



# Bridging the gap with interdisciplinary home visits for Parkinson's disease

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Approximately 2 million people in the US are homebound and frail with multiple medical conditions. This population is underserved with only 11.9% receiving primary care in their home (1). Yet the last several generations of physicians trained in the US may be completely unfamiliar with medical house calls. Up to the mid 1900's, it was common for the physician to travel to the patient. Over time changes in the availability of transportation, medical technology, and payment for medical services contributed to the concentration of medical care into office and hospital settings (2). By 1980 less than 1% of physician encounters were house calls and numbers continued to decline through the 1990's (3). In 1998, Medicare established new billing codes and increased reimbursement for home visits. Since that time the number of house calls has increased annually though the overall number remains very low. In 2011 a representative sample of physicians billing Medicare indicated that less than 5% of physicians did any home visits at all (4). It is possible or even likely that a physician could complete medical school, internship, and residency without ever experiencing a visit to a patient in their home.

In recent years there has been increased attention to expanding medical access to the home setting. The Medicare Independence at Home Demonstration began with 15 centers in 2012 and has been extended through 2020. This demonstration tests a service delivery model of primary care in the home setting, monitoring Medicare expenditures, patient outcomes, and patient and caregiver

satisfaction (5). Hospital systems incentivized to decrease readmissions are increasingly developing geriatric and post-discharge house calls programs. Home based primary care services reduce spending without any difference in quality, mortality, or average time to death (6,7).

People with Parkinson's disease represent a portion of the frail homebound population, and prevalence is expected to increase over time (8). Inherent to Parkinson's disease is increasing physical disability and a high likelihood of cognitive disability over time (9,10). The need for home based medical services with specific expertise in PD and related disorders is a natural extension of these factors. The number of neurologists seeking additional education or board certification in palliative medicine is increasing, and neurologists may be increasingly available to participate in home based palliative services.

In "*Interdisciplinary Palliative Care for People with Advanced Parkinson's Disease: A View from the Home*" Dr. Fleisher and her colleagues describe two models of interdisciplinary home visits for patients with advanced Parkinson's disease. The Edmond J. Safra Interdisciplinary Home Visit Program (HVP) which has been described in detail previously (11), served elderly patients with advanced Parkinson's disease who were homebound by Medicare criteria. A movement disorders specialist neurologist, nurse, and social worker conducted quarterly in person visits to patient's homes. They intervened by discovering medication errors, recommending medication changes, recommending

non-pharmacologic changes in diet or equipment, and connecting the patient with community and therapy resources through referrals. Both patients and caregivers were highly satisfied with the home visit program. This model occurred in the high-density urban setting of New York city and was funded by philanthropic support.

In the second iteration of the home visit program, Dr. Fleisher and her colleagues attempt to address limitations of scalability and financial feasibility. The Chicago-based model of Interdisciplinary Home Visits for Parkinson's Disease (IN-HOME PD) expands the service area to include urban, suburban, and rural areas within a 30 miles radius around Rush University. A nurse, social worker, and study coordinator attend the initial in person visit. Use of telemedicine allows the movement disorders specialist to participate via videoconference at all visits. In addition, the social worker participates via videoconference after the initial in person visit. As of the time of publication, 52 patient-caregiver dyads have completed their first visit with plans to enroll 65. Patients will have four visits over 1 year.

In addition to describing the logistics of the two home visit programs, Dr. Fleisher provides two case studies of specific patient experiences. In both of these cases, detailed attention to a holistic view of the patients' needs resulted in major improvements in function and quality of life. Both cases reflect an intimate understanding of the home situation by the care team and it appears that this understanding is the key to the interventions. In addition, while some of the problems discovered in the home have simple solutions (removing oxygen tubing as a tripping hazard for example), they are problems that likely would not come to light outside of the home in the office setting.

This work is critically important. It offers a glimpse into a phase of Parkinson's disease that is largely ignored by the current health care system of the United States. As people develop symptoms and are diagnosed with Parkinson's disease, they are generally mobile enough to visit their primary care doctors and neurologists in the office setting. Over time the burden and disability associated with the disease increase, and what was once a relative inconvenience within a day (some time off from work to visit the physician) becomes an all-consuming task for both the patient and the caregiver. The amount of effort to get to the office increases exponentially and the benefits of being in that office are less and less apparent. It is little wonder that people can lose connection to their health care providers and become isolated at home. People experience a gap in care during which they may suffer unnecessary complications. The

strain on patients and caregivers comes to light only when their distress results in costly emergency room visits or hospitalizations. After surviving several of these events and the gaps in care in between, they may ultimately land on the cushion of hospice care, finally receiving interdisciplinary holistic support. In the United States this support is tied to prognosis despite the fact that people with neurologic disease may be homebound with palliative goals for years before their terminal decline. The programs described in this study are an attempt to bridge the gap between office-based care and end of life care.

Future work will continue to examine the structure, benefits, and costs of models of home care. It will be important to consider a broad range of costs. In most assessments of home care programs, costs are examined in terms of savings to Medicare or the health system. Investing in some primary care in the home reduces emergent and hospital care, leading to an overall decrease in costs to the payor. However, a decrease in one set of costs comes with an increase in costs for greater utilization of therapies, ancillary services, and clinician visits. It is possible that a subset of patients "in the gap" who have been receiving limited care will now have access to a team of care and corresponding therapies, and costs for that subset of people—as viewed by the payor—will increase. In this case, future studies will also need to consider the costs to the caregivers and families. Days missed from work to attend appointments, long term health consequences of isolation and stress, wasted time seeking appointments that are unproductive—these costs may be invisible to the institutional payor but are important to our patients.

An additional issue to explore in detail will be which team members are most necessary in the home. In the hospice model, nurses visit most frequently, followed by periodic visits by a physician, social worker, chaplain, and volunteer. Home based palliative programs commonly involve a nurse, social worker, and generalist or palliative physician or nurse practitioner. Dr. Fleisher's model is unique in offering specialist level of expertise in movement disorders. One can argue that all team members do not need to be in the home, and that redundancy in the skill sets of different team members is wasteful. However, one could also argue that redundancy among team members is beneficial, provides a system of double checking, and a more robust ability to identify problems. At this stage it is appropriate for more teams with different structures to describe their operations, interventions, and results. We are far from considering what is the optimal model and endeavors to define that at this

stage might hinder progress. Resist the tendency to abandon an idea because “the system” won’t pay for it. Maybe it’s the system that needs to change.

Finally, when should telemedicine replace in person visits? It is logical that reducing or eliminating travel time from visit to visit allows for more patients to be reached. There is a growing body of evidence that telemedicine visits for Parkinson’s disease are feasible and effective (12). In those studies, both physicians and patients are largely satisfied with telemedicine (13). However, have those physicians and patients experienced in-person visits in the home? Would a home visit be equally, more, or less satisfying? Over a screen, does the provider miss a glance by the caregiver, a shift in body position, or other subtle cue that lets them know that their message is not landing, or that the issue needs to be explored further? Does the physician benefit from the drive time between visits to decompress from an emotional end of life conversation? Finally, does the physician miss out on the magical human connections that can occur when they are a guest in a person’s home? Can that connection enhance the sense of service, emphasize the meaningful nature of the work, and provide restoration that prevents burnout? This transcends any simple measure of “satisfaction” (14,15).

So many unanswered questions remain. In the meantime, the developing study by Dr. Fleisher and colleagues reminds us of several things. First, home visits are both possible and valuable. This is an important reminder in an era where the great majority of physicians do not even consider home visits. Second, problems in the home may have dire consequences yet they also may have simple, accessible solutions when they are discovered. In the home, a clinician can discover duplicate or conflicting medications in the kitchen cupboard, bathroom vanity, and bedside table. Lining up and eliminating duplicate medications and physically reorganizing them can illuminate problems and offer solutions that are not apparent when a clinician reviews a summary medication list in an outpatient office. Just by walking into the house, clinicians can see the oxygen tubing or other tripping hazards and offer immediate, practical, tangible solutions. This kind of problem may never come to light in the office setting. Finally, symptoms of late stage progressive neurologic disease can sometimes improve through holistic interdisciplinary attention including specialist expertise. This addresses a potential bias in general palliative services, which might not universally recognize the potential for improvements in neurologic disease.

Clinicians at the intersection of neurology and palliative medicine must keep finding ways to wade into the gap in care, to address the needs of the homebound but not yet dying. Studies must continue to be mindful of resource utilization and celebrate cost savings when they occur—but be driven by the needs and outcomes for patients and their caregiving team, which includes their family and their medical professionals. We must extend care into the home with whatever team, technology, and funding are available. We must extend care into the home because the people are there, they are struggling, and they are waiting for us to help.

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## Footnote

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