



## Taking Neurology to the Underserved – A Pilot Initiative in an Urban Homebound Program

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### Abstract

**Background:** Over 2 million people are homebound in the United States with an increase of 50% expected over the next twenty years. Though home-based primary care programs are effective in reducing hospitalizations among this population, they have been slow to develop and lack subspecialty care. The objective of this pilot program was to establish a volunteer neurology consult service within the Mount Sinai Visiting Doctors (MSVD) Program serving over 1000 homebound patients in New York City.

**Description:** Neurology consults were requested by primary care providers from MSVD to PGY-3, PGY-4 Mount Sinai neurology residents and Multiple Sclerosis Fellows. Home visits were conducted by the trainee based on their availability. Patients were seen throughout Manhattan. Neurology attending served as preceptors for residents and fellows providing indirect supervision. Consult findings and recommendations were documented into the electronic medical record and the visits were not billed. Neurology trainees' perceptions were captured through a self-reflection questionnaire

**Results:** Over the course of three years, 30 home visits were conducted: 29 new consults and 1 follow up. The average age of the patients were 71 years, with females outnumbering males 2:1. 79% were 60 years and older. The most common diseases and conditions consulted on were: parkinsonism, demyelinating disease, stroke, headache, and neuropathy. Treatment interventions included medical management, supportive care, and one inpatient admission to the epilepsy-monitoring unit. Neurology trainees' perceptions, were influenced in areas related to doctor-patient relationship, caregiver support, the impact of the home environment in patient care, and challenges to delivering neurological care for this population.

**Conclusion:** Homebound patients are widely afflicted with chronic neurological illnesses, and this pilot program demonstrated both the need and the feasibility of providing neurologic care to this population, as well as educational impact for neurology trainees.

### Introduction

Over 2 million people are permanently homebound in the United States, with a large proportion being elderly patients with chronic illnesses and functional impairment [1]. Studies have shown that homebound patients have higher rates of emergency room visits [2], chronic medication use [3], and twice the rate of annual hospitalizations [2]. Their medical conditions and symptoms include dementia, depression, congestive heart failure, cancer, chronic pain and fatigue [4]. With this population set to increase by 50% over the next twenty years, home based primary care (HBPC) will be critical to the well-being of this group. To date, HBPC programs have been slow to develop [5] due to financial incentives and primary care workforce shortage causing the needs of many homebound patients to go unmet.

The Mount Sinai Visiting Doctors (MSVD) Program [6] is a large urban academic HBPC program that takes care of more than 1000 homebound patients in Manhattan each year. The eligibility criteria for this program include living in Manhattan, being older than 18 years, and meeting the Medicare definition of homebound: able to leave home only with great difficulty and for absences that are infrequent or of short duration [6]. The MSVD has 14 physicians (8 FTEs) trained in internal medicine or family medicine and most have specialized in geriatrics and/or palliative medicine. MSVD has 2 nurse practitioners, 2 registered nurses, 4 social workers, and 8 administrative staff. All internal medicine residents, geriatrics and palliative medicine fellows and third year medical students rotate through MSVD. One major limitation of all home based primary care programs nationwide is the lack of subspecialty home visits. MSVD has set up small pilot programs through which patients are seen by psychiatry residents and rheumatology fellows, but otherwise patients must come to the hospital/clinic to access subspecialty care. With dementia (60%), 6 and cerebrovascular disease and stroke (21%) 6 afflicting a large proportion of patients in the Mount Sinai visiting doctors program, accessible neurology consultations are needed in shaping an effective treatment plan.

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**Table 1:** Trainee feedback questions

1. Describe any new perspective(s) you have garnered regarding this neurologic process.
2. Has your understanding and/or ability to evaluate and diagnose this condition changed after this home visit? If so, please elaborate.
3. Is your management of this particular disease/condition different in the home setting as opposed to an inpatient or outpatient (private office, clinic) environment?
4. What are the challenges to providing neurologic/medical care to this patient? Were you aware of these challenges prior to this home visit? Do you foresee obstacles (logistical, financial, social, etc.) in implementing your intended treatment plan?
5. Can this patient benefit from learning about his/her disease/condition? If so, what educational modalities would be most useful?
6. Suggestions for logistical improvement of Neurology home visits

**Table 2:** Patient demographics

Characteristic	No. (%)
Sex	
Female	19 (66)
Male	10 (34)
Race	
Hispanic	8 (28)
White	14 (48)
Black	5 (17)
Other	2 (7)
Age	
<50	4 (14)
50-59	2 (7)
60-69	9 (31)
70-79	1 (3)
80-89	10 (34)
>90	3 (10)

The purpose of establishing a neurology pilot home visit program was to determine the role neurology residents and fellows could play in providing care for homebound patients, helping to diagnose, treat, and manage their chronic neurological conditions alongside primary care physicians. Given the success of the MSVD program as well as the educational impact it has had on medicine trainees [6], understanding the educational value of this pilot program for neurology residents and fellows was also essential.

## Methods

This pilot program was reviewed and approved by the institutional review board of Mount Sinai. Consults were requested by MSVD primary care providers (PCPs) to the neurology residency point-person (R.R.), who assigned consultations to PGY-3 and PGY-4 Mount Sinai neurology residents and Multiple Sclerosis fellows participating in the neurology home visit program. Consult requests were reviewed by the point-person in the order in which they were requested and prioritized based on the level of urgency indicated in the referral. As this was a pilot initiative to determine the clinical utility of community based neurology home care, there was no fixed schedule for neurology home visits, and the MSVD's administrative staff arranged the visits on an ad-hoc basis pending trainee availability. Neurology residents/ fellows made home visits with medical students or internal medicine residents. Because this was a pure volunteer effort, the consults were not billed.

Reason for the consult, demographic information, current neurological condition, comorbid conditions and diagnostic/treatment recommendations were recorded at each visit. Neurology attending served as preceptors for the resident or fellow, discussing the findings and impression of each case to provide indirect supervision. Consult findings and recommendations were then documented into the electronic medical record and sent to the PCP. Neurology trainee's perspectives were captured in a standardized series of self-reflection questions (Table 1) following each home visit. This was intended to provide a structured set of subjective educational outcomes.

## Results

Between April 2010 and May 2013, 113 neurology home visit consults were requested. 30 home visits were made: 29 new consults (26%) and 1 follow-up. 1 patient was also followed up in the Multiple Sclerosis Center. Three consults were classified as urgent: 2 concerning for acute strokes and 1 for ongoing seizure activity. The

**Table 3:** Clinical diagnoses

	No. (%)
Parkinsonism	9 (31)
Demyelinating Disease	8 (28)
Neuropathy	3 (10)
Stroke	3 (10)
Migraines	2 (7)
Tremor	1 (3)
Dementia	1 (3)
Seizure	1 (3)
Ataxia	1 (3)

remaining consults were prioritized based on their date of request. Home visits were made in Manhattan, predominantly in lower income neighborhoods such as East Harlem and the Lower East Side, as well as in more middle income and affluent regions in the Upper East and West Sides. Of the patients seen, the average age was 71.5 years (33-102), with an approximate female to male ratio of 2:1. 48% were white, 28% were Hispanic, and 17% were black (Table 2).

Common reasons for referral included diagnostic questions regarding MS, acute stroke, and hand numbness, as well as management of chronic illness such as parkinsonism, dementia, and epilepsy. The diseases seen are listed in Table 3. Parkinsonism was most common (31%), with 6 patients having idiopathic Parkinson's Disease, and 3 newly diagnosed with drug induced parkinsonism, 2 of whom had underlying Alzheimer's disease. 28% had demyelinating disease with 6 patients having MS (5 SPMS, 1 RRMS), 1 clinically isolated syndrome (CIS), and 1 patient having possible Neuromyelitis Optica (NMO). The two headache patients were found to have chronic migraines. Notably, 2 of the 3 consults for stroke were deemed to be acute (i.e., third nerve palsy and ataxia), while the third one was seen for management of chronic hemiplegia. The two acute stroke patients were managed conservatively at home as per their and their family's wishes. Among the two patients with hand numbness, one had carpal tunnel syndrome and the other had findings consistent with cervical radiculomyelopathy from cervical stenosis.

Brain and spine imaging was recommended and completed in 4 of the 29 patients while the neurologic exam and clinical history enabled confirmation as well as diagnosis of conditions such as Parkinson's Disease, drug induced parkinsonism, stroke, seizures, and migraines. Management of disease modifying and antispasmodic agents in MS patients, titration of levodopa and/or dopamine agonist formulation(s) in those with Parkinson's disease, risk factor optimization in the stroke patients, and initiation of migraine prophylactic agents were some of the disease specific approaches utilized in this homebound cohort.

Based on the trainee feedback questionnaire (Table 1), several challenges to delivering care were often encountered: 1) polypharmacy; 2) poor functional status; 3) lack of insurance coverage; and 4) limited patient and caregiver health literacy and language barriers, which compounded the difficulty of taking care of a chronically ill individual. These challenges oftentimes refocused the goals of care on managing quality of life measures such as pain control, incontinence, fatigue, and mobility.

The following are three patient experiences encountered by our consultants illustrative of the kind of opportunities available for neurologists to contribute to a homebound care program at a personal, medical, and educational level.

## Case 1

A 76-year old female with advanced Parkinson's disease was seen in her home for management of her disease. She was on 750mg of levodopa daily and taking ziprasidone for an unknown reason. Over the last several years, she developed severe motor fluctuations and dyskinesias which made it difficult for her to leave her home. Several videos were taken, with the consent of the patient's daughter, by the neurology consultant and PCP at different times over the ensuing weeks. These videos captured her severe hand tremors and bradykinesia when she was off levodopa as well as her debilitating dyskinesias. The videos were also reviewed during a weekly movement disorder's videoconference at Mount Sinai with input on the patient's management from several of the movement disorders faculty. The patient was cross-tapered from ziprasidone to quetiapine, which improved her oral dyskinesia. She continues to be followed with ongoing titration of her levodopa for better control of her motor fluctuations.

## Case 2

A 33-year-old woman with Lennox-Gastaut was seen in her home for ongoing seizure activity. She was nonverbal, bedbound, and had minimal comprehension. According to a seizure log kept by her family, she was having daily seizure episodes for the last several months. The patient was on levetiracetam 2500mg twice a day and topiramate 400mg twice a day for at least ten years. Routine blood work revealed a serum CO<sub>2</sub> of 11 with an anion GAP of 16. Due to concern that she was having refractory seizures and that topiramate was causing her metabolic acidosis, an inpatient admission to Mount Sinai's Epilepsy Monitoring Unit was proposed. The patient's family was reluctant at first to pursue hospital admission, but through extensive discussion, their trust was obtained and admission was arranged several weeks later. The patient was monitored with video EEG, which captured a number of seizures superimposed on a disorganized background. She was tapered off topiramate and her metabolic acidosis resolved. The addition of clobazam and valproate reduced her seizure frequency to once a week.

## Case 3

A 52-year-old male with a past medical history significant for Type 2 diabetes and agoraphobia was evaluated in his home by the multiple sclerosis fellows. Due to his psychiatric disease the patient was reluctant to come in to the MS Clinic for an evaluation, but did agree to have the fellow see him in his home. A year prior to evaluation he began to have pain in a bilateral thoracic distribution. 11 months later he developed right hemi-facial spasm and paroxysmal spasms of his left hand. His primary doctor ordered him a brain and cervical spine MRI that revealed extensive, disease in a configuration that was typical for multiple sclerosis, including multiple gadolinium-enhancing lesions. A diagnosis of MS was confirmed during the home visit and he was started on glatiramer acetate. Follow up visits were made to ensure compliance.

## Discussion

As HBPC grows as a model of care, subspecialty care for homebound patients remains minimal and challenging. Our pilot program is to our knowledge the first dedicated home based neurology experience and highlights the important role that a neurology trainee can play in the home setting. Though longitudinal monitoring of variables of efficacy such as the Unified Parkinson's Disease Rating Scale [7] for Parkinson's, Expanded Disability Status Scale for MS [8], or a headache diary for migraineurs were not implemented in this pilot program, positive outcomes included establishing or validating neurologic diagnoses, educating patients and caregivers, tailoring treatment for chronic illnesses such as Parkinsonism, MS, stroke, and headache, and identifying potential risks to physical and mental wellbeing (i.e., pain, dementia). The ability to characterize neurodegenerative diseases is essential, and elucidating a correct diagnosis helps to guide medical management and facilitate avoidance of medications and procedures that might place patients at risk of decompensation.

Collaborating and fostering meaningful relationships with PCPs allowed for constructive discussion and ultimately better care for patients. This was evident in the care the patient in Case 1. These videos served as useful follow-up for the neurology consultant and allowed both the neurologist and PCP to better understand the nature of her condition and severity of dyskinesia. This was a testament to the clinical utility of video/telemedicine in this setting, which has previously been shown to be advantageous in stroke [9] and Parkinson's disease care [10] in terms of patient outcomes, quality of life, reduced travel burdens, and feasibility in connecting with specialists at urban medical centers. In the home visit context, video/telemedicine offers an opportunity for all those involved in the care of a patient to observe and derive greater understanding of the nature of complex neurological illnesses and their impact on an individual's real-world physical and mental function.

Case 2 demonstrates how neurologists integrated in home-based care can offer urgent assessment and neurological inpatient hospitalization, if warranted. Stroke and epilepsy monitoring units, general neurology wards, or neuro-intensive care unit beds can be made available to these patients should their illness necessitate it. By building bridges with homebound patients in the community, both they and their families have an opportunity to learn about their disease and benefit from the resources available at a large tertiary or quaternary medical center.

Throughout this initiative, medical students, residents, and fellows were afforded the opportunity to gain a new perspective on how chronic neurological diseases affect an individual's daily life. The home visits illustrated, in an intimate way, the debilitating impact that neurological diseases can have on homebound patients. Trainees described that evaluating such conditions, within the confines of often cramped, musty rooms, with chipped paint falling from ceilings, non-air conditioned humidity, and/or bed bugs, warranted careful observation and critical thinking, in considering the real-world intersection of disease and living environment that impacts these patients' comfort, mobility, and happiness. Many of the neurology trainees who conducted home visits came to realize that a patient's living environment became part of the neurological exam, which started immediately upon entering their living quarters. Understanding the confines of the patients' apartments, including the feasibility of using assistive devices within them, added a unique perspective that contributed to how the management recommendations were devised. In facing these challenges and socioeconomic obstacles, neurology trainees who took part in this initiative reported recognizing the importance of establishing and fostering patient and caregiver relationships based on trust, compassion, dedication, and commitment to serving unconditionally, regardless of the limited resources. This perspective is not always attainable in many neurology residency or fellowship programs, justifying the need for more neurology community outreach from academic training centers. It is often the patients that neurologists and neurology trainees *don't* see in the outpatient office setting that most need our care, and from whom we could learn important lessons. The trauma of neurological illness can be devastating, but the opportunity to address the cognitive, psychiatric, ambulatory, and coping mechanisms, especially in a homebound environment, has the potential to enhance the dignity of life for many of these patients.

Since the inception of this pilot program, the large number of neurology consultations reflects the need for neurological home-based care as an important clinical, educational, and palliative paradigm. It remains to be established if outcomes from home-based neurologic care services improve with the direct involvement of specialist providers. Future studies focused on specific disease outcome measures as well as feasibility metrics (i.e. ratio of number of referrals to actual consults seen, time from referral to consult, cost assessments) are needed to refine and operationalize the delivery of effective neurologic homecare. Relevant outcomes in subsequent studies should include morbidity and mortality as well as patient-oriented outcomes (i.e., quality of life). Such studies can only be done when neurology home visits have become integrated in to a home

care system, which can ensure a higher consult completion rate than was achieved through a pure volunteer effort. This pilot initiative has taken the first step towards such a paradigm.

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