with Parkinson's disease. *J Neurosci Nurs* 1986;18:344–348.

31. Hack N, Akbar U, Monari EH, et al. Person-centered care in the home setting for Parkinson's disease: operation house call quality of care pilot study. *Parkinsons Dis* 2015;2015:639494.
32. Willis AW, Schootman M, Evanoff BA, Perlmutter JS, Racette BA. Neurologist care in Parkinson disease: a utilization, outcomes, and survival study. *Neurology* 2011;77:851–857.
33. Lavan AH, Gallagher P, Parsons C, O'Mahony D. STOPPFrail (Screening Tool of Older Persons Prescriptions in Frail adults with limited life expectancy): consensus validation. *Age Ageing* 2017;46:600–607.
34. Guiding principles for the care of older adults with multimorbidity: an approach for clinicians. Guiding principles for the care of older adults with multimorbidity: an approach for clinicians: American Geriatrics Society Expert Panel on the Care of Older Adults with Multimorbidity. *J Am Geriatr Soc* 2012;60:E1–E25.
35. Fleisher JE, Shah K, Fitts W, Dahodwala N. Associations and implications of low health literacy in Parkinson's disease. *Mov Disord Clin Pract* 2016;3:250–256.
36. Hirdes JP, Poss JW, Mitchell L, Korngut L, Heckman G. Use of the interRAI CHES scale to predict mortality among persons with neurological conditions in three care settings. *PLoS One* 2014;9:e99066.
37. Carlozzi NE, Victorson D, Sung V, et al. Hd-PRO-TRIAD™ validation: a patient-reported instrument for the symptom triad of Huntington's disease. *Tremor Hyperkinetic Mov* 2014;4:223.



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