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Virtual visits for Parkinson disease

A case series

Vinayak Venkataraman, BS

Sean J. Donohue

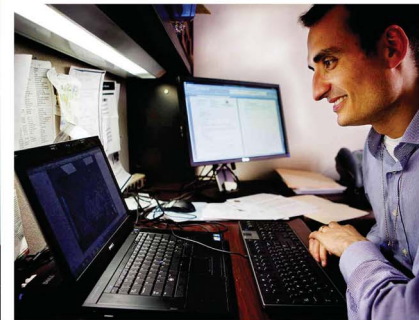
Kevin M. Biglan, MD, MPH

Paul Wicks, PhD

E. Ray Dorsey, MD, MBA

Summary

We sought to characterize recommendations and feedback of patients with Parkinson disease, each offered a free telemedicine consultation with a specialist. Visits consisted of history, neurologic examination, and recommendations. Midway through the program, patients were asked to complete an online satisfaction survey. From August 2012 to May 2013, 55 patients in 5 states (mean age 67.8 years) participated, with 80% of visits conducted from their home. Patients with Parkinson disease were recommended to exercise (86%), change current medication (63%), and add new medication (53%). Thirty-three of 35 consecutive patients completed a survey. Patient satisfaction exceeded 90% for virtually all aspects of the visit measured. Providing care to patients in their homes via telemedicine is feasible, results in changes to care, and is well-received.



Telemedicine has the potential to transform patient care. Applications within neurology have grown rapidly, and included virtually every subspecialty,¹ but have generally focused on providing care to patients in hospitals (e.g., telestroke)² or remote clinics (e.g., within the Veterans Affairs system or in Canada).^{3,4} Using Web-based video conferencing to deliver care to individuals with neurologic conditions in the

Department of Neurology (VV, ERD), Johns Hopkins Medicine, Baltimore; Johns Hopkins University (SJD), Baltimore, MD; Department of Neurology (KMB), University of Rochester Medical Center, NY; and PatientsLikeMe (PW), Cambridge, MA.

Funding information and disclosures are provided at the end of the article. Full disclosure form information provided by the authors is available with the **full text of this article at Neurology.org/cp**.

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Correspondence to: ray.dorsey@chert.rochester.edu

Four patients with unknown diagnoses were diagnosed with likely essential tremor, multiple system atrophy, psychogenic parkinsonism, and restless legs syndrome.

home is still in its infancy. A recent small randomized controlled trial demonstrated the feasibility and value for such an approach in individuals with Parkinson disease (PD) who had previously been seen in clinic.⁵

While physicians commonly provide telestroke or teleICU care to patients they have never previously seen, similar approaches directly into home have not been evaluated. Given that over 40% of Medicare beneficiaries with PD have not seen a neurologist and neurologic care is associated with better health outcomes,⁶ such an approach can provide care to patients who have difficulty accessing care because of distance, disability, and distribution of doctors. Here we describe the results of a program developed to provide individuals with PD or related disorders a one-time telemedicine consultation with a remote movement disorder specialist delivered primarily into the patients' homes.

METHODS

We developed a telemedicine program that offered a free one-time remote consultation with a specialist (E.R.D.) for patients with PD or related disorders. To participate in the program, patients had to be physically located in 1 of 5 states (California, Delaware, Florida, Maryland, or New York) where the physician was licensed and to have access to a nonpublic computer or Internet-enabled device. The program was promoted via the institution's (Johns Hopkins Medicine) Web site, community outreach, national meetings, social media, and media coverage. In addition, PatientsLikeMe,⁷ a social networking site for patients, promoted the availability of the program via targeted e-mails to its members in select states. Recruitment focused on patients with PD, but patients were not required to have a known diagnosis of PD to participate in the program.

Interested patients or their family or friends could request an appointment by e-mail or toll-free number. All individuals who requested an appointment were provided one. In advance of the appointment, patients were provided secure, Health Insurance Portability and Accountability Act–compliant Web-based videoconferencing software (Vidyo, Hackensack, NJ, provided through ID Solutions, Indianapolis, IN) via e-mail link. A research assistant (V.V.) or undergraduate student (S.J.D.) performed a test video connection with the patient or caregiver, or both, and provided all necessary technological support (e.g., use of Web camera, installation of software, test connection) by phone. Prior to each visit, patients were instructed to provide a medication list and contact information for their local neurologist or physician caring for their PD.

The specialist conducted 30- to 60-minute visits, which included a history, a focused neurologic examination (including components of the Unified Parkinson's Disease Rating Scale, such as remote analysis of rest tremor, action tremor, finger taps, hand movements, arising from chair, and gait), and discussion of recommendations. A summary letter was sent both to the patient and the local physician. Midway through the program, we started asking every patient to complete a brief online survey, immediately following his or her visit (appendix e-1), that assessed satisfaction with the communication technology, the visit's personal nature, and the visit's quality. Patients were asked how much they would be willing to pay per month for regular telemedicine consultations with a specialist. Patients also provided feedback through free-text responses, which were analyzed by theme.

Supplemental Data

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Table Baseline characteristics of 55 patients

Demographics	Values
Age, y, mean (SD)	67.8 (10.4)
Sex, % female	41.8
Race, % white	95.6
Education, % completing high school or more	100
Employment, % currently working	18.2
Clinical	
Baseline diagnosis, n (%)	
Parkinson disease	50 (91)
Essential tremor	1 (2)
Unknown	4 (7)
Duration of condition, y, mean (SD)	6.0 (4.1)
Geography, n (%)	
Distribution by state	
California	16 (29.1)
Delaware	9 (16.4)
Florida	7 (13.6)
Maryland	20 (36.4)
New York	3 (5.5)
Distance to local neurologist, miles, median	8.9

The analyses conducted were descriptive. The Johns Hopkins Institutional Review Boards approved this study.

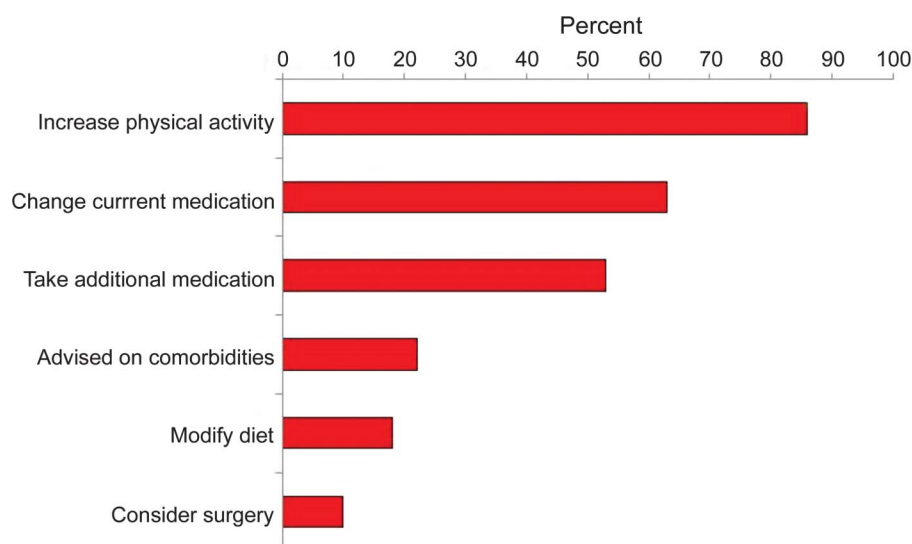
RESULTS

Patients

From August 2012 to May 2013, 55 patients received a telemedicine consultation with a specialist (table). No patients were excluded from participation. The patients were 35–90 years of age, the vast majority (91%) had a baseline diagnosis of PD with disease duration of 1 to 16 years, and most (80%) of the visits occurred in the patient's home. The remaining visits were conducted in local facilities (e.g., health centers). The telemedicine software was properly supported by each patient's device. Technical issues included software (difficulty with first-time download and installation, interference with other videoconferencing software), audio-visual system (selecting correct microphone, speaker, and camera, eliminating feedback echo), and external factors (temporary issues with computer and local Internet service provider). All technical issues were easily dealt with over the phone, and all visits were completed as scheduled (figure e-1).

Recommendations

The most common recommendations made to patients with PD were to exercise more (86%), change current medication (63%), and add new medication (53%) (figure 1). Baseline diagnoses were changed for one patient from PD to likely progressive supranuclear palsy. Four patients with unknown diagnoses were diagnosed with likely essential tremor, multiple system atrophy, psychogenic parkinsonism, and restless legs syndrome. Four individuals were identified as potentially having an impulse control disorder and counseled about its cause and treatment.

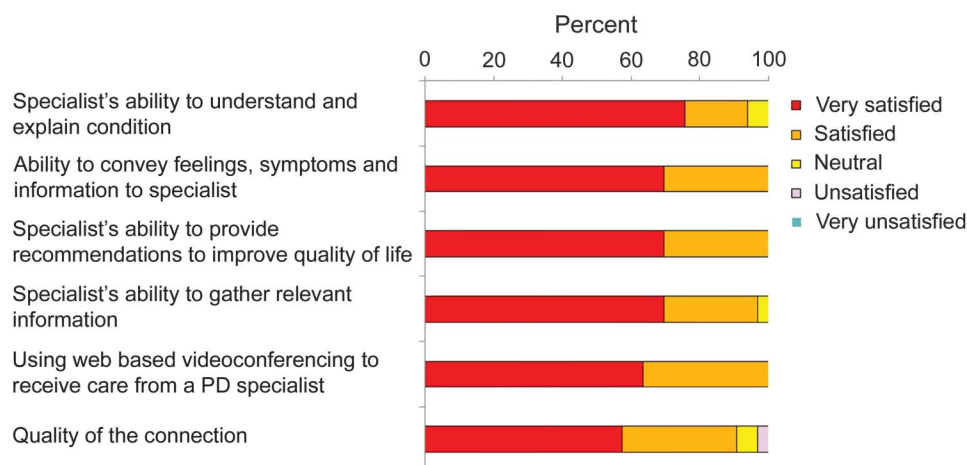
Figure 1 Recommendations for patients with Parkinson disease (n = 49)

Feedback

Thirty-three of 35 patients (94%) completed a post-visit survey. Patients were generally satisfied with all aspects of their visit (figure 2) and likely to recommend telemedicine to a friend (100% likely or very likely).

Compared to an in-person visit, patients established more of a personal connection (18%), the same level of a personal connection (67%), or less of a personal connection (15%) with the specialist. Patients were willing to pay \$0–\$49 (55%), \$50–\$99 (21%), \$100–\$149 (15%), \$150–\$199 (3%), and more than \$200 per month (6%).

Patients appreciated the care that they receive from the specialist (“The PD literacy and knowledge was amazing”), the convenience (“It’s great not having to drive the 2 hours...having the added expense of my wife missing an entire day of work, [and] saving on gas for the car, tolls, [and] parking”), and the visit’s comfort and personal nature (“I liked the interaction being personal despite the 3000 mile distance...it felt somehow protected by the veil of technology, which enabled the exchange to be more honest”).

Figure 2 Patient satisfaction with aspects of their telemedicine visit (n = 33)

PD = Parkinson disease.

Where barriers to reimbursement for telemedicine care do not exist (e.g., Canada and the Veterans Affairs system), telemedicine is flourishing and expanding access to care.

Patients were generally concerned with using unfamiliar technology (“Simplify the setting up instructions for older patients who have very limited computer skills”), the available information at the specialist’s disposal (“Doctor does not get complete information: blood pressure, pulse, temperature, etc.”), and the connection quality (“The picture could have been somewhat more clear”).

DISCUSSION

As demonstrated by more than 50 remote consultations, providing neurologic care to new patients with PD and related disorders directly in their home is feasible, results in recommended changes to care, and is largely well-received. Such an approach has the potential to transform care and increase access for patients not only with PD, but also other chronic neurologic conditions from autism to Alzheimer disease. In addition, this approach changes the care paradigm from having patients travel to a foreign institution to receive care to bringing care directly to patients in their environments.

Despite the generally positive feedback from patients on the care (“We had a good family crying moment after the appointment from just pure joy of finally having the opportunity for him to see a PD specialist”), convenience (“I could have access to a movement specialist, which I currently don’t where I live”), and comfort (“I am more relaxed in my home setting”), few were willing to pay more than \$50 per month for such care despite potential time and travel savings.⁵ Broader adoption may require reimbursement by insurers, funding by third parties, or changes in the behavior of patients and families. Where barriers to reimbursement for telemedicine care do not exist (e.g., Canada and the Veterans Affairs system), telemedicine is flourishing and expanding access to care. Demand for such models that use mobile (cell phone) technologies will only increase as the burden of PD grows, especially in developing economies.^{8,9}

This case series was limited by the patients it served, the physician involved, and the outcomes measured. The visits conducted were single encounters generally with patients who had access to neurologic, if not subspecialty care, and who were generally familiar with the Internet. In addition, the encounters were with a single specialist who is familiar with telemedicine. Finally, whether the recommendations made were implemented or improved the individual’s health or quality of life remains to be established in future studies. Although recent evidence suggests greater frequency of neurologic care is associated with fewer PD-related hospitalizations and thus potential cost savings to insurers,¹⁰ economic outcomes were not captured. To address these limitations, future efforts should include the following: 1) targeted outreach to the underserved; 2) integrated models of physicians, additional providers (e.g., psychologists, nurses, therapists), and online communities¹¹ to increase the scope of services available to patients; and 3) health and economic outcomes assessed over multiple visits over longer time periods. Such changes and evidence could help overcome current policy barriers to this model (e.g., licensure and reimbursement) and catalyze dissemination and adoption of this potentially patient-centered model of care.

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STUDY FUNDING

Supported by the Verizon Foundation, National Parkinson Foundation, Medtronic, private philanthropy, and PatientsLikeMe.

DISCLOSURES

V. Venkataraman and S.J. Donohue report no disclosures. K. Biglan serves on the Scientific Advisory Board for the Tourette's Syndrome Association; serves on the editorial board of the *Journal of Huntington Disease*; has filed a patent application related to telemedicine; is a consultant for Lundbeck and Omeros; and has received research funding from Presbyterian Home of Central New York, Susquehanna Nursing Home and Rehabilitation Center, Excellus/Blue Cross of Western, NY, Lundbeck, Neurosearch, National Institute of Neurological Disorders and Stroke (NINDS), National Center for Complementary and Alternative Medicine, National Parkinson Foundation, Michael J. Fox Foundation, and Huntington Disease Society of America. P. Wicks is an Associate Editor for the *Journal of Medical Internet Research*; is employed as Research and Development Director of PatientsLikeMe and owns stock options in the company; has filed patents related to Personalized management and monitoring of medical conditions; Systems and methods for encouragement of data submission in online communities; and Systems, methods, and computer-readable media for context-linked importation of user information; and has received research support from The Robert Wood Johnson Foundation and the Alkaptonuria Society. The PatientsLikeMe Research and Development team has received funding from Abbott, Acorda, Anavir, AstraZeneca, the AKU Society, Biogen, Boehringer Ingelheim, Genzyme, Johnson & Johnson, Merck, Novartis, the Robert Wood Johnson Foundation, Sanofi, and UCB. E.R. Dorsey serves on Scientific Advisory Boards for Lundbeck, Huntington's Disease Society of America, and NINDS; serves on the editorial board of the *Journal of Huntington Disease*; has filed a patent application related to telemedicine; has served as a consultant to Amgen, Avid Radiopharmaceuticals, Clintrex, Lundbeck, Medtronic, and the NINDS; has a clinical practice as a movement disorders specialist (20% effort); has received research support from Google, Lundbeck, Prana Biotechnologies, Avid Radiopharmaceuticals, Agency for Healthcare Research and Quality, Patient-Centered Outcomes Research Institute, NINDS, Verizon Foundation, Michael J. Fox Foundation, and Davis Phinney Foundation; and has stock options in Grand Rounds (formerly ConsultingMD). Full disclosure form information provided by the authors is available with the **full text of this article at Neurology.org/cp**.

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Neurol Clin Pract 2014;4;146-152 Published Online before print December 4, 2013

DOI 10.1212/01.CPJ.0000437937.63347.5a

This information is current as of December 4, 2013

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