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Interdisciplinary Home Visits for Individuals with Advanced Parkinson's Disease and Related Disorders

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Abstract

Parkinson's Disease (PD) is a complex, multi-symptom, neurodegenerative disease affecting primarily older adults. With progression, many individuals become homebound and estranged from coordinated, expert care, resulting in excess morbidity, mortality, and healthcare expenditures in acute care settings and institutions. Home visit care models have achieved the triple aim of improving individual and population health while reducing costs in many frail, community-dwelling geriatric cohorts. This study details a novel, interdisciplinary home visit program specifically designed for individuals with PD and related disorders and their family caregivers, built upon best practice principles in the care of multimorbid geriatric populations. At each quarterly home visit, a movement disorders-trained neurologist, social worker, and nurse work in parallel with the patient and caregiver to complete a history, physical, detailed medication reconciliation, psychosocial needs assessment, and home safety assessment. A comprehensive, patient-centered plan is agreed upon, referrals to community resources are made, standardized documentation is shared, and follow-up communication is instituted. In the first two years, 272 visits were conducted with 85 individuals who represent one of the oldest and most disabled PD populations yet reported. Satisfaction with and retention in the program were high. This study represents the first translation of the success of interdisciplinary and home-based geriatric care models to a neurologic population. Preliminary evidence supports the need for such programs in a vulnerable population. Future studies will prospectively assess patient-centered outcomes, the impact of using telemedicine on sustainability, and cost effectiveness.

Keywords

Home visits; health services; Parkinson's Disease; interdisciplinary; neurology

INTRODUCTION

Parkinson's Disease (PD) is a debilitating, progressive, and costly neurodegenerative condition affecting over one million people annually in the US.¹ As PD progresses, individuals become homebound, losing previous access to care.^{2,3} Symptoms increase in number and severity, quality of life declines,⁴ and caregiver strain increases.^{5,6} Simultaneously, there is a surge in emergency room (ER) visits, hospitalizations, and

institutionalization,^{7,8} each of which confer excess morbidity and mortality to individuals with PD.^{9–11} PD patients are commonly hospitalized for falls and fractures, aspiration pneumonia, infections, and mental status changes.⁹ Neurologist-treated PD patients are also less likely to sustain and be hospitalized for many of these conditions than patients not connected to neurologic care.^{12–14}

Home-based programs provide high quality care while reducing healthcare costs in complex elderly populations.^{13–15} Most successful models are interdisciplinary, incorporating nursing and social work care coordination.^{12,14,15} Home visit programs reduce symptoms and healthcare utilization, and increase the likelihood of dying at home concordant with patient wishes.^{16–19} Moreover, numerous modalities of physical, occupational, and speech therapies—which can be delivered in the home—improve independence in activities of daily living and minimize caregiver burden.^{20–23} Such therapies have never been investigated in advanced PD patients. To our knowledge, only two home visit programs for PD have been described.^{24,25} One did not describe the patients served, outcomes achieved, or cost effectiveness, while the other included only seven individuals.²⁵

We sought to translate what is known about innovative geriatric care models and guiding principles for high-quality management of elderly, multimorbid adults^{26,27}, into an interdisciplinary home visit program to provide continuity of expert neurologic care to homebound individuals with advanced PD and related disorders.

METHODS

Setting

The Edmond J. Safra Interdisciplinary Home Visit Program for Advanced Parkinson's Disease (HVP) was launched in 2014 at the Marlene and Paolo Fresco Institute for Parkinson's and Movement Disorders at New York University (NYU). The Fresco Institute is recognized as a Parkinson Foundation Center of Excellence offering comprehensive care, outreach, education, and research on PD and related disorders.

The aims of the HVP are to 1) identify homebound²⁸ patients at risk of loss to follow-up and 2) deliver comprehensive care to facilitate aging-in-place. The specific objectives have been fourfold: 1) to increase access to care by extending team-based medical treatment, psychosocial support, and health education; 2) to enhance safety; 3) to reduce caregiver strain; and 4) to empower patients and families to achieve the best possible quality of life. The HVP was made possible through a grant from the Edmond J. Safra Philanthropic Foundation, with subsequent support from the Parkinson Foundation.

Team Members and Structure of the HVP

The HVP team consists of one movement disorders neurologist, one movement disorders fellow, one nurse, and one social worker/program coordinator, each with training in movement disorders and geriatric experience. Potential participants are referred by NYU neurologists or identified by chart review. We identified individuals seen at least once at the Fresco Institute with a diagnosis of PD, PD Dementia, Dementia with Lewy Bodies, or an atypical parkinsonism, living in the five boroughs of New York City—a catchment area of

8.5 million²⁹—and meeting Medicare criteria for homebound status as potential participants. Participation required at least one high-risk condition for hospitalization or institutionalization in PD (see supplemental information). While this pilot was intended to be limited to NYU patients, program reach was increased by word of mouth, participant support group discussions, website and electronic newsletter postings, and referrals from patient foundations. All external referrals required at least one evaluation by a movement disorders neurologist at the Fresco Institute for diagnostic confirmation.

Home Visit Activities

As shown in Figure 1, the program coordinator confirmed eligibility and phoned the patient or caregiver to explain the HVP, gauge interest, and schedule the initial visit. The team sent a welcome letter, confirming the visit, accompanied by the Unified Parkinson's Disease Rating Scale (UPDRS) for the patient's subjective rating of his motor and non-motor symptoms, and activities of daily living.³⁰

At the initial visit, the nurse, social worker, and neurologist traveled to the patient's home. Team member tasks are depicted in Figure 1. After introductions, the team reiterated the objectives and HVP structure. The social worker reviewed the patient's demographics, living situation, in-home services, hospital and ER visits in the past year, and conducted a psychosocial needs assessment of the patient and caregiver(s), if present. The social worker determined whether the patient had an accessible primary care provider (PCP), as the aim of the HVP neurologist was to complement, rather than supplant, the role of the PCP. The social worker discussed goals of care, identifying and clarifying advance directives to ensure all parties understood the patient's wishes. If an informal, unpaid caregiver was present, the social worker administered the Multidimensional Caregiver Strain Index.³¹

While the social worker was speaking with the caregiver, the nurse gathered vital signs including orthostatic blood pressure due to its prevalence and associated falls.³² With the neurologist present, the nurse reviewed the UPDRS I & II, specifically, tremor, falls, freezing of gait, dysphagia, and ability to dress, toilet, and ambulate independently. The nurse completed a detailed medication reconciliation, reviewing the patient's strategy for managing multiple medications (e.g., pillbox, timers) and each prescription, over-the-counter medication, or supplement, comparing the actual regimen to that listed at the most recent outpatient encounter. The nurse then conducted a home safety assessment to identify potential fall risks and safety hazards, with particular attention to bathrooms, kitchen safety, clutter, and uneven floors.

Simultaneously, the neurologist reviewed new symptoms or concerns, including unintentional weight loss, constipation, and other advanced PD symptoms not represented on the UPDRS. The neurologist inquired about benefits, side effects, and timing of the therapeutic regimen. Next, she conducted a thorough physical examination, including the UPDRS motor scale.

Following completion of respective tasks, the team regrouped in the patient's presence to formulate a comprehensive assessment and plan, including medication changes, dietary recommendations, fall precautions, home safety recommendations, and referral provision.

Referrals ranged from in-home physical, occupational, speech and swallowing therapies, to supportive counseling and friendly visitor services, and home-based primary care referrals for qualifying patients in an eligible area. For patients without access to other care, the neurologist managed pressing medical issues based on team expertise. In-home assessment included identifying and managing life-threatening medical and psychosocial issues with activation of emergency medical services.

All recommendations were negotiated with the patient, written in plain language, verbally reviewed with teach-back, and remaining concerns were solicited. Patients were given a copy of the recommendations, updated medication list, details about referrals being made, and team contact information. Patients were provided and educated about a Parkinson Foundation Aware in Care Kit³³ designed to mitigate excess morbidity and mortality in the inpatient setting through patient empowerment and provider education.

Following each visit, the HVP neurologist reviewed all recommendations with the referring neurologist to establish consensus and ordered prescriptions and referrals. Team members documented their portions of the visit using program-specific electronic medical record (EMR) templates. The neurologist created one comprehensive, interdisciplinary note shared with all of the patient's healthcare providers, including any identified PCP. Two weeks after each visit, the nurse or social worker conducted a follow-up phone call with the patient or caregiver, addressing any remaining needs. Finally, the entire team convened weekly to review recent patients, identify outstanding issues, and strategize about process improvement.

Subsequent visits were scheduled every four months with reminders at one-month and 48 hours prior to visit. At each visit, the team obtained the number of hospital and ER visits since the prior home visit, and utilization within our institution was confirmed by chart review. Some HVP patients continued to see their referring specialist in the outpatient clinic, as many had longstanding relationships. For those maintaining in-clinic visits, home and clinic visits were offset by two months to avoid service duplication.

After four visits, patients and caregivers were asked to complete and mail back the Client Satisfaction Inventory-Short Form (CSI-SF) after the HVP team left.³⁴ Participants were instructed to provide honest, anonymous feedback regarding satisfaction with the HVP. Patients could leave the HVP at any time, or be discontinued if care needs were met, if they no longer met homebound criteria, or if the patient moved out of the catchment area.

Data Collection and Analysis

We conducted a retrospective chart review via the institutional EMR for all HVP visits performed through July 2016. Data was collected and managed using REDCap secure, web-based tools hosted at NYU,³⁵ and exported to STATA 14 for analyses.³⁶ The NYU Institutional Review Board approved this study.

At Visit 1, we collected demographic and PD-relevant variables, including diagnosis and disease duration. At each visit, we assessed Hoehn and Yahr disease stage, where 1 = mild, unilateral symptoms; 2 = mild, bilateral symptoms; 3 = bilateral symptoms with balance

impairment; 4 = severe symptoms but able to ambulate; and 5 = wheelchair- or bedbound state.³⁷ To capture program effort, feasibility, and quality, we analyzed the number of patients reached, visit numbers and duration, time spent traveling to and from visits, and data on protocol adherence and therapeutic recommendations at each visit. We administered the CSI-SF to participants completing 4 visits, beginning in 2015. We collected data on the duration of follow-up time in the HVP in person-months, and the percentage of patients reporting any ER and hospital visits in the 12 months preceding HVP entry and during follow-up.

RESULTS

Patient Characteristics

Between February 2014–July 2016, the HVP team conducted 272 visits with 85 unique patients. The baseline characteristics of the cohort are shown in Table 1. The median age of patients was 79.6 years (interquartile range (IQR) 72.5–84.8), and 51.8% were female. Individuals with PD comprised 78.8% of the cohort. The median Hoehn & Yahr stage at Visit 1 was 4.0 (IQR 3–5), with 37.7% of individuals at stage 4 and 31.8% at stage 5. Median disease duration was 9 years (IQR 5.7–15.6). The majority of patients identified at least one individual assisting with their care, however 12.9% had no caregiver.

Feasibility

Patients received a median of 3 visits (range 1–7) during the study period, with 28% seen only once. At the time of data censoring, 26 patients had withdrawn from the program: 19 expired; 2 moved out of the area, 1 left the NYU practice, and 4 were deemed well enough by the HVP team to no longer require visits. Of those within the catchment area and with continued need, 58 of 59 opted to continue visits (98.3% acceptability). Among those with at least 2 home visits, 70.5% continued to visit their outpatient neurologist at least once (median of 1 visit, IQR 0–4), however 63.9% also had at least one missed or cancelled appointment (median of 1 visit, IQR 0–3).

Median travel time for visits was 30 minutes (IQR 20–40 minutes), and 70 minutes (median) for visit duration (IQR 60–90). A completed visit was defined as one in which the following were documented: vital signs, history, examination including UPDRS, medication reconciliation, psychosocial evaluation of the patient, and interdisciplinary care plan. As defined, 83.5% of all visits were completed. Home safety assessments were completed at 98.2% of all visits, and advance directives were addressed at least once with 89.4% of patients (62.4% of all first visits).

Medication changes were recommended at 41.9% of all visits. Non-pharmacologic treatment changes were recommended at 45.2%, including specific recommendations for dietary or behavioral changes, fall precautions, or assistive devices. Moreover, therapy or service referrals (Table 2) were made at 92.7% of all visits.

Satisfaction

Almost half (48.8%) of patients completed the CSI-SF as did 31.4% of caregivers. The seven-item scale is scored from 0–100, with 100 being perfect satisfaction. Among patients, the median satisfaction score was 96.3 (IQR 88.9–100), and among caregivers, the median score was 98.1 (IQR 94.4–100).

Utilization

In Table 3, we demonstrate that prior to their first home visit, 41.2% and 31.8% of subjects reported at least one hospital or ER visit, respectively. Among the 61 subjects for whom at least 2 home visits were conducted, 36.1% and 29.5% reported at least one hospital or ER visit, respectively. Combining both visit types, this represents a significant decrease in utilization (Pearson X^2 : 0.04).

DISCUSSION

For the first two years of our interdisciplinary HVP for PD and related disorders, in over 270 visits, our team provided coordinated, in-home care to 85 individuals, the majority of whom had severe disease or were bed- or wheelchair-bound at program entry. Thirteen percent lacked any form of caregiver, decreasing access to outpatient appointments. Thus, we believe we served a unique population whose advanced disease typically causes estrangement from care.³⁸ Of those eligible to continue participation, only one chose to discontinue further visits and satisfaction was extremely high, highlighting HVP feasibility and subjective value.

High retention and satisfaction may have been due to perceived lack of healthcare alternatives. However, we believe that the interdisciplinary structure, well-defined workflows and communication protocols, and connection to community and in-home resources yielded a thorough, high quality experience.²⁷ This included more effective medication reconciliation than likely possible during an office visit, with an emphasis on treatment feasibility, reduction of polypharmacy, and detection of medication errors. We detected 41.9% of all visits with at least one medication change; to our knowledge, the rate of outpatient PD medication changes has not otherwise been reported. We suspect that our rates may be higher than in most outpatient settings due to availability of time for comprehensive review and screening for inappropriate medications, non-adherence, and previously untreated non-motor symptoms and comorbidities. Supporting this hypothesis are data from a single-center, pharmacist-led study of a structured medication review and intervention for individuals with PD, in which 95 medication intervention opportunities were identified among 90 patients.³⁹

Our psychosocial evaluation focused on unmet needs and corresponding solutions. Furthermore, in-home assessments illuminated potential undetected comorbidities and safety hazards to address proactively *before* falls, injuries, ER visits, or hospitalizations ensued. By fostering continuity of care through enhanced counseling and education, follow-up calls, and subsequent visits, fragmentation of care was diminished, likely reducing caregiver strain and resulting institutionalization for these high-risk patients.⁴⁰

Our comprehensive, interdisciplinary plan was grounded in attention to patient preferences, comorbidities, prognosis, and shared decision-making, with the provision of evidence-based recommendations when possible,²⁶ highlighted by the high percentage of patients (89.4%) with whom advance care planning was addressed at some point during their HVP tenure. The prevalence of such discussions in neurologic populations is generally unknown. One study in palliative-stage PD demonstrated many were unaware of whether they had an advance directive.³⁸ In a broader study of New York City's elderly population, only 32% of participants reported any advance care planning.⁴¹ More recently, for 2155 patients with stage IV cancer, oncologists documented goals of care discussions with only 27% despite a median of 6 visits.⁴² Identifying best practices for goals of care discussions in the PD population requires further study. Finally, we detected a small decrease in hospital and ER visits prior to and during HVP enrollment, suggesting a potential benefit to healthcare utilization in this high-cost population.

Limitations

Despite demonstrating the HVP as a feasible model of care, certain limitations challenge generalizability. New York City's resources helped minimize travel time and costs, both of which may be greater elsewhere. Similarly, non-urban areas may have a relative lack of general neurologists, movement disorders specialists, and community resources for homebound patients,^{43,44} suggesting a role for telemedicine to achieve expansion.^{44,45}

Our selection of outcome measures is another potential limitation. Selecting optimal measures is challenging, particularly in a neurodegenerative condition in which many symptoms inevitably worsen over time, and multimorbidity is common. Evaluation data were collected through chart review, and we lack data on fall rates, hospital days, or costs. In ongoing work, we are studying the UPDRS decline in these advanced patients, along with fall rates, hospital days, ER visits, percentage dying at home with hospice, and healthcare utilization costs. Also, our response rate to the satisfaction instrument was relatively low, which might reflect social desirability bias.

Finally, to be applicable for broader implementation and dissemination, data on sustainability and cost effectiveness will be necessary. As with many intensive programs in complex elderly populations, sustainability will be predicated on a reduction of high-cost utilization, such as ER visits, hospital days, and nursing home placement, which can only be addressed with a larger sample size, a longer time horizon, and comparator data.

Implications

With the increasing burden of chronic disease, the need for a sustainable home-based care model remains of utmost importance to address the growing needs of our aging population.⁴⁶ Programs like Independence at Home (IAH)⁴⁷ have successfully served elderly patients with chronic conditions besides PD and have highlighted the need to shift the paradigm of how we deliver quality, effective, patient-centered care to our most vulnerable populations.^{48–50} Despite the value of home-based care, and the estimated two to four million homebound individuals in the US, there is a shortage of primary care providers for these patients.^{51,52} Indeed, among our 85 patients, our team uncovered many reporting lack of

access to primary care, yet we were only successful in referring five individuals to home-based primary care due to long wait lists and limited catchment areas. In our view, this PD-focused HVP differs from a traditional home-based practice in the same way that an outpatient movement disorders center differs from a PCP's office; namely, the HVP's focus is the patient's neurologic condition. While our program was never intended to replace the critical primary care connection, our experience highlighted this significant unmet need.

The challenges of travel for specialty care access have raised interest in telemedicine for delivering care specifically for PD patients with difficulty reaching a trained specialist. In ongoing, NIH-funded work, we will be comparing the HVP model with a telemedicine component to usual care for patients with advanced PD.

Conclusion

By fostering continuity of expert, interdisciplinary care for advanced PD through a home visit model, we have demonstrated not only the ability to *reach* this vulnerable population, but to provide meaningful services and care to those most in need of them.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Impact Statement

We certify that this work is novel. The potential impact of this research on clinical care or health policy includes the following: expansion of care to vulnerable populations of geriatric patients with Parkinson's Disease and related disorders unable to access outpatient services, with the potential for expansion to other complex neurologic and non-neurologic conditions affecting older adults.

Figure 1. Interdisciplinary Home Visit Program structure, visit flow, and discipline-specific activities and responsibilities.

PD: Parkinson's Disease. SW: Social worker. RN: Registered nurse. MD: Movement disorders specialist. UPDRS: Unified Parkinson's Disease Rating Scale

Table 1

Characteristics of Participants (N = 85) in the Edmond J. Safra Interdisciplinary Home Visit Program (HVP) for Advanced Parkinson's Disease

Characteristic	Value
Age, median (IQR)	79.6 (72.5–84.8)
Female, n (%)	44 (51.8)
Race [/]	
White	73 (85.9)
Black	6 (7.1)
Asian	6 (7.1)
Hispanic	13 (15.3)
Diagnosis, n (%)	
Parkinson's Disease	67 (78.8)
Atypical Parkinsonism, not otherwise specified	6 (7.1)
Dementia with Lewy Bodies	4 (4.7)
Progressive Supranuclear Palsy	4 (4.7)
Multiple System Atrophy	2 (2.4)
Corticobasal Syndrome	1 (1.2)
Huntington's Disease	1 (1.2)
Caregiver Identity, n (%) [/]	
Spouse/Partner/Significant Other	41 (48.2)
Adult Child	20 (23.5)
Other Family Member	6 (7.1)
Friend/Neighbor	3 (3.5)
Part-time Home Health Aide	41 (48.2)
24 hr. Home Health Aide	18 (21.2)
Other	1 (1.2)
Hoehn & Yahr Stage, median	4.0
Hoehn & Yahr Stage distribution, n (%)	
2-Bilateral disease, balance normal	4 (4.7)
3-Mild-moderate disease, balance impaired	22 (25.9)
4-Severe disease, stands unassisted	32 (37.7)
5-Wheelchair or bedbound	27 (31.8)
Education, n (%)	
High School Diploma	7 (14.3)
Some College	4 (8.2)
College Graduate	21 (42.9)
Post-College	17 (34.7)

[/] values may summate >100% (patients may identify with multiple races/caregivers)

^a
n = 49 (cases of missing data: questions not answered)

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Table 2

Referrals Made Through Home Visit Program

Visits with referrals (%)	92.7
Type of Referral ^I (%)	
Physical Therapy	71.7
Occupational Therapy	61.2
Speech & language pathology/swallow therapy	43.6
Psychotherapy	43.6
Psychiatry	17.7
Formal home safety assessment/barrier-free design	25.9
Other	41.1

^I values may summate >100% (patients may have received multiple referrals at each visit)

Table 3

Acute Healthcare Utilization Before and During Home Visits

	12 Months Prior to HVP (n = 85)	During HVP* (n = 61 with 2 home visits)
Percentage of patients reporting any hospitalization	41.2%	36.1%
Percentage of patients reporting any ER visit	31.8%	29.5%

HVP: Home Visit Program; ER: emergency room

* Total OF 818.3 person-months of longitudinal follow-up, with a median of 14.1 person-months per patient (IQR 8.4–18.4)