

Virtual visits for Parkinson disease

A multicenter noncontrolled cohort

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Abstract

Objective: Previous small-scale studies have demonstrated the feasibility of providing remote specialty care via virtual visits. We assessed the feasibility and benefits of a one-time consultation between a remote Parkinson Disease (PD) specialist and an individual with PD at home on a larger scale. **Methods:** We conducted a multicenter non-controlled cohort of virtual visits administered over videoconferencing between remote PD specialists and individuals with PD in their home. Specialists performed a patient history and a PD-specific physical examination and provided recommendations to patients and their local physicians. The primary outcome measures were feasibility, as measured by the proportion of visits completed as scheduled, and the 6-month change in quality of life, as measured by the Parkinson's Disease Questionnaire 39. Additional outcomes included satisfaction with visits and interest in future virtual visits. **Results:** A total of 277 participants from 5 states enrolled, 258 participants completed virtual visits with 14 different physicians, and 91% of visits were completed as scheduled. No improvement in quality of life was observed at 6 months (0.4-point improvement; 95% confidence interval -1.5 to 0.6 ; $p = 0.39$). Overall satisfaction with virtual visits was high among physicians (94% satisfied or very satisfied) and patients (94% satisfied or very satisfied), and 74% of participants were interested in receiving future care via virtual visits. **Conclusions:** Providing specialty care remotely into the homes of individuals with PD is feasible, but a one-time visit did not improve quality of life. Satisfaction with the visits was high among physicians and patients, who were interested in receiving such care in the future. **Classification of evidence:** This study provides Class IV evidence that



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for patients with PD, remote specialty care is feasible but does not improve quality of life. **Clinicaltrials.gov identifier:** NCT02144220. **Neurol Clin Pract** 2017;7:283-295

Telehealth, the use of telecommunications technologies to deliver care at a distance, is growing rapidly.¹ In less than 2 decades, telehealth has transformed acute neurologic care, especially for stroke,² where telestroke is increasingly part of standard care.³⁻⁵ Today millions have access to expert stroke care that previously was not possible simply because of where they lived.⁶ However, applications of telehealth to chronic neurologic conditions have been few,^{7,8} even though access to care for these patients is limited.⁹

In Parkinson Disease (PD), for example, over 40% of Medicare beneficiaries with PD do not see a neurologist soon after diagnosis, and those who do not are more likely to have adverse health consequences, lose independence, and die.⁹ Distance, disability, and the distribution of doctors all play a role in the limited access to care.¹⁰ Multiple studies of telehealth for PD have demonstrated its feasibility and value.¹¹⁻¹⁶ However, almost all of these studies have been single-center and small (fewer than 100 participants), and have relied on a small number of specialists.

Therefore, we conducted a larger, multicenter, noncontrolled cohort providing remote specialty care directly into the homes of individuals with PD to assess the feasibility and value of such an approach.

METHODS

Study design

We conducted a multicenter noncontrolled cohort study that provided individuals with PD a one-time virtual visit with a PD specialist directly in their homes. The visits were conducted over web-based videoconferencing. The primary research questions were as follows: Was it feasible to provide remote specialty care to a large number of individuals with PD in their own homes? Would a one-time remote consultation between a PD specialist and an individual with PD have an effect on quality of life after 6 months? A classification of Class IV evidence applies to both outcomes.

Standard protocol approvals, registrations, and patient consents

The study was approved by the institutional review boards of the University of Rochester (coordinating center), the University of California–San Francisco, and the University of Florida. All participants provided written informed consent before enrollment into the study.

Participants

Eligible study participants were individuals with a self-reported diagnosis of PD who had access to a nonpublic, broadband Internet-enabled device with the capacity for videoconferencing, and who were physically located in a state (California, Delaware, Florida, Maryland, New York) where a participating site investigator was licensed to practice medicine. Participants were required to have the ability and willingness to provide informed consent and complete study requirements. Participants were enrolled at the University of Rochester Medical Center, University of Florida Medical Center, and the University of California–San Francisco Medical Center.

Recruitment and enrollment

Recruitment was primarily online through mass e-mail messaging from the Davis Phinney Foundation, Internet listings on Fox Trial Finder (the Michael J. Fox Foundation), messages from PatientsLikeMe (a patient social networking site), Google AdWords (keyed to searches related to PD) in eligible states, and outreach to support groups.

Individuals indicated their interest in participating by either visiting the Davis Phinney Foundation's "funded research" web page where individuals completed an online screening

The patient survey also asked patients to rate their relative preference for virtual visits to in-person visits across care, convenience, comfort, and overall dimensions.

survey or by contacting study coordinators at the University of Rochester Medical Center by phone or e-mail. Individuals who completed the screening surveys were contacted by the study team at the coordinating center by phone to assess eligibility and initiate the enrollment process. Eligible individuals who wished to enroll were invited to review and complete an electronic consent form. Sample size was determined based on feasibility, intended to be substantial, and therefore was targeted to be 250. The sample size calculation did not incorporate a power analysis.

Intervention

All participants enrolled in the study received an e-mail link to download secure, Health Insurance Portability and Accountability Act–compliant virtual visit software provided by SBR Health (Cambridge, MA) that embeds videoconferencing software from Vidyo (Hackensack, NJ) and is hosted by ID Solutions (Indianapolis, IN). Participants who did not have access to a web camera received one (Creative Labs Live! Cam Chat HD camera) by mail. A study coordinator performed a test connection with participants prior to the one-time study visit and provided technical support by phone, e-mail, and through the SBR Health interface.

All study participants were asked to complete a patient survey and the Parkinson Disease Questionnaire 39 (PDQ-39) prior to their one-time virtual visit. The content of the virtual visit was determined by both the clinician and the patient but generally consisted of a patient history, a PD-focused examination,¹⁵ addressing the patient's questions and concerns, and discussion of recommendations. Due to differences in state laws regarding remote prescription of medications,¹⁷ recommendations, including medication changes (if indicated), were mailed to the patient and the patient's local clinicians for implementation.

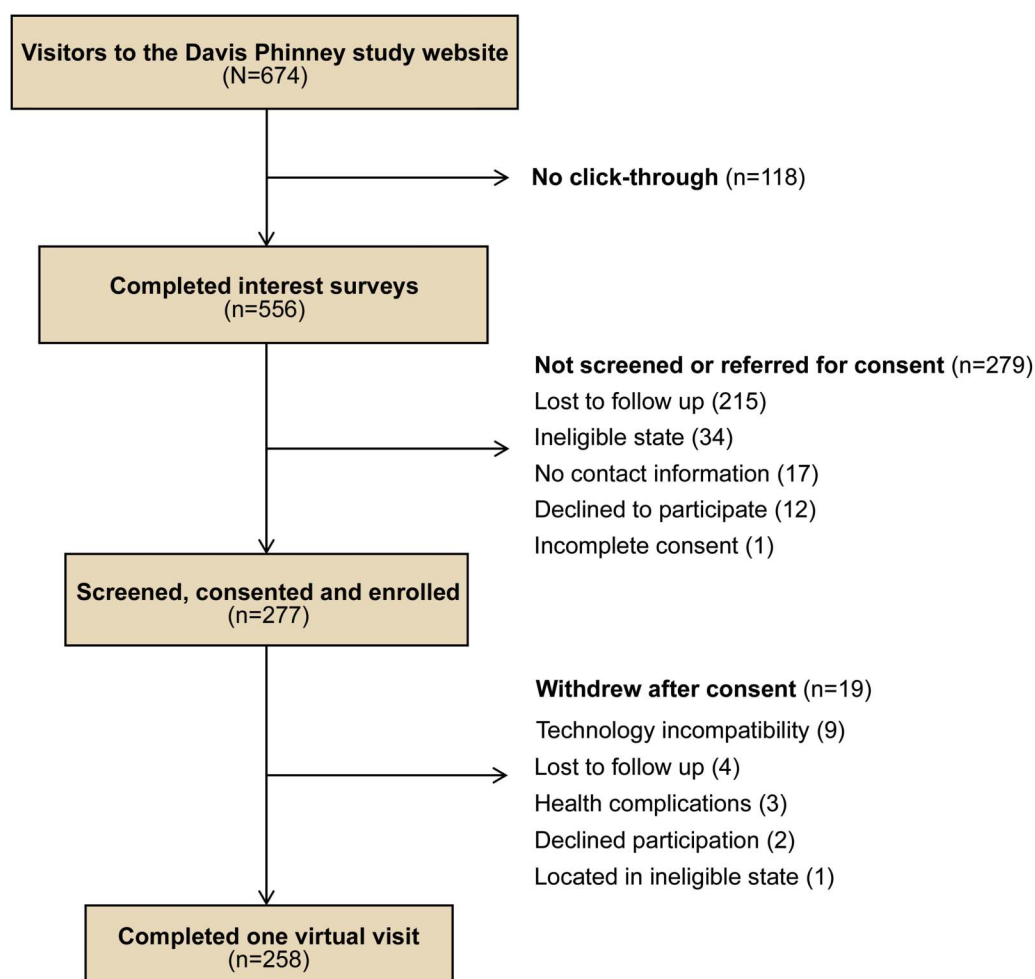
After the one-time visit was concluded, the remote physician was asked for the most likely diagnosis. Both physicians and patients were surveyed electronically, based on previous research,¹³ on their satisfaction with various aspects of the visits (e.g., technical quality, care, convenience, and overall satisfaction) on a 5-point Likert scale (from very satisfied to very dissatisfied). The patient survey also asked patients to rate their relative preference for virtual visits to in-person visits across care, convenience, comfort, and overall dimensions. After 6 months, participants again completed the PDQ-39 and received a survey, which asked about the usefulness of the recommendations made by the PD specialist.

Outcomes

The primary outcome measures were (1) feasibility, defined by the proportion of visits completed as scheduled, and (2) efficacy, as measured by the 6-month change in the PDQ-39. Secondary outcomes included calculated time and travel savings, participants' adherence to physician recommendations, physician and patient satisfaction, relative preference for virtual visits, and patient interest in future virtual visits.

Analysis

Feasibility of virtual visits at home was determined by the proportion of visits completed as scheduled with at least 80% completion considered feasible. Reasons for missed or delayed

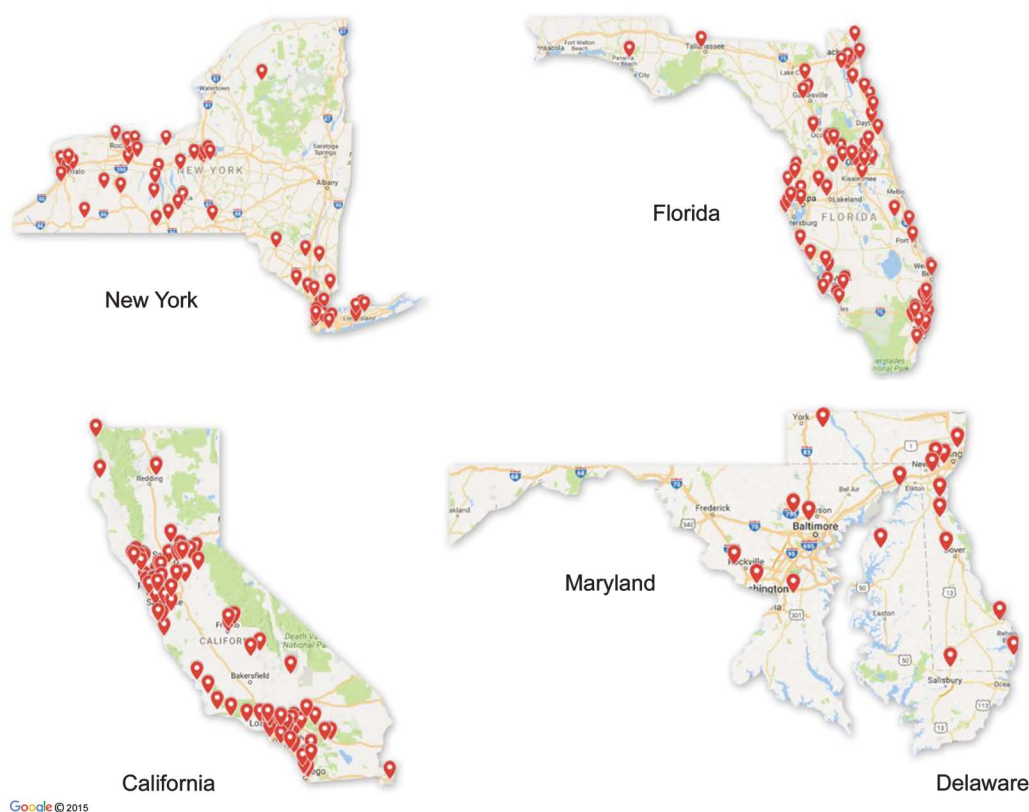
Figure 1 Flowchart of study participants

visits were summarized. The mean change with 95% confidence interval (CI) in PDQ-39 scores over 6 months was determined and a paired *t* test was used to test whether this mean was significantly different from zero. A *p* value <0.05 was considered statistically significant. The mean difference with SD in time spent associated with virtual visits compared to in-person care visits was calculated. Proportions of reported physician recommendations, adherence to physician recommendations, physician and patient satisfaction, and preference for virtual visits were described. Virtual visits were considered acceptable to participants if at least 80% reported interest in future virtual visits for their PD. Analyses were based on available data and no imputations were performed.

RESULTS

Enrollment

From April 1, 2014, to February 20, 2016, 674 individuals from 25 states and 4 countries visited the study page, and 556 individuals with self-reported PD completed the study interest form. The majority of participants learned about the study from the Davis Phinney Foundation website ($n = 245$), Michael J. Fox Foundation's Fox Trial Finder ($n = 129$), and PD support groups ($n = 90$). Of the 556 completed forms, we excluded individuals who did not have self-reported PD, were not located in an eligible state, did

Figure 2 Geographic distribution of enrolled participants (n = 277)

Two participants traveled across state lines to receive care remotely (one from Arizona to California and one from Pennsylvania to Delaware). Map data: Google, ©2016. Accessed December 5, 2016.

not provide sufficient contact information, were lost to follow-up, or later declined participation. Ultimately, 277 participants enrolled into the study. After enrolling, 19 individuals withdrew from the study. The most common reasons were technology incompatibility, losses to follow-up, and health complications due to non-PD-related illnesses (figures 1 and 2).

The baseline characteristics of the enrolled population are detailed in table 1. The characteristics of those who withdrew did not significantly differ from the rest of the enrolled study population (table e-1 at Neurology.org/cp). Study participants were mostly white (95%) and college educated (70%), on average 67 years old (range 30–91), and had an average disease duration of 6.4 years (table 1). The most likely diagnosis made by the remote specialist was PD in 97.7% of cases. Six individuals were diagnosed with another parkinsonian disorder (diffuse Lewy body disease [$n = 3$], multiple system atrophy [$n = 2$], and corticobasal syndrome [$n = 1$]).

Primary outcome measures

A total of 258 virtual visits were completed, and 253 (91%) of the visits were completed as scheduled. Five visits were not completed as scheduled due to audio/video quality issues ($n = 3$), connectivity problem ($n = 1$), and a personal scheduling conflict ($n = 1$). Two of the 5 visits were completed after a short delay, and the other 3 visits were rescheduled and completed.

On the primary efficacy outcome, quality of life did not improve 6 months after the one-time virtual visit (0.4 points improvement on a 100-point scale; 95% CI -1.5 to 0.6 ; $p = 0.39$).

Supplemental Data

Neurology.org/cp

Table 1 Baseline characteristics of study participants

	All enrolled participants (n = 277)
Demographics	
Women, n (%)	138 (48.4)
Age as of screening, y, mean (SD)	67.1 (9.1)
Bachelor's degree or higher education (n = 272), n (%)	191 (69.5)
Race (n = 275), n (%)	
White	262 (95.3)
Black or African American	3 (1.1)
Asian	3 (1.1)
More than one race	5 (1.8)
Preferred not to answer	2 (0.7)
Ethnicity (n = 270), n (%)	
Hispanic/Latino	5 (1.9)
Not Hispanic/Latino	253 (93.7)
Prefer not to answer/unknown	12 (4.4)
Married or in a domestic partnership (n = 274), n (%)	203 (74.1)
Clinical characteristics and care	
PD duration (n = 254), y, mean (SD)	6.4 (5.0)
Average number of visits with PD care provider in the last 12 months (n = 272)	2.7
Currently seeing a PD specialist (n = 271), n (%)	160 (59.0)
Usually drives self to PD appointments (n = 169)	120 (71.0)
Average time spent traveling to and from PD appointments (n = 274), min, mean (median)	80.5 (45)
Average time spent waiting at appointment (n = 274), min, mean (median)	19.6 (15)
Average time seeing health care personnel besides PD provider (n = 273), min, mean (median)	14.4 (10)
Average time spent seeing PD provider (n = 272), min, mean (median)	27.9 (20)
Average Parkinson's Disease Questionnaire 39 Total Baseline Score (n = 238) (0-100), ^a mean (SD)	26.4 (14.4)
Internet usage	
Devices used by participants to access the internet (n = 272), n (%)	
Desktop or laptop computer	243 (89.3)
Smartphone	127 (46.7)
Tablet	142 (52.2)
Participants who use the Internet or e-mail at home (n = 271), n (%)	264 (97.4)
Participants who use the Internet to look for health or medical information online (n = 273), n (%)	260 (95.2)
Participants who have ever used their desktop or laptop computer to participate in a video call or video chat (n = 240), n (%)	126 (52.5)
Abbreviation: PD = Parkinson disease.	
^a Higher scores indicate lower quality of life.	

Almost 3-quarters of participants (74%) indicated interest in receiving future care via virtual visits.

Secondary outcomes

The average amount of time that physicians spent with patients during each virtual visit was 42 minutes. Compared to their in-person care visits, the total average time of virtual visits (time spent connecting and waiting plus time with physician) was 47 minutes vs 144 minutes for an in-person care visit (including traveling and waiting), resulting in an average savings of 97 minutes (SD 49 minutes) per visit. The most common recommendations were to begin an exercise program (88%), to adjust PD-specific medications (76%), and to begin rehabilitative therapies (46%) (figure e-1). At 6 months, 200 (84%) participants reported having followed at least one recommendation made during their virtual visit and a majority of patients (56%) felt that the recommendations provided during the virtual visit improved their health and PD.

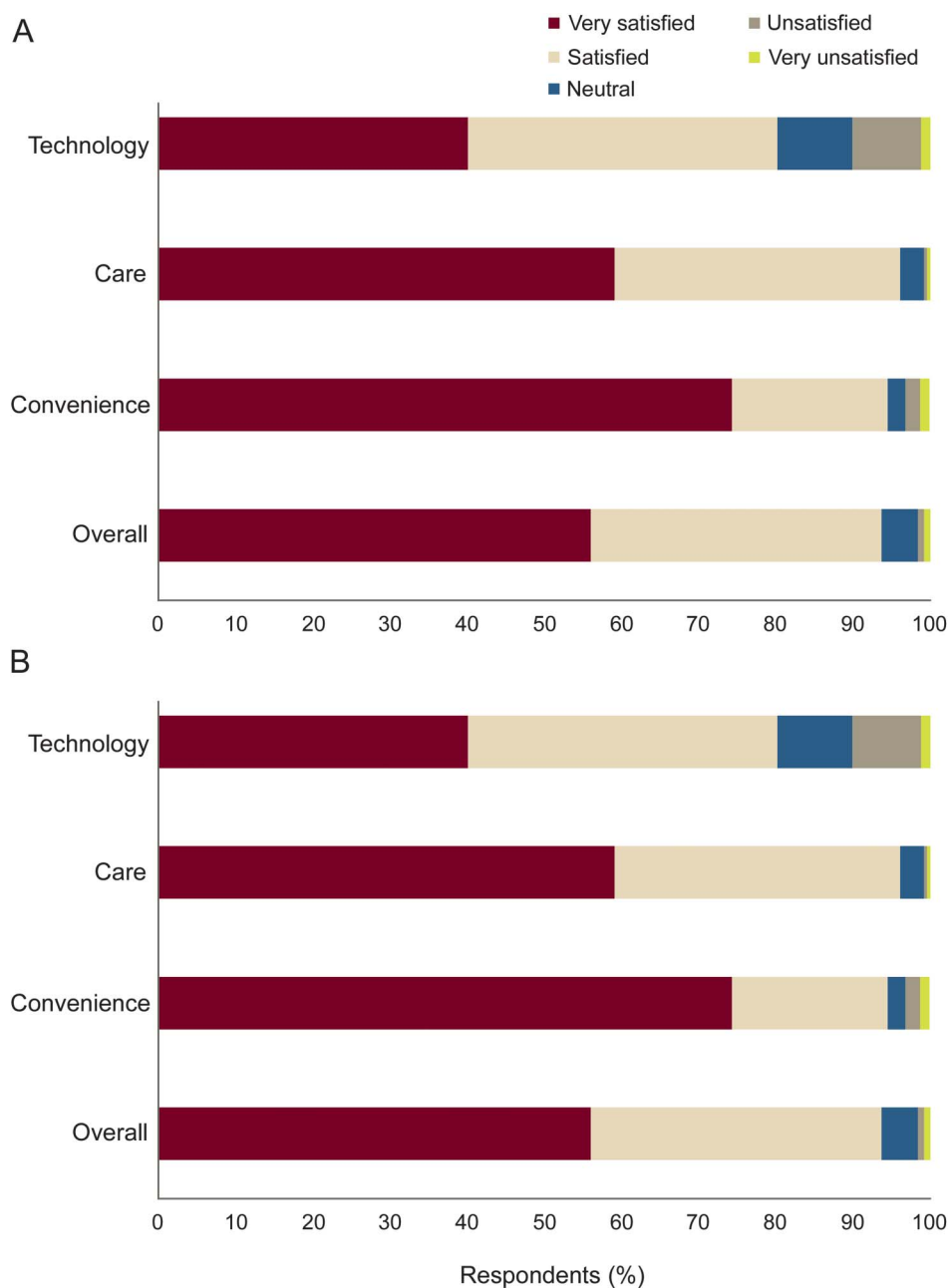
Physicians were least satisfied with the technical quality of the visit (80% satisfied or very satisfied) but otherwise were highly satisfied with all other measured aspects of the visit, including 94% of whom were satisfied or very satisfied with the virtual visit overall (figure 3A). Patients were also satisfied with all measured aspects of the visits, including technical quality (86% satisfied or very satisfied), convenience (95%), comfort (96%), care (93%), and the virtual visit overall (94%) (figure 3B).

Patients preferred the convenience (86% favored virtual visits vs 4% favored in-person visits) and comfort (54% favored virtual visits vs 11% favored in-person visits) of virtual visits to in-person visits. On other dimensions, such as personal connection, care, and the visits overall, preference was similar between the 2 visit types (figure 4). Almost 3-quarters of participants (74%) indicated interest in receiving future care via virtual visits.

DISCUSSION

In this large, multicenter, noncontrolled cohort, providing remote specialty care to individuals with PD directly in their homes was feasible. However, a one-time visit was insufficient to improve the quality of life of individuals over 6 months and the rate of acceptability of virtual visits by participants was slightly lower than expected. Such expectations for a one-time physician visit are likely unreasonable and may also reflect the required reliance (due to some state licensing laws) on local physicians to implement the recommendations and the high proportion of individuals seeing a PD specialist at baseline. Notwithstanding the absence of improvement in quality of life, the virtual visits were patient-centered, as they met many of the preferences, needs, and values of patients with PD.

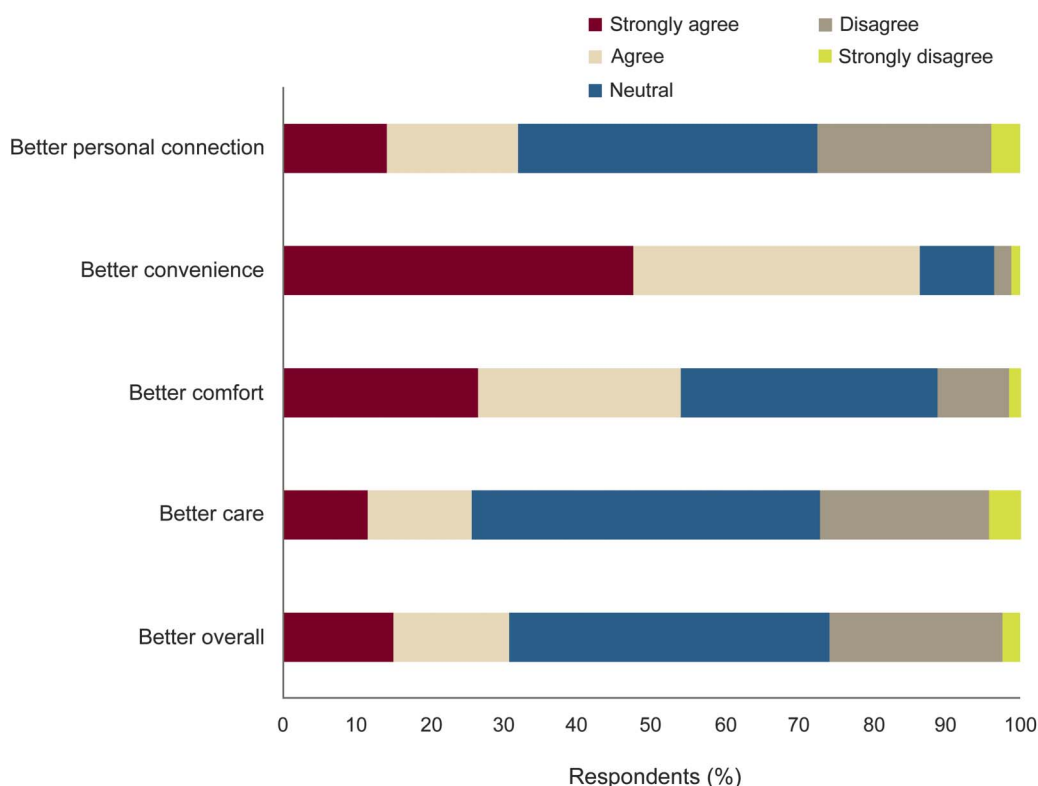
While virtual visits reduced geographical barriers to care, obviated the need for driving in a population with impaired driving ability,^{18,19} and saved patients substantial time and travel, participation in this study likely reflected the digital divide.²⁰ The digital divide is the differential access to the Internet and related technologies due to social and economic factors. For example, individuals who are older, have less education, and have more chronic conditions are all less likely to have Internet access.^{21,22} In this study, in which all aspects were conducted remotely, the majority of participants were white, well-educated, and much more familiar with the Internet than the general population.^{22–24} Consequently, the study results may not be generalizable to the broader population of individuals with PD, including the most underserved. Future efforts will need to evaluate a more representative population of individuals with PD. For telehealth to overcome the social and economic barriers that plague PD²⁵ and medical care more generally,²⁶ in-person

Figure 3 Physician and patient satisfaction

Physician satisfaction (A) and patient satisfaction (B) with different aspects of the virtual visit (n = 257 responses).

outreach,²⁷ satellite clinics staffed by medical personnel,^{11,12} and increased broadband access will likely be required.

This observational study had additional limitations. First, as an observational study, there was no control group to serve for comparisons. Randomized controlled studies, perhaps with a noninferiority design, are needed to address the evidence gap in telehealth. Second, the technical connections were sometimes limited, resulting in suboptimal evaluations and frustrating visits for patients and physicians. As technology, especially reliability and ease of use, and access to broadband improve, such barriers will be reduced. Third, the sample size calculation did not include a power analysis. Future studies will need to incorporate this analysis to estimate a sufficient sample size and achieve adequate power. Fourth, the study only incorporated a one-time

Figure 4 Patient preference for virtual visits relative to in-person visits (n = 258 responses)

visit from a PD specialist and was in addition to, rather than in lieu of, usual clinical care. Multidisciplinary care^{28,29} provided over longer periods of time is both feasible^{30,31} and likely to produce greater benefits. Other telehealth models including satellite telehealth clinics and combinations of in-person and remote care may provide additional benefits.^{11,12} Fifth, the visits were aimed at those with a prior diagnosis of PD. In-person visits are likely to be preferred (if available) for initial evaluations of those with other parkinsonian disorders (e.g., progressive supranuclear palsy) that require detailed assessments of eye movements, for example.

Despite the limitations, the results regarding satisfaction and benefits offered to patients are promising but face policy barriers. First, while veterans, Medicaid beneficiaries, and an increasing proportion of the commercially insured in the United States can already reap the benefits of telehealth, most Medicare beneficiaries, who account for the vast majority of those with PD, cannot.³² In 2015, Medicare spent less than 0.01% of its budget on telehealth³³ and does not cover medical services provided into the home remotely.³⁴ Second, state licensing laws¹⁷ generally restrict patients to receiving care from physicians that are licensed in the state where they are physically located. In this study, 2 participants (one in Arizona and another in Pennsylvania) drove from their homes across state borders just to receive care as part of this study. Proposed legislation, such as the TELE-MED Act,³⁵ would allow any Medicare beneficiary to receive care from any Medicare provider. Third, some states³⁶ restrict patients from receiving care via telehealth until they have had an in-person encounter first. While such a model may be optimal in some situations, it does not account for the substantial geographic and disability barriers that many, including the 2 million homebound Medicare beneficiaries,³⁷ face. In this study, almost none of the participants had previously seen their remote physician, yet satisfaction with the visits was very high and in some cases preferred to their in-person care. Finally, the increased access to convenient care may lead to more physician visits,

a concern expressed by the Congressional Budget Office.³⁸ However, more visits to a neurologist are associated with a lower risk of hospitalizations related to PD and lower Medicare expenditures.³⁹ In addition, the substantial economic benefits (in travel and time) of telehealth to patients are inappropriately neglected and discounted.⁴⁰ For example, a conservative estimate of the time and travel savings is \$80–\$100 per visit,¹⁴ which is favorable in relation to the cost of web cameras (\$30) and virtual visit software (~\$150 per month per 20 users).

As the burden of PD grows,⁴¹ the need for patient-centered care that “is respectful of and responsive to individual patient preferences, needs, and values”⁴² will only increase. This study adds to the growing evidence of the feasibility and potential value of virtual visits to deliver patient-centered care for individuals with PD where it is most needed—at home.⁴³ Future efforts and policy solutions will hopefully make this care model increasingly available to those with PD and, ideally, those with other chronic neurologic conditions.

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AUTHOR CONTRIBUTIONS

R. Korn: analysis or interpretation of the data, drafting or revising the manuscript for intellectual content. A. Wagle Shukla: analysis or interpretation of the data, drafting or revising the manuscript for intellectual content. M. Katz: analysis or interpretation of the data, drafting or revising the manuscript for intellectual content. H. Tait Keenan: analysis or interpretation of the data, drafting or revising the manuscript for intellectual content. S. Goldenthal: analysis or interpretation of the data, drafting or revising the manuscript for intellectual content. P. Auinger: analysis or interpretation of the data, drafting or revising the manuscript for intellectual content. W. Zhu: analysis or interpretation of the data, drafting or revising the manuscript for intellectual content. M. Dodge: analysis or interpretation of the data, drafting or revising the manuscript for intellectual content. K. Rizer: analysis or interpretation of the data, drafting or revising the manuscript for intellectual content. M. Achey: analysis or interpretation of the data, drafting or revising the manuscript for intellectual content. E. Byrd: analysis or interpretation of the data, drafting or revising the manuscript for intellectual content. R. Barbano: analysis or interpretation of the data, drafting or revising the manuscript for intellectual content. I. Richard: analysis or interpretation of

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