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Attitudes Toward Telehealth Services Among People Living With Parkinson's Disease: A Survey Study

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ABSTRACT: Background: Telehealth has been widely adopted in providing Parkinson's disease care during the coronavirus disease 2019 pandemic.

Objective: The aim of this study was to survey people living with Parkinson's disease (PwPD) about their attitudes toward and utilization of telehealth services.

Methods: A survey was administered to PwPD via Parkinson's Foundation and Columbia University mailing lists.

Results: Of 1,163 responses, 944 complete responses were analyzed. Telehealth awareness was 90.2% (850/942), and utilization was 82.8% (780/942). More than 40% of PwPD were equally or more satisfied with telehealth compared with in-person visits in all types of services used. The highest satisfaction was observed in speech-language pathology appointments (78.8%, 52/66) followed by mental health services (69.2%, 95/137).

Conclusions: In selected circumstances and indications, such as speech-language pathology and mental health services, telehealth may be a useful tool in the care of PwPD beyond the coronavirus disease 2019

Supporting Data

Additional Supporting Information may be found in the online version of this article at the publisher's web-site.

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Key Words: Parkinson's disease; Telehealth

The traditional, in-person model of care was challenged by the novel coronavirus pandemic beginning in 2019. For many sites in the United States, care abruptly shifted from in-person to virtual via telehealth. People living with Parkinson's disease (PwPD) are among those affected by this shift. In a prior United States-wide survey, we observed an increase of telehealth utilization from 9.7% before the coronavirus disease 2019 (COVID-19) pandemic to 63.5% in June 2020,¹ and a similar trend was observed globally.²⁻⁷ Although loosening of federal regulations during the COVID-19 pandemic made telehealth more feasible in the United States, many states have recently reinstated pre-COVID restrictions. With mass vaccinations and reduction in COVID-19 incidence, more PwPD are returning to the traditional format of care⁴; however, it is important to understand the circumstances in which telehealth may be a useful alternative to in-person visits for PwPD in the postpandemic era.

To understand PwPD's perspective on telehealth utilization and quality, we administered an anonymous survey to the same cohort of PwPD surveyed in June 2020,¹ as well as to PwPD who were new to the Parkinson's Foundation mailing list between 2020 and 2021. In April 2021, we sent the telehealth survey to e-mail addresses on the electronic mailing lists of the Parkinson's Foundation and Columbia University Parkinson's Disease Center of Excellence and posted on the Parkinson's Foundation Facebook page.

Patients and Methods

A review of publicly available surveys related to telehealth quality and satisfaction was conducted. Visit methods were defined in the questionnaire as in-person and telehealth (video or phone) in Section Five: Satisfaction, and as in-person, video, or phone in Section Six: Quality. Relevant questions were used or modified to fit this current survey.^{8,9} The survey was then reviewed by a PwPD (D.N.) to ensure relevance and readability. The survey was open from April 28, 2021, to August 4, 2021. The design of the study and the questionnaire are available in the Supporting Information Methods.

The Columbia University Irving Medical Center institutional review board approved this study. A waiver of written consent was approved given the minimal risk to participants. A protocol-specific information sheet was

electronically presented to respondents before starting the survey.

Descriptive statistics were used to summarize survey responses. We compared responses to quality questions across service delivery methods—in-person, video, or phone—using chi-square tests (Fisher's exact test when applicable), and post hoc Bonferroni test was used to determine the source of significance.¹⁰ Statistical analysis was performed using SPSS 25.0 (SPSS Inc., Chicago, IL, USA). Open text collected in the survey was evaluated through thematic and frequency analysis using the R software package and programming language through RStudio desktop version 1.2.5042.^{11,12} Additional information on statistical analysis is available in the Supporting Information Methods.

Results

We sent the telehealth survey to 16,026 e-mail addresses and received 1,163 responses (response rate of 7.3%, assuming all e-mail addresses are active). After deduplication of the two cohorts and exclusion of incomplete responses, 944 complete responses were available for analysis out of 1,163 returned surveys. Respondent demographics were presented in Supporting Information Table S1. Telehealth awareness was at 90.2% (850/942), and telehealth utilization was 82.8% (780/942).

When asked about the previous 12 months (ie, April 2020–April 2021), respondents reported in-person visits as the most used method in all service types (primary care, movement disorders specialist, neurology, physical therapy, occupational therapy, speech-language pathology [SLP], and mental health), followed by video and phone (Table 1). More than 40% of the respondents reported telehealth visits (video or phone) to be equally or more satisfying than in-person visits in all service types surveyed. The highest rate of telehealth satisfaction (equally or more satisfied than in-person) was reported in SLP appointments (78.8%, 52/66) and mental health appointments (69.2%, 95/137). When asked about the respondents' most recent PD-related medical visit, we found no difference in almost all aspects of the perception of quality of care received in-person or via video (Table 2), while phone visits had lower performance in aspects related to communication and time spent during the visits (Supporting Information Table S2). In addition, we found the in-person visit performance score differed significantly between healthcare facilities ($P = 0.012$), but not in video or phone visit performance score (Supporting Information Table S3).

Telehealth satisfaction questions were followed with an open text question to capture why respondents were satisfied or dissatisfied with telehealth services. Reason for satisfaction included reduced travel time (46.0%, 160/348), ease and convenience (21.6%, 75/348), and

TABLE 1 Visit method, service type, and satisfaction of clinical appointments in the past 12 months

Visit method	Responses	PCP	MDS	Neurologist	PT	OT	SLP	Mental Health	Other
Visit summary	Any visit, n	840	791	220	419	146	165	182	621
	At least 1 telehealth visit, n (%)	392 (46.7)	510 (64.5)	95 (43.2)	78 (18.6)	25 (17.1)	70 (42.4)	141 (77.5)	235 (37.8)
Phone	None, n (%)	14 (6.4)	8 (5.6)	15 (31.9)	6 (24)	4 (33.3)	5 (29.4)	2 (3.2)	10 (9.3)
	1–3 appointments, n (%)	169 (77.5)	108 (75)	30 (63.8)	7 (28)	5 (41.7)	6 (35.3)	24 (38.7)	81 (75)
	>3 appointments, n (%)	35 (16.1)	28 (19.4)	2 (4.3)	12 (48)	3 (25)	6 (35.3)	36 (58.1)	17 (15.7)
N (total responses)		218	144	47	25	12	17	62	108
	None, n (%)	12 (4.8)	7 (1.7)	15 (18.3)	0 (0)	1 (5)	5 (7.2)	2 (2.1)	6 (3.8)
Video	1–3 appointments, n (%)	216 (86.4)	373 (88.2)	63 (76.8)	25 (41)	9 (45)	19 (27.5)	33 (35.1)	120 (76.4)
	>3 appointments, n (%)	22 (8.8)	43 (10.2)	4 (4.9)	36 (59)	10 (50)	45 (65.2)	59 (62.8)	31 (19.7)
N (total responses)		250	423	82	61	20	69	94	157
	None, n (%)	9 (1.3)	16 (3.2)	16 (9.2)	13 (3.4)	11 (8)	4 (3.6)	6 (8.6)	19 (3.8)
In-person	1–3 appointments, n (%)	574 (86.1)	421 (84)	144 (82.8)	82 (21.2)	51 (37)	42 (37.5)	33 (47.1)	366 (74.1)
	>3 appointments, n (%)	84 (12.6)	64 (12.8)	14 (8)	291 (75.4)	76 (55.1)	66 (58.9)	31 (44.3)	109 (22.1)
N (total responses)		667	501	174	386	138	112	70	494
	More satisfied, n (%)	31 (8.4)	32 (6.5)	12 (12.9)	7 (9.7)	2 (9.1)	14 (21.2)	24 (17.5)	28 (13.3)
Telehealth or virtual visit compared with in-person	Equally satisfied, n (%)	181 (48.9)	210 (42.8)	36 (38.7)	24 (33.3)	10 (45.5)	38 (57.6)	71 (51.8)	107 (50.7)
	Less satisfied, n (%)	158 (42.7)	249 (50.7)	45 (48.4)	41 (56.9)	10 (45.5)	14 (21.2)	42 (30.7)	76 (36)
N (total responses)		370	494	93	72	22	66	137	211

PCP, primary care physician; MDS, movement disorders specialist; PT, physical therapy; OT, occupational therapy; SLP, speech-language pathology.

TABLE 2 Quality question responses in in-person versus video visits

Quality questions	Responses	In-person	Video	P
Did your most recent visit start on time?	Yes, definitely, n (%)	373 (63.7)	163 (56.6)	0.121
	Yes, somewhat, n (%)	163 (27.8)	98 (34)	
	No, n (%)	50 (8.5)	27 (9.4)	
	Total responses, N	586	288	
Did this provider explain things in a way that was easy to understand?	Yes, definitely, n (%)	486 (83.2)	242 (83.7)	0.105
	Yes, somewhat, n (%)	85 (14.6)	46 (15.9)	
	No, n (%)	13 (2.2)	1 (0.3)	
	Total responses, N	584	289	
Did this provider listen carefully to you?	Yes, definitely, n (%)	489 (83.3)	245 (84.8)	0.741
	Yes, somewhat, n (%)	86 (14.7)	40 (13.8)	
	No, n (%)	12 (2)	4 (1.4)	
	Total responses, N	587	289	
Did this provider show respect for what you had to say?	Yes, definitely, n (%)	518 (88.4)	261 (90.9)	0.489
	Yes, somewhat, n (%)	61 (10.4)	24 (8.4)	
	No, n (%)	7 (1.2)	2 (0.7)	
	Total responses, N	586	287	
Did this provider spend enough time with you?	Yes, definitely, n (%)	461 (78.4)	228 (78.9)	0.867
	Yes, somewhat, n (%)	98 (16.7)	45 (15.6)	
	No, n (%)	29 (4.9)	16 (5.5)	
	Total responses, N	588	289	
Did this provider have the medical information they needed about you?	Yes, definitely, n (%)	500 (85.5)	246 (85.1)	0.42
	Yes, somewhat, n (%)	75 (12.8)	41 (14.2)	
	No, n (%)	10 (1.7)	2 (0.7)	
	Total responses, N	585	289	
Did your provider request additional follow-up care or tests?	Yes, n (%)	322 (55.1)	135 (46.7)	0.012 ^a
	No, n (%)	262 (44.9)	154 (53.3)	
	Total responses, N	584	289	
Did you feel comfortable sharing an issue, problem, or concern with your provider?	Yes, definitely, n (%)	493 (84.6)	241 (83.4)	0.896
	Yes, somewhat, n (%)	74 (12.7)	39 (13.5)	
	No, n (%)	16 (2.7)	9 (3.1)	
	Total responses, N	583	289	
Did your provider help resolve an issue or problem?	Yes, definitely, n (%)	213 (45.2)	107 (46.7)	0.953
	Yes, somewhat, n (%)	184 (39.1)	89 (38.9)	
	No, n (%)	74 (15.7)	33 (14.4)	
	Total responses, N	471	229	
Total performance score, ^b mean (SD)		12.1 (2.7)	12.2 (2.7)	0.424

SD, standard deviation.

^aSignificant.^bTotal performance score was calculated by summarizing the answers from the nine quality questions above (yes, definitely = 1, yes, somewhat = 2, no = 3; or yes = 1/no = 2); higher score represents lower quality. Mann–Whitney test was used.

option for follow-up appointments or minor issues (18.7%, 65/348). However, respondents also suggested limiting the use of telehealth to less clinically complicated visits only (eg, “When I am just checking in on how I am doing.”; Supporting Information Table S4) or SLP (eg, “Speech therapy over virtual is easier when we do it daily.”). Among those who preferred in-person appointments (285), 42.8% (122/285) felt that their provider was able to better notice symptoms or changes in-person than on a virtual platform (eg, “It is difficult for my doctor to really see my gait, movements responses, etc., when I am not there in person.”; Supporting Information Table S5), 20.0% (57/285) felt that in-person appointments were more thorough, and 19.6% (56/285) mentioned the importance of sight and touch in a physical examination. Two respondents commented that although they preferred in-person for movement disorders specialist visits, telehealth worked well for mental health sessions (Table S6).

Discussion

This study surveyed a large PwPD cohort ($n = 944$) on telehealth utilization and healthcare quality one year after the COVID-19 outbreak began, suggesting that telehealth remains important in the care for PwPD. Telehealth visits were perceived as most useful in SLP, mental health, and relatively straightforward follow-up visits. Telehealth care is clearly preferred to no care. It was reportedly used for several clinical services, relieving travel and time constraints. Televisits conducted via video were reported to offer a comparable quality of care to in-person visits, while visits via phone were perceived to have lower quality in communication than in-person visits.

Of the allied health services included in our survey, televisits (video or phone) with speech-language pathologists received the highest percent of satisfaction (78.8%). This finding is critical given that disorders of speech and swallowing in PD result in significant decrements to health and quality of life but have also been found to be amenable to improvements with targeted SLP intervention.^{13,14} In addition, recent work has identified that SLP services delivered via telehealth are feasible and efficacious in the treatment of Parkinson’s disease.¹⁵⁻¹⁷ In a recent study by Chan and colleagues,¹⁷ intensive voice therapy sessions delivered over smartphone videoconferencing were perceived to be an equivalent alternative to traditional face-to-face in 70% of participants. In addition, there is emerging evidence that swallowing evaluation and treatment may also be reliable and feasible via telehealth in PwPD.¹⁸ Several factors may have contributed to high patient satisfaction in SLP televisits. First, it is possible that the PwPD who completed the survey were already receiving SLP services in-person before the COVID-19 pandemic.

Therefore, the reduced burden (eg, travel, wait times) and the possibility of having more frequent sessions was likely favorable. In addition, PwPD may have preferred that mask wearing was not required during telehealth visits, therefore allowing for the visualization of the lower face, which is essential for cueing and training specific to speech and swallowing intervention. Lastly, being able to complete swallowing and speech interventions in their homes may have facilitated the translation of treatment improvements to actual speaking and eating in the PwPD’s known environment.

These data are especially promising in the context of major expansions in telehealth use by SLPs around the world. For example, the Movement Disorders unit at Tel Aviv Sourasky Medical Center started offering telehealth SLP services in 2020, and in 2021, 40% of clinical services were provided by telehealth (compared with 0.0% in 2019). A pilot survey demonstrated high satisfaction among patients and SLPs. In contrast, the usage of telehealth for physician appointments in 2021 was minimal (Yael Manor, personal communication).

A clear limitation of our study is the low response rate. Because we do not know how many of the e-mail addresses were active, we compared the response rate to prior surveys distributed in a similar fashion to the same cohort. Our study’s total number of responses was lower than a survey administered in 2020 (19.3% response rate),¹ partly because of a server error during the initial distribution of e-mail invitations and partly because the original survey was distributed in the height of the pandemic when social distancing was more closely adhered. The cohort demographics (eg, age, disease duration, age at onset, sex, and race distribution) were similar between this cohort and the cohort from 2020; thus, it is unlikely that a clear bias was caused by the reduced response rate in this population. Our cohort was also limited in respondent ethnic diversity: more than 90% of respondents self-identified as white, which is similar to the respondent population from a previous survey study.¹ Because the invitation was distributed via e-mail and social media and conducted electronically, it is likely that our cohort is biased toward those with better technological skill or with access to caregivers familiar with technology. These may reduce the generalizability of our findings. To reach additional populations not currently included in this survey, multiple other approaches such as phone or in-person recruitment are suggested for future studies. The satisfaction questions did not separate video and phone visits, and thus should be interpreted with the quality question responses, which showed that phone visits had lower quality in communication comparing with video or in-person visits. The quality questions included in our survey are adopted from a subset of those from the Agency for Healthcare Research and Quality, and performance scores were calculated by summarizing

the totals by response options. Therefore, the performance scores from this study are not directly comparable to other Agency for Healthcare Research and Quality quality reports and should be interpreted with caution.

In summary, telehealth was effective, widely used, and reported as satisfying by PwPD in the past year. Although telehealth may not be appropriate for every clinical service, the use of telehealth for PD appointments within a hybrid model of patient care should remain an option for PwPD, especially for SLP and mental health, and legislation should ensure the accessibility of this option in the future. ■

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Data Availability Statement

Data available on request from the authors

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Supporting Data

Additional Supporting Information may be found in the online version of this article at the publisher's web-site.

Efficacy of Caffeine in ADCY5-Related Dyskinesia: A Retrospective Study

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