Response to Telemedicine Visits From Patients With Parkinsonism During the COVID-19 Pandemic on Postvisit Surveys

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Wissam Deeb, MD^{1,2}, Christopher W Hess, MD^{1,2}, Noheli Gamez, MHA^{1,2}, Bhavana Patel, DO^{1,2}, Kathryn Moore, MD^{1,2}, and Melissa J Armstrong, MD, MSc^{1,2}

Abstract

Parkinson's disease and parkinsonism are common chronic neurodegenerative disorders that tend to affect older adults and cause physical and sometimes cognitive limitations. Given that these limitations could impact successful telemedicine use, we aimed to investigate the experiences of patients with parkinsonism using telemedicine during the COVID-19 pandemic. A 19-item survey was emailed to patients with parkinsonism following telemedicine visits at a single US tertiary care parkinsonism specialty clinic. Seventy-four individuals responded, out of 270 invitations sent. Almost two-thirds (61.6%) of the respondents were comfortable with using technology in general, and almost all were very satisfied with their telemedicine experience. The most commonly reported benefits included cost and travel savings, ease of access to a specialist, and time savings. Issues with technology and previsit instructions were the most commonly identified challenges (28%). Urgent implementation, due to the pandemic, of telemedicine care for patients with parkinsonism was feasible and well received. The challenges most commonly reported by patients could be potentially alleviated by better education and support.

Keywords

telemedicine, parkinsonism, COVID-19, pandemic, access to care

Introduction

Parkinson's disease (PD) is the fastest growing neurological disorder in the world. An estimated 6.1 million people had a diagnosis of PD in 2016, 2.4 times higher than in 1990 (1). The prevalence of PD in the United States is estimated to be around 930 000 individuals in 2020 (2). Parkinson's disease is the most common parkinsonism, a term reflecting a group of neurological disorders with PD-like movement problems such as rigidity, slowness or bradykinesia, and tremor (3,4). Less common parkinsonisms include other neurodegenerative diseases such as dementia with Lewy bodies, multiple system atrophy, progressive supranuclear palsy, drug-induced parkinsonism, and vascular parkinsonism. Many of the parkinsonisms are associated with cognitive decline in addition to physical impairments.

Approximately 40% of individuals with PD in the United States do not see a neurologist (2), even though access to specialty care is associated with decreased morbidity and mortality and improved adherence to a treatment plan (5,6). Multiple factors impede access to specialty care, such as geographic clustering of specialists, devaluation of clinical care, systemic barriers to care for minorities, and financial limitations (7). The access problem is expected to worsen as PD's prevalence is projected to rise in the United States to 1 238 000 in 2030 and 2 000 000 by 2040 (8). Similarly, access to care is problematic for other parkinsonisms (9). Many of these conditions are uncommon and require diagnosis and management at tertiary care centers, which may be hours away from patients' homes.

Interest in telemedicine for the evaluation and management of parkinsonism dates to the early 1990s (10). In 2010,

Corresponding Author:

Wissam Deeb, Department of Neurology, University of Florida College of Medicine, 3009 SW Williston Rd, Gainesville, FL 32608, the United States. Email: wissam.deeb@neurology.ufl.edu



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¹ Department of Neurology, University of Florida College of Medicine, Gainesville, FL, the United States

² Fixel Institute for Neurological Diseases, UF Health, Gainesville, FL, the United States

the first randomized controlled trial comparing telemedicine care to usual care revealed significant improvements in quality of life for individuals with PD treated with telemedicine (11). Other research has also found comparable clinical outcomes between telemedicine and in-person care (12). Persons with PD report that advantages of telemedicine include cost and travel reduction and describe a hybrid system of telemedicine and in-person visits as the ideal approach (13-15). Despite this, telemedicine use for care in parkinsonisms has remained limited in distribution and scope, primarily due to the lack of health insurance coverage for telemedicine care in the United States (16). Additional challenges in telemedicine implementation include ethical and legal issues, the need for secure platforms, and the digital access divide (eg, low-quality videoconferencing systems and patient access to adequate bandwidth) (17,18). Additionally, in the setting of parkinsonisms, challenges to telemedicine care could include impaired motor function (eg, stiffness, decreased dexterity) and cognitive limitations affecting home technology use. Given that the majority of individuals with parkinsonism are older than 60 years, age-related limitations could include difficulty with hearing or lack of experience with technology (19,21). Clinician challenges could include limitations in performing an examination that relies on both visual and physical/touch-based assessments (22).

Access to telemedicine suddenly increased in early 2020, with the spread of COVID-19 to pandemic proportions. Many US states issued stay-at-home orders, and Congress passed temporary coverage of telemedicine visits. Because of the limited "real-world" experience with telemedicine for people with parkinsonism and potential patient- and clinician-based challenges with telemedicine care in these diseases, we aimed to investigate the experiences of individuals with parkinsonism receiving telemedicine visits during the initial months of the COVID pandemic.

Methods

The study utilized a survey investigating the telemedicine experiences of individuals with parkinsonism during the COVID-19 pandemic. Telemedicine had to be deployed urgently after the pandemic, as it was not implemented regularly prior. The study received a certificate of registration from the University of Florida Quality Improvement Project Registry. The institutional review board of the University of Florida identified the study as exempt.

The survey used REDCap electronic data capture tools hosted at the University of Florida (23,24). One investigator drafted the survey (M.J.A.), and 2 additional investigators revised it (W.D., C.H.), including 1 with telemedicine experience preceding COVID (W.D.). One research assistant and 2 investigators completed pilot testing. The final survey (Supplemental File 1) started with a description of the survey purpose followed by 19 questions (6 demographics/background, 5 about the telemedicine encounter, 8 about the telemedicine experience). It extended over 3 pages with an anticipated time for completion of 15 to 20 minutes. The survey used branching logic. When appropriate, an option for "I don't know" or "other" was provided. Consent was presumed if the respondent completed the survey, documentation of informed consent was not required, given the quality improvement designation.

Patients were recruited through the University of Florida Health Normal Fixel Institute for Neurological Diseases. A research assistant screened patients scheduled for telemedicine visits. They were eligible if they (1) had a diagnosis of parkinsonism (ie, PD, dementia with Lewy bodies, multiple system atrophy, progressive supranuclear palsy, corticobasal syndrome, unspecified parkinsonism, and secondary parkinsonisms), (2) were scheduled for a telemedicine visit early during the COVID-19 pandemic (recruitment April 21, 2020, to June 28, 2020), and (3) had access to an email account. For patients meeting inclusion criteria, clinic staff sent an email to the address provided for the telemedicine appointment on the same day as the scheduled appointment. The email included a nonspecific link to the survey (ie, links were not specific to the email recipient). Because there was no way to track survey respondents (responses were anonymous), no survey reminders were sent. No incentives were used. Telemedicine appointments were offered using a University of Florida business version of Zoom videoconferencing technology that protected personal health information (25).

Multiple-choice responses were analyzed descriptively using percentages. Investigators grouped write-in responses that shared matching themes and reported these descriptively. Microsoft Excel 2016 tables were used to organize and analyze data. Analyses were reported for the total completed responses; no adjustment was made for skipped items. χ^2 , Fisher's exact, and Spearman association tests were used, as appropriate, to assess whether the need to ask for help during the encounter was associated with the respondent type (patient vs family member), sex of the person with parkinsonism, age of the person with parkinsonism, type of visit (new patient vs follow-up), comfort with technology, and type of device used during the telemedicine visit. The median and interquartile range (IQR) were calculated for patient satisfaction with telemedicine as assessed using a Likert scale (scores 1-7). The Checklist for Reporting Results of Internet E-Surveys checklist (26) guided study reporting (Supplemental File 2).

Results

Seventy-four individuals with parkinsonism and/or family members responded to the survey (out of 270 possible respondents, response rate 27.4%). Sixty (81%) survey responses were received within the same week as the clinic visit. Forty-six (62.1%) respondents reported that they were evaluated by a single health care professional (physician or advanced practice provider) and 24 (32.4%) by multiple health care professionals (ie, resident, fellow, or advanced practice provider along with a specialty physician). Sixty-



Figure 1. Baseline and demographic characteristics and distribution.

eight (91.9%) respondents completed all survey items. One person opened the survey but did not answer any questions, and 5 respondents skipped some items.

Demographics and Background

The individuals with parkinsonism completed 73.6% of the surveys independently; 15.3% of surveys were completed by family members and 11.1% by the individual with parkinsonism with a family member. When involved, most of the family members were spouses or partners (72.2%). Most respondents were men (60.3%) and between the ages of 70 to 79 years (40.3%). Respondents were typically established patients or family members of established patients (86.3%). Close to two-thirds of the patients reported being very comfortable with technology in general (61.6%), with only 4.1% being not comfortable (Figure 1).

Telemedicine Encounter: Technology

A laptop computer was the most commonly used device for the telemedicine visit with 28 (38.9%) users; 19 (26.4%) used a tablet, 14 (19.4%) used a desktop computer, and 11 (15.3%) used a smartphone. The software platform used was largely Zoom (97.2%), which is the institutional default application. One person used FaceTime, and 1 person's visit was switched to a telephone visit due to local power outage preventing the use of Zoom.

Most respondents did not need help from other people to set up the telemedicine service (71.8%). When help was needed (n = 20), they reported receiving assistance from a child (47.1%), a spouse or partner (25%), someone from the clinic (20%), a friend (10%), other family members (5%), or a neighbor (5%). There was no significant association between the survey respondent type, sex of the person with parkinsonism, age of the person with parkinsonism, type of visit, comfort with technology, or type of device used and the need to ask for help during the telemedicine encounter (P > .05).

Telemedicine Encounter: Instructions and Communication

Sixty-two (91.2%) respondents reported receiving the instructions to download zoom and how to access the telemedicine visit far enough in advance. Fifty-three (77.9%) rated the email instructions as totally clear and 13 (19.1%) as somewhat clear. Only 2 (2.9%) respondents felt that the instructions were not clear at all.

Forty-seven (71.2%) respondents reported no challenges during their telemedicine visit, 21 reported 1 or more difficulties (Figure 2). Write-in responses echoed those to the multiple-choice survey options, with 5 respondents commenting that they had difficulty understanding the emailed telemedicine instructions, 3 respondents reporting not receiving the instructions or receiving them too late to have time to review them, and several respondents describing challenges with Zoom. One respondent said that it was challenging to prepare for the appointment because he/she did not know if the doctor's office had the necessary records and forms. Another respondent mentioned that the physician never showed up for the visit and they gave up after 70 minutes. One respondent said that it was hard to hear during the telemedicine encounter. A couple of respondents mentioned that they met with a technician in advance of the clinic visit to help set up the visit with the medical provider.

Fifty-three (79.1%) of the respondents were aware that the telemedicine visit would be billed as a regular visit and that this might incur associated co-pays, while 11 were not aware, and 3 were not sure. One respondent did not specifically answer this question.

Telemedicine Experience

The most common perceived benefits to telemedicine were "can stay home during the COVID-19 pandemic" (86.8%), "don't have to travel distance to clinic" (86.8%), "more time efficient" (70.6%), "able to see my doctor and have them see



Figure 2. Venn diagram showing the significant areas of challenge during the telemedicine visit.

me" (66.2%), and "able to obtain specialty care for my diagnosis" (52.9%; Table 1). Every respondent who completed their survey perceived at least some benefit to telemedicine. The most common perceived limitation to telemedicine was "provider cannot perform as thorough of an examination through video" (58.2%). Notably, 25 (37.3%) respondents, when asked about the limitations of telemedicine, answered, "I do not perceive limitations to telemedicine." Write-in responses noted benefits of telemedicine, including convenience, particularly for long-distance patients (n = 4). Respondents described that the clinicians were focused on the visit, took the necessary time, were able to do many parts of the clinical evaluation, positioned the camera in such a way that facial expressions could be seen, and the visit was interactive (n = 3). Many respondents indicated that they would like telemedicine to continue (n = 16). One respondent felt that telemedicine was not an adequate replacement for office visits. Four respondents mentioned that their comfort with technology affected the success of the visit.

Using a Likert-type scale that ranged from 1 (not at all satisfied) to 7 (very satisfied), 68 respondents evaluated their overall telemedicine experience. The median score was 7 (IQR = 1); only 2 individuals were not at all satisfied (score

of 1) with the overall telemedicine experience. Both selfreported a 5-out-of-7 level of comfort in using technology, and both felt that the instructions for using Zoom were not clear and, as a result, could not establish video contact with the provider.

Discussion

Despite potential limitations in telemedicine use due to parkinsonism-related challenges (eg, motor, cognitive impairments), this single-center survey study revealed that a vast majority of people with parkinsonism and/or family members reported at least 1 benefit from telemedicine encounters performed early in the COVID pandemic, noting safety, travel, and access to specialty care as the main benefits. Conversely, 19 respondents faced challenges and limitations, primarily relating to problems of communication (eg, unclear instructions or poorly timed instructional emails) or problems with technology.

Our sample's reported benefits of telemedicine mirrored those of a recent randomized controlled case-based qualitative study, which evaluated virtual house calls for 149 patients with PD (22). Reported benefits included less travel,

Table I. Reported Benefits and	l Limitations of Telemedicine.
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n	Benefits	n	Limitations
59	Can stay home during the COVID-19 pandemic	39	Provider cannot perform as thorough of an examination through video
59	Don't have to travel distance to clinic	25	I do not perceive limitations to telemedicine
48	More time efficient	П	Difficulty with technology
45	Able to see my doctor and have them see me	8	Telemedicine visit was shorter than an in-person visit would have been
	Able to obtain specialty care for my diagnosis		Provider was less certain with the assessment from the telemedicine encounter than he/she would have been after an in-person visit
26	Can allow for less in-person visits	0	l/my loved one was not comfortable (or as comfortable) sharing things in telemedicine as l/he/she would have been in person
18	Reduced risk of falls getting to and from clinic appointments		
0	l do not perceive benefits to telemedicine		

less wait time, less expense, access to the specialist, and good communication. Furthermore, a review of publications from 2000 to 2018 on the topic of telemedicine in neurology concluded that research supports specific roles for telemedicine in PD, such as better access to multidisciplinary care and reduction of travel time and cost in underserved areas (27). Likewise, the main telemedicine limitations reported in our survey-technological problems and difficulty performing a complete examination-were consistent with published reports (22,27). For instance, the inability to assess rigidity and postural stability can hamper a full evaluation of parkinsonism. A modified Unified Parkinson Disease Rating Scale without components requiring physical contact is available (15,28), but concerns about variability in scoring (due to the video feed quality and positioning) and the fact that the scale was validated only in early-stage PD patients remain.

There were a few differences between telemedicine experiences reported by current study respondents and prior research. First, 8 survey respondents indicated that telemedicine visits were shorter than in-person visits. This is in contrast to studies finding that telemedicine offered more time with the doctor (22). Conversely, the literature notes decreased comfort or intimacy associated with telemedicine visits (22), which was not explicitly queried in the current survey, but it was not described as an appreciated limitation in the write-in responses.

Some reported limitations of telemedicine can be addressed by technological adaptations, while others will require changes at the level of multiple stakeholders such as payors, health institutions, physicians, and patients. The increased availability and use of wearable sensors offer promise to improve clinical examinations of parkinsonism at a distance and remove the constraint on assessing rigidity and postural instability. The continued miniaturization and democratization of high-quality video and streaming equipment are addressing challenges relating to the affordability and quality of the audiovisual feed (29). While evolving technologies hold promise for addressing current telehealth challenges, widespread use will require a change at governmental and payor levels in the United States. One successful approach for parkinsonian patients, supported by physicians, health centers, payors, legislators, and patients in Italy during the COVID-19 pandemic, was a 2-step model. In step 1, a nurse specialist used a semistructured interview and then offered medical advice to solve the concern of the patient with parkinsonism. If needed, the nurse specialist could refer the patient for a tele-multidisciplinary evaluation (step 2). Almost two-thirds of the inquiries were managed by the nurse specialist alone, and only one-third required a multidisciplinary or physician evaluation (30). Such a model could potentially help with access challenges in the United States should telemedicine receive approval for ongoing use and rapidly increase the number of individuals with parkinsonism seeking specialty evaluations.

Strengths and Limitations

This study investigated the experiences of individuals with parkinsonism "and/or family members" using telemedicine in a real-world setting as opposed to the controlled environment of a randomized controlled trial. Most of the responses were received soon after the telemedicine encounter (within the week), thus decreasing the chance of recall bias. The survey response rate was 27.4%, which is relatively typical for online surveys (31). The main limitation is that the response rate was likely higher in individuals who are more comfortable with technology, as the invitation and the survey participation were done electronically (email and RED-Cap). Indeed, 61.6% of the respondents reported being very comfortable with technology. Thus, results may not be generalizable to individuals who are less comfortable with or do not have access to this technology, as they may have declined telemedicine assessments for this reason (and thus never received a survey at all). Generalizability is also limited by the single-center US experience and dedicated use of the Zoom videoconferencing platform. Demographics other than age and sex were not collected, but most clinic attendees are from a white non-Hispanic background and have generally high educational attainment. As this was an open survey, we could not prevent an individual from submitting multiple responses.

Conclusion

This single-center survey revealed that, even in urgent implementation due to the pandemic, telemedicine was well accepted by individuals with parkinsonism and/or family members (most of whom reported being comfortable with technology) and provided substantial perceived benefits. Improving communication and education regarding the use of technology could help alleviate identified obstacles to virtual visits. If telemedicine gains increased widespread use, given the changes prompted by the COVID pandemic, research would need to identify patient-focused strategies to assist telemedicine use across diseases and degrees of comfort with technology. Future research is also needed to optimize virtual examination in parkinsonism, potentially including virtual cognitive assessments and wearable technologies.

Authors' Note

WD: Dr Deeb received a training fellowship grant from the Dystonia Medical Research Foundation. He also received a training grant from the Tourette Association of America and the American Brain Foundation. He received royalties from a book published with Rose Publishing. He received compensation for a consultation with Medtronic.

CH: Dr Hess has served as a research committee member and consultant/speaker for the Michael J. Fox Foundation and the Parkinson Foundation. As the director of the Movement Disorders Fellowship at the University of Florida, he receives industry grants for educational support for the fellowship program that are paid directly to the University of Florida. Dr Hess has participated in CME and educational activities sponsored by Allergan, Ipsen, Mertz Pharmaceuticals, UptoDate, Peerview Online, and QuantiaMD.

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Declaration of Conflicting Interests

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ORCID iD

Wissam Deeb, MD (https://orcid.org/0000-0003-3794-8359

Supplemental Material

Supplemental material for this article is available online.

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Author Biographies

Wissam Deeb completed his MD in Lebanon at the University of Balamand. He completed his residency in neurology at the University of Massachusetts in 2015. He then moved to the University of Florida to pursue a movement disorders fellowship, then stayed there in faculty until June 2020, when he moved back to UMass as an assistant professor of neurology. Dr Deeb has a clinical and research interest in Parkinson disease and Tourette syndrome, focusing on incorporating technological advancements such as wearable devices in clinical and everyday care.

Christopher W Hess, MD, is an assistant professor of Neurology and the Movement Disorders Fellowship Director at the University of Florida College of Medicine, and serves as the Director of the Veterans Administration Parkinson's Disease Consortium Center at the North Florida/South Georgia VA Medical Center. Dr Hess received his medical degree from the Albert Einstein College of Medicine in New York and completed his neurology residency and fellowship training at Columbia University Medical Center with additional training in movement disorders neurophysiology. His current research interests include the use of wearable technologies in movement disorders and high-density electroencephalography (HD-EEG) to evaluate cortical activity during movement. Dr Hess has published on a variety of topics, including movement disorders neurophysiology and methods of tremor analysis, neuroimaging in movement disorders, invasive and non-invasive brain stimulation in Parkinson's disease.

Noheli Gamez, MHA is a Clinical Research Coordinator at the University of Florida. Noheli received her Master's in Health Administration from the University of Florida prior to beginning her role. Her primary responsibilities are to support the University of Florida Lewy Body Dementia Association Research Center of Excellence and the Center's three Lewy Body Dementia specialists. She is responsible for research and grant oversight, administrative support and supporting the Lewy body dementia community.

Bhavana Patel is currently an assistant professor in the Division of Movement disorders and Behavioral Neurology at the University of Florida. She joined the UF Department of Neurology and the Fixel Institute in 2019. Dr Patel graduated from Butler University in 2008 with a double major in chemistry and Spanish, followed by a Master's degree in Biology at Purdue University in Indianapolis. She completed medical school at the West Virginia School of Osteopathic medicine in 2013, followed by a preliminary internal medicine year and neurology residency at University of Kansas in 2017. Upon completion of her neurology training she pursued a two year fellowship in Movement Disorders at University of Florida from 2017-2019. She has a personal connection to Dementia with Lewy Bodies and during her training she completed additional clinical and research training in Lewy Body disease under the mentorship of Dr Melissa Armstrong. In 2018 she was the inaugural recipient of the Clinical Research Training Scholarship in Dementia with Lewy Bodies from the American Brain Foundation and the Mary E. Groff Charitable trust, in collaboration with the American Academy of Neurology and was recently awarded research funding by the Mangurian-Fixel-McKnight Collaboration for pilot studies in LBD. Dr Patel's research interests include Lewy body dementia, neurostimulation for movement and cognitive disorders, along with a strong interest in improving the delivery of healthcare to patients with Lewy body disease. Currently part of her research focuses on understanding how patients with Lewy body dementia and caregivers are receiving care in Florida. She has a specific interest in

improving specialty access to patients with Lewy body disease using telemedicine.

Kathryn Moore is originally from North Carolina where she completed medical school and neurology residency at the University of North Carolina in Chapel Hill. She is currently a movement disorders fellow.

Melissa J Armstrong is an associate professor in the Department of Neurology in the University of Florida College of Medicine. She directs the Dorothy Mangurian Clinical Research Headquarters for Lewy Body Dementia at the Normal Fixel Institute for Neurologic Diseases. Her main research interests focus on the lived experiences of individuals with parkinsonism and dementia, including topics relating to communication of dementia diagnoses, hospital outcomes, and end-of-life care.