

ORIGINAL RESEARCH

Telehealth Experiences of Autonomic Dysfunction and Parkinson's Disease Patients

Sachin Vallamkonda, BA^{1,2}; Leah Gorfinkel, BS^{2,3}; and Anna DePold Hohler, MD^{1,2,4}

¹Tufts University School of Medicine, Boston, Massachusetts, USA; ²Department of Neurology, St. Elizabeth's Medical Center, Boston, Massachusetts, USA; ³Lehigh University, Bethlehem, Pennsylvania, USA; ⁴Boston University School of Medicine, Boston, Massachusetts, USA

Corresponding Author: Sachin Vallamkonda; Email: sachin.vallamkonda@tufts.edu

Doi: <https://doi.org/10.30953/thmt.v9.461>

Keywords: autonomic dysfunction, health care access, neurology, Parkinson disease, telemedicine

Abstract

Objective: We aim to characterize the telehealthcare experiences of autonomic dysfunction in patients with Parkinson disease (PD).

Background: Telemedicine is a popular modality for receiving healthcare. Due to its rising use, ensuring efficacy, satisfaction, and safety is important. Current literature finds high satisfaction with physical and emotional health benefits and desired feasibility among patients with PD. The results are promising. However, there is a need for more literature relevant to the autonomic dysfunction patient population, including qualitative data in the analysis of care experiences.

Methods: We conducted a descriptive cross-sectional study using anonymous survey responses from patients with autonomic dysfunction findings within a large health system. The study questionnaire included Likert-scale prompts and open responses.

Results: Twenty-five patients with autonomic dysfunction or a PD diagnosis who completed the questionnaire successfully participated. More than 80% of participants reported they were confidently able to access medical appointments and providers via telehealth services. In 88% of cases, access to telehealth services was achieved without assistance. However, 68% did not agree that telehealth appointments were accessible during an impacted internet connection. More than nine out of 10 respondents (92%) were satisfied with the quality of care from telehealth appointments, with 76% finding the care comparable to in-person visits. Notably, 76% experienced improved care access to care and had telehealth met their needs. Among open responses, 43% highlighted how physical barriers and distance hindered in-person attendance. Four respondents discussed affected fine motor movements limiting telehealth access. Three preferred in-person appointments, denoting the importance of thorough physical exams.

Conclusions: Compared to in-person visits, telehealth meets the needs of patients with autonomic dysfunction, improves access to care, and delivers high satisfaction. This modality is still inadequate during limited internet connection and for those with impacted fine motor skills. Telehealth holds promising utility for autonomic dysfunction and the care of patients with PD. Continued study into furthering accessibility for patients of all abilities and technological constraints is warranted.

Plain Language Summary

Today, there is an increasing rise in accessing one's health care providers via telehealth services, such as video appointments. Properly characterizing how patients with autonomic dysfunction symptoms and Parkinson's Disease (PD) benefit from and feel about telehealth visits is important when maximizing care satisfaction and safety. Through an anonymous questionnaire-based study, we have found that the majority of interviewed patients with autonomic dysfunction were confidently able to access their providers via telehealth, felt satisfied with their care, noted that their needs were met, and also explained that their access to health care was improved due to the existence of telehealth services. However, more study is needed to further accessibility for patients with different physical abilities and technological constraints, such as limited internet access.

Submitted: December 12, 2023; Accepted: January 24, 2024; Published: February 29, 2024

Telemedicine is becoming an increasingly more common modality for receiving healthcare. It includes using electronic information and other technologies to provide and support health care at a distance.¹ Telemedicine involves several crucial functions such as teleconsultations, telemonitoring, and teletreatment.² Before the COVID-19 pandemic, telemedicine and its related services were underused and understudied.³ Since then, its use has rapidly increased, and services have become more optimized. This is especially true for neurodegenerative diseases and conditions such as Parkinson disease (PD)—a neurological disorder characterized by unintended, uncontrollable movement and progressive mental and behavioral changes.⁴ Because of the disease's manifestations during later stages, it is increasingly difficult for a patient to travel and attend in-person provider visits. Increased access to telemedicine, once patients become homebound, allows for better symptom management and advanced care.⁶ A primary goal is to increase the quality of life and care for patients with PD and autonomic dysfunction.

Existing literature on telemedicine characterizes the experiences and satisfaction of patients with PD but often does not include the broader population of all patients with autonomic dysfunction diagnoses. Among those with PD, current literature reports high patient satisfaction with the use of telemedicine.^{7,8} In addition, satisfaction with telehealth visits is comparable to in-person visits. In 2000, Peacock and researchers reported that 80% of participants would use telehealth again for follow-up neurology appointments.^{7,8} In fact, a 2018 questionnaire-based study of a movement disorder clinic mainly comprised of patients with PD reported highly positive experiences and preferences for telehealth visits among patients and physicians.⁹ Moreover, telehealth has been seen as a method for reducing barriers to care. For instance, in 2015, Qiang and Marras discovered an average reduction in health visit travel costs of \$200 and time savings of about 3.5 h for patients with PD using telemedicine services.¹⁰ These positive findings and improved care are yet to be documented within the broader community of dysautonomia patients.

This study includes participants with autonomic dysfunction and PD in order to address the scarcity of literature characterizing the telehealth care experiences of this larger patient community. Qualitative and quantitative approaches in data analysis offer more comprehensive insight into telemedicine experiences as they relate to neurology patients across diagnoses and age groups. While telehealth can encompass audio and video modalities, our study focuses on video-based telehealth visits. Audio-based meetings may be adequate for certain health needs, but neurological care often requires more intensive examination, which video-based visits can provide.

Methods

We conducted a descriptive cross-sectional study. An anonymous questionnaire was created using SurveyMonkey and disseminated to adult patients with autonomic disease and/or PD diagnoses within a large medical center network. This questionnaire was conducted among 25 patients and included Likert-scale prompts and open responses. Open-ended responses were coded into common categories based on topic and sentiment. Quantitative and qualitative data analyses are incorporated into the discussed findings.

All questionnaire responses were voluntarily, anonymously, and confidentially collected. No humans or animals were subjected to experimentation before, during, or after data collection.

Results

Twenty-five patients with either PD or autonomic dysfunction at St. Elizabeth's Medical Center network anonymously and completed the questionnaire. All participants queried in this study received video-based telehealth visits.

As shown in Figure 1, at least 76% of participants agreed that they were confident in their ability to access their telemedicine appointments ($n = 20$), could easily access their provider via telehealth ($n = 21$), felt satisfied with the quality of care from telehealth appointments ($n = 23$), found the care from telehealth appointments comparable to in-person appointments ($n = 19$), experienced improved access to care due to telehealth ($n = 19$), could access telehealth services without others' assistance ($n = 22$), found the information provided on telehealth platforms well-organized and easy to navigate ($n = 20$), easily learned how to use telehealth services ($n = 20$), and had their needs met by telehealth services ($n = 19$). Only 32% of participants ($n = 8$) agreed they could access telehealth appointments when their internet connection was impacted, while 52% ($n = 13$) felt neutral about the issue.

The statement with the most agreement responses was regarding being satisfied with the quality of care of telehealth appointments ($n = 23$). The statement with the greatest number of participants strongly agreeing was regarding being confidently able to access one's telehealth appointments ($n = 15$). The most disagreement was found for the prompt stating that patient care in telehealth is comparable to in-person appointments, with 24% of participants disagreeing ($n = 6$).

Responses from the open-ended comments section produced diverse responses (Table 1). Six participants commented on the physical barriers or distances preventing them from attending in-person appointments; four brought up the issue of fine motor movements still being necessary to access telehealth appointments; three remarked about various technology issues occasionally presenting as relevant barriers to telehealth

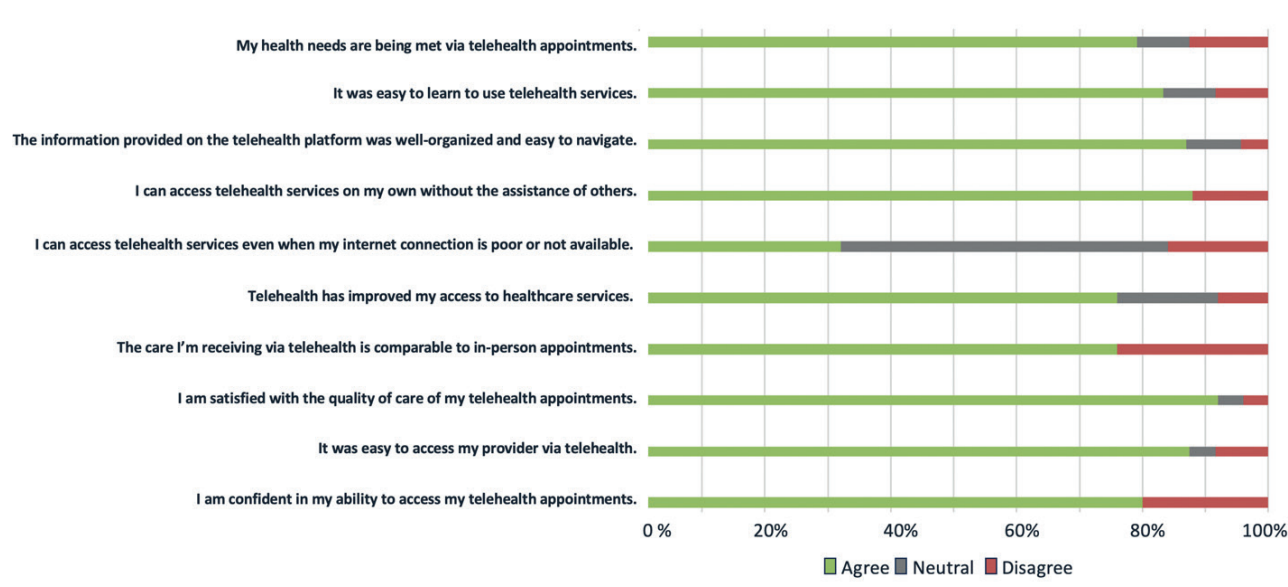


Fig. 1. Telehealth experiences among among patients with autonomic dysfunction and Parkinson disease ($n = 25$).

Table 1. Patients' open-ended responses by topic

Responses by Coded Topic	Frequency
Physical barriers and/or distance made in-person visits difficult.	6
Fine motor skills are still necessary to access telehealth visits.	4
Technology issues were sometimes present and made accessing visits difficult.	3
Preference for in-person visits	3
In-person visit's correlated expenses are a barrier for accessing health care.	1

Thirteen of twenty-five participants provided open-ended responses. Comments and descriptions within these responses were coded by topic.

visits; three spoke about their continued preference for in-person appointments, specifically for initial meetings and thorough physical exams; and one highlighted the barrier of expenses relevant to traveling for in-person appointments.

Discussion

The results of our descriptive cross-sectional study suggest promising efficacy, favorability, and usability of telehealth visits among the adult autonomic dysfunction and PD patient communities. Analysis of quantitative results and open-ended responses supports high utility but also brings to light pertinent deficits and areas of improvement for this novel modality.

Patient Satisfaction

Among multiple prompts, our autonomic dysfunction and PD patient cohort displayed high patient satisfaction with telehealth visits. This included 79% of patients stating their health needs were met with telemedicine visits ($n = 19$), and 92% ($n = 23$) felt satisfied with the quality of care of these visits.

Multiple studies confer PD patients' high satisfaction with telehealth visits.^{8,11,12} A 2014 study reported high approval among six different categories ranging from the patient's contentment with the clinician's ability to gather important information and explain their condition to the patient's satisfaction with their ability to convey symptoms and feelings to the clinician and the connection quality.¹¹ Similar to our findings, high patient satisfaction was demonstrated throughout multiple aspects of telehealth.

In a 2022 survey study that analyzed the responses among close to 1,000 patients with PD, Xu and colleagues reported high satisfaction with telehealth visits relating to speech and language pathology (79%) and mental health (69%).¹² These promising findings suggest that, even beyond specifically neurology appointments, the telehealth modality holds utility for patients with PD and autonomic dysfunction alike.

Furthermore, 76% ($n = 19$) of our autonomic dysfunction and PD-patient cohort found the care they received during telehealth visits to be comparable to that of in-person visits (Figure 1). Xu and colleagues. Similarly, it demonstrated that more than 40% of their respondents

found telehealth either on-par or more satisfying than in-person visits.¹² Alongside general satisfaction, showcasing patient perception and favorability of telehealth compared to in-office visits is important, especially when implementing new practice changes and altering patient care modalities. In addition, Xu and colleagues noted significant variability in the performance scores among different care facilities; however, this was not the case with the performance scores of video and phone telehealth visits.¹² This finding highlights the often unspoken but significant impact of the extraneous factors in a patient's care experience, such as those that pertain to the healthcare facility. The telehealth modality may offer a role in neutralizing these peripheral factors and standardizing care.

While the majority of patients interviewed found telehealth care comparable to in-person visits and reported high satisfaction with the novel modality, three of 17 collected responses noted a preference for in-person appointments (Table 1). One said they preferred in-person visits for initial consultations and another mentioned concern that the telehealth appointment did not allow for adequate physical examination. Similarly, Venkataraman and colleagues highlighted patient concerns about providers being unable to retrieve complete information in this modality.¹¹

Along this line, Saiyed and others report that although the majority of surveyed physicians enjoyed telehealth patient visits, 71% did not feel they could adequately assess their patients through telehealth.¹³ Concern about receiving adequate care is integral to the patient's health outcomes, care experience, and the patient-physician relationship. These concerns warrant further study of visit types that are most optimal for telehealth. Patient preferences for care modality may also impact provider and practice selection.

Usability

The telehealth modality was found to have promising usability in multiple domains for autonomic dysfunction and patients with PD based on respondents' agreement with multiple questionnaire prompts. Specifically, 83% ($n = 20$) of patients found telehealth services easy to learn, 80% ($n = 20$) were confident in their ability to access appointments, and 88% ($n = 22$) could access their telehealth visit without assistance from others. Patients' confidence and perception of the feasibility of telehealth services, as documented, speak to the modality's favorable usability.

Among the respondents, 87% ($n = 20$) also found the information on the telehealth platform to be easily navigable and well organized. This finding may contextualize the previously aforementioned high agreement found within the other usability-related prompts. While telehealth modality does allow for easy use, the extent of its

feasibility also depends on the specific telehealth system and the manner in which it is designed and organized. In a systematic review of technology implementation for PD patient care, Laar and researchers describe a technology's particular usability as a determining factor for patient satisfaction and its utility.¹⁴ Concordantly, 18% ($n = 3$) of collected open-ended responses pertained to technological issues limiting a patient's access to telehealth visits (Table 1). As such, technical difficulties pertaining to specific telehealth systems allow for variable and potentially impacted usability. Further study of user interface within telehealth systems may allow for further optimization of the care experience.

About 24% ($n = 4$) of open-ended responses described their issues with fine motor skills, leading to an impacted ability to utilize telehealth services without assistance (Table 1). Diminished fine motor skills impact certain patients with autonomic dysfunction and PD, and there is a dearth of literature documenting autonomic dysfunction and PD patients' motor difficulties when attempting to access telehealth services. Video-based telehealth services that require the unimpacted use of a computer may not be feasible for some patients without assistance. Future designs of new telehealth care services should account for this accessibility challenge. The innovation of related telehealth tools has the potential to achieve greater patient-centered care and healthcare accessibility.

Current literature documenting telehealth usage in PD populations similarly attests to usability acting as both a promising and limiting factor for telehealth services.¹⁴⁻¹⁶ Bendig and others report that even in the use of a multimodal telehealth intervention, the TelePark App, patients with PD showcased high completion rates of telehealth-related tasks throughout the study duration and particularly showcased a decrease in technical difficulties within only 1 week of use.¹⁵ The 2022 study describes how favorable usability was achievable as long as technical support was available to users throughout the telehealth intervention use period.¹⁵ A recent 2023 study of physical therapy for patients with PD via telehealth modality similarly describes increased technical competence among users with time and practice; however, external support, such as from family, was a facilitating factor in using these telehealth services.¹⁶ As illustrated, the telehealth modality holds the potential for easy feasibility and highly competent care when a technology's usability is well-designed and patients are supported externally by family and technicians.

Along this line, internet availability is a key factor in telehealth's usability, with 68% of respondents not agreeing that telehealth services were accessible when the internet connection was poor (Figure 1). Current literature on telehealth usability among patients with PD also finds internet access to be a supporting element when

strong and a barrier when inadequate.^{15,16} As such, the design and implementation of telehealth services within patient care must include a discussion of patients' access to available, reliable internet as both a key aspect of the service's usability and a factor of equitable access to care. Telehealth services have shown promise in delivering care to patients in remote settings.¹⁷ However, consideration of internet costs and stability is integral to properly characterizing telehealth's utility in specific locations and populations.

Increased Access

Increased access to care from primary and specialized providers is a well-documented and prominently motivating strength of the telehealth modality.^{11,14,16,17} Among our autonomic dysfunction and PD cohort, a majority of patients reported increased access due to telehealth care through agreement to standardized prompts and open-ended responses. In 76%, patients agreed that telehealth improved their access to health services, and 88% specifically noted that it was easy to access their provider through telehealth (Figure 1).

Analysis of open-ended responses showcased 41% of comments related to access issues pertaining to in-office attendance (Table 1). They described physical barriers, distance, and travel costs as factors that impacted their care experience during in-person visits. Venkataraman and others similarly noted patient comments alluding to difficulties with accessing specialists and having to leave the comfort of their own homes.¹¹ Telehealth services relieve these negative elements, allowing for greater care accessibility and even satisfaction. Wilkinson and researcher's randomized control trial, which documented high satisfaction with telehealth care among patients with PD, similarly reported accessibility and convenience as factors integral to greater patient satisfaction ratings.⁸

Autonomic Disease and Parkinson Disease

There is a shortage of literature characterizing the telehealth experiences of autonomic dysfunction patients. The previously referenced literature on PD patients' telehealth care experiences may offer some insight but does not adequately encapsulate all patients' experiences. PD is a disease that may involve autonomic dysfunction; however, the needs of patients with multiple systems atrophy, diabetic neuropathy, postural orthostatic tachycardia syndrome, and other dysautonomias vastly differ in a wide spectrum in the realms of mobility, psychiatric afflictions, clinical evaluation, medication management, and care monitoring.¹⁸ This descriptive cross-sectional study works to more inclusively involve the broader amalgam of care experiences of patients with dysautonomia, including those with PD.

Limitations

Although incorporating the wider community of patients with autonomic dysfunction, our study does not segregate the cohort by distinct diagnoses and evaluate for differences in care. Future research should assess telehealth experience variations among different dysautonomia patients. Demographical data were not collected due to prioritization of a brief questionnaire and maintaining participant anonymity; future study incorporating demographical data would allow for further characterization of patient care experiences.

Conclusion

Telehealth services hold significant utility within health care for patients with autonomic disease. Patients have noted significant improvement in access to care and comparable quality of care to in-person visits. High satisfaction and feasibility have repeatedly been reported for the telehealth modality. Further study into improving technological accessibility of telehealth services is still needed. Future research should also work to characterize specific care experience differences among patients of distinct autonomic disease diagnoses.

Funding

No outside funding was utilized in the preparation of the article.

Financial and Non-Financial Relationships and Activities

The authors have no conflicts of interest to disclose. All co-authors authorize the submitting author to vouch for the information as accurate and correct.

Contributors

All authors engaged in the study design and manuscript review stages. Leah Gorfinkel and Sachin Vallamkonda contributed significantly to the relevant literature review, data collection, and manuscript writing processes. Sachin Vallamkonda led the data analysis and manuscript planning.

Acknowledgments

n/a

References

1. Institute of Medicine (US) Committee on Evaluating Clinical Applications of Telemedicine. 1. Introduction and background. In: Field MJ, editor. *Telemedicine: a guide to assessing telecommunications in health care*. Washington, DC: National Academies Press (US); 1996. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK45440/> [cited 10 December 2023].
2. van den Bergh R, Bloem BR, Meinders MJ, Evers LJW. The state of telemedicine for persons with Parkinson's disease. *Curr Opin Neurol*. 34(4):589–97. <https://doi.org/10.1097/WCO.0000000000000953>

3. Shaver J. The state of telehealth before and after the COVID-19 pandemic. *Prim Care*. 2022 Apr;49(4):517–30. <https://doi.org/10.1016/j.pop.2022.04.002>
4. National Institute on Aging. Parkinson's disease: causes, symptoms, and treatments [Internet]. National Institute on Aging; 2022. Available from: <https://www.nia.nih.gov/health/parkinsons-disease> [cited 10 December 2023].
5. Katz M. Telehealth increases access to palliative care for people with Parkinson's disease and related disorders. *Ann Palliat Med*. 2020 Feb;9(S1):S75–9. <https://doi.org/10.21037/apm.2019.11.12>
7. Peacock D, Baumeister P, Alex, Siever J, Yoneda J, Wile D. Perception of healthcare access and utility of telehealth among Parkinson's disease patients. *Can J Neurol Sci*. 2020 May 26;47(5):700–4. <https://doi.org/10.1017/cjn.2020.99>
7. Wilkinson JR, Spindler M, Wood SM, Marcus SC, Weintraub D, Morley JF, et al. High patient satisfaction with telehealth in Parkinson disease: a randomized controlled study. *Neurol Clin Pract*. 2016 May 3;6(3):241–51. <https://doi.org/10.1212/CPJ.0000000000000252>
8. Hanson RE, Truesdell M, Stebbins GT, Weathers AL, Goetz CG. Telemedicine vs office visits in a movement disorders clinic: comparative satisfaction of physicians and patients. *Mov Disord Clin Pract*. 2019;6(1):65–9. <https://doi.org/10.1002/mdc3.12703>
9. Qiang JK, Marras C. Telemedicine in Parkinson's disease: a patient perspective at a tertiary care centre. *Parkinsonism Relat Disord*. 2015 May;21(5):525–8. <https://doi.org/10.1016/j.parkreldis.2015.02.018>
10. Venkataraman V, Donohue SJ, Biglan KM, Wicks P, Dorsey ER. Virtual visits for Parkinson disease. *Neurol Clin Pract*. 2014 Apr;4(2):146–52. <https://doi.org/10.1212/01.CPJ.0000437937.63347.5a>
11. Xu Y, Feeney MP, Surface M, Novak D, Troche MS, Beck JC, et al. Attitudes toward telehealth services among people living with Parkinson's disease: a survey study. *Mov Disord*. 2022;37(6):1289–94. <https://doi.org/10.1002/mds.28990>
12. Saiyed S, Nguyen A, Singh R. Physician perspective and key satisfaction indicators with rapid telehealth adoption during the coronavirus disease 2019 pandemic. *Telemed J e-Health*. 2021 Nov;27(11):1225–34. <https://doi.org/10.1089/tmj.2020.0492>
13. Laar A, Silva de Lima AL, Maas BR, Bloem BR, de Vries NM. Successful implementation of technology in the management of Parkinson's disease: barriers and facilitators. *Clin Parkinsonism Rel Disord*. 2023 Jan 1;8:100188. <https://doi.org/10.1016/j.prdoa.2023.100188>
14. Bendig J, Wolf AS, Mark T, Frank A, Mathiebe J, Scheibe M, et al. Feasibility of a multimodal telemedical intervention for patients with Parkinson's disease—a pilot study. *J Clin Med*. 2022 Feb 18;11(4):1074. <https://doi.org/10.3390/jcm11041074>
15. Colón-Semenza C, Zajac JA, Schwartz A, Darbandsari P, Ellis TD. Experiences from the implementation of physical therapy via telehealth for individuals with Parkinson disease during the COVID-19 pandemic. *Disabil Rehabil*. 2023;1–9. <https://doi.org/10.1080/09638288.2023.2202418>
16. Harkey LC, Jung SM, Newton ER, Patterson A. Patient satisfaction with telehealth in rural settings: a systematic review. *Int J Telerehabil*. 2020;12(2):53–64. <https://doi.org/10.5195/ijt.2020.6303>
17. Mathias CJ. Autonomic diseases: clinical features and laboratory evaluation. *J Neurol Neurosurg Psychiatry*. 2003 Sep 1;74(suppl 3):iii31–41. https://doi.org/10.1136/jnnp.74.suppl_3.iii31

Copyright Ownership: This is an open-access article distributed in accordance with the Creative Commons Attribution Non-Commercial (CC BY-NC 4.0) license, which permits others to distribute, adapt, enhance this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0>.