

## Commentary

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# Care, Convenience, Comfort, Confidentiality, and Contagion: The 5 C's that Will Shape the Future of Telemedicine

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**Abstract.** The COVID-19 pandemic has driven rapid, widespread adoption of telemedicine. The distribution of clinicians, long travel distances, and disability all limit access to care, especially for persons with Parkinson's disease. Telemedicine is not a panacea for all of these challenges but does offer advantages. These advantages can be summarized as the 5 C's: accessible care, increased convenience, enhanced comfort, greater confidentiality to patients and families, and now reduced risk of contagion. Telemedicine also has its limitations, including the inability to perform parts of the physical examination and inequitable access to the Internet and related technologies. Future models will deliver care to patients from a diverse set of specialties. These will include mental health specialists, physiotherapists, neurosurgeons, speech-language therapists, dietitians, social workers, and exercise coaches. Along with these new care models, digital therapeutics, defined as treatments delivered through software programs, are emerging. Telemedicine is now being introduced as a bridge to restart clinical trials and will increasingly become a normal part of future research studies. From this pandemic will be a wealth of new telemedicine approaches which will fundamentally change and improve care as well as research for individuals with Parkinson's disease.

**Keywords:** Parkinson disease, telemedicine, patient comfort, confidentiality, COVID-19, quarantine, health care reform, organizational innovation

In the span of a few weeks, the COVID-19 pandemic has changed—possibly permanently—the way that we care for individuals with Parkinson's disease. Telemedicine, the delivery of health care at a distance, has instantly transformed from a niche practice into the dominant means of providing care. In this commentary, we will reflect on how the fast-growing hands-on experience during this time of crisis has

shed new light on both the advantages and limitations of telemedicine. We will also look into the future, a future that will be much different than the past.

Telemedicine has long offered 4 C's: care, convenience, comfort, and confidentiality [1, 2]. Technology can make care more accessible to individuals with Parkinson's disease [3]. Many, if not most, individuals with Parkinson's disease lack access to care either due to distance, disability, or simply due to the absence of doctors [4]. While traditional clinics are accessible to individuals with early or mild Parkinson's disease, they are often inacces-

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sible to those with a later stage of the disease. In 1993, Hubble and colleagues demonstrated the ability of telemedicine in the setting of satellite clinics to deliver care to rural Kansas residents [5]. Several other programs have since demonstrated the ability to reach individuals with advanced Parkinson's disease, including those in United States nursing homes who account for up to a quarter of older adults in this country [6–8]. Finally, many individuals with Parkinson's disease remain undiagnosed, especially in parts of the world where the demand for care far exceeds the supply of specialists [9]. In Beijing, for example, the rate of undiagnosed persons with Parkinson's disease is 48%, and China has the fastest increasing rates of Parkinson's disease [10, 11]. Smartphones, which are increasingly ubiquitous, could greatly expand access to care by connecting those in need to a wide range of global clinicians [12].

In addition to increasing access, telemedicine makes care more convenient. Studies have demonstrated that a typical 30-minute office visit for Parkinson's disease door to door consumes over four hours for patients and caregivers [13]. The vast majority of that time is spent traveling and waiting. Telemedicine visits save money, avoid many miles of difficult travel for those with impaired driving ability, and reduce the risk of falls and accidents [1, 13]. The economic costs of travel and parking can exceed an insurance co-payment and thus become another major barrier limiting access to care.

Telemedicine allows patients to be evaluated from the comfort of their own home. In many ways, telemedicine represents the second generation of the classical house call. In the 1930s, 40% of physician-patient encounters occurred in the home [14]. Telemedicine enables physicians to re-enter the home and to examine the patient in their own natural setting. This setting may provide better insights into how individuals function in their daily lives. Telemedicine offers the enhanced understanding of social circumstances, and the possibility of a more patient-centered experience. The “power asymmetry” between patients and clinicians can be reduced because in telemedicine both parties are seated at eye level and both are operating in their environment. Additionally, most patients and families prefer the comfort and convenience of telemedicine visits [1].

While the privacy and security of video visits and the platforms that support them are potential serious concerns, virtual visits offer a different form of confidentiality. In-person attendance in a movement disorders clinic broadcasts to everyone present,

“I have a neurological disorder.” The confidentiality offered by telemedicine may be critically important, not only for asymptomatic individuals at (genetic) risk for Parkinson's disease, but also for the large group of individuals who are not (yet) ready to share their diagnosis with others.

Despite these four advantages, it took a fifth C, contagion, to tip the scale toward a global embrace of telemedicine (Fig. 1). COVID-19 has forced many ambulatory clinics to close, and a large proportion of traditional in-person visits to clinics have transitioned to phones or to video conferencing. This rapid transition was necessary to minimize the spread of the infectious disease, to protect the presumably more vulnerable individuals with Parkinson's disease, and to preserve personal protective equipment or other resources for those in greatest need. As a result of this change, many clinicians and patients have experienced telemedicine for the first time. The number of telemedicine visits has increased dramatically and now represent the vast majority of clinical encounters for patients with Parkinson's disease [15–17]. Given the uncertainty about COVID-19 and the potential for recurrent outbreaks, telemedicine is likely to remain an important part of Parkinson's care.

In addition to its advantages, telemedicine has well established limitations. Many elements of the physical examination (e.g., detailed assessments of eye movements, evaluating rigidity, testing of reflexes) are challenging to assess remotely [15]. Despite these limitations, numerous parts of the exam can be conducted remotely with some creativity and guidance [18, 19]. For example, with the help of a family member or friend, asymmetries in rigidity can be assessed in a seated patient by observing how the legs—when passively swung by the examiner—gradually come to a standstill (Supplementary video). Future research will be required to separate rigidity in this example from spasticity or paratonia.

The need to focus on the voice during telephone conversations could perhaps improve the accuracy of assessment of dysarthria. A telephone call can be a very simple and straightforward form of telemedicine. Some relevant information is missed when a patient is only contacted by telephone, thus missing out on the visual information. Much implicit information is provided by simply observing a patient, such as a head turning sign in the patient with an early stage of dementia. Further work will be needed to define which medical questions can be addressed using a telephone, and for which videoconferencing is preferable.

While the examination is important, 80% of medical diagnoses remain based on history, which can readily be obtained remotely [20, 21]. Indeed, Dr. James Parkinson's original description was largely based on observation (noting patients walking in the streets of London), while Sir William Osler wrote in 1892, "When well established, [Parkinson's disease] is very characteristic, and the diagnosis can be made at a glance" [22].

The digital divide, the differential access to the Internet based on geographic, social, and economic factors, is another real concern, representing a serious barrier for many people to realize the benefits of telemedicine [23]. For example, in the United States, 20% of households lack broadband access at home or have no access to a smartphone [24]. Increasing global access to these technologies will be necessary for telemedicine to grow and to address existing disparities in care.

Finally, telemedicine, which most often presents as a 1:1 visit between a specialist and a patient, does not fundamentally address the relative scarcity of Parkinson's disease specialists. Other models that use telemedicine to care for groups of patients or to apply the technology to train or increase the capacity of local clinicians will be necessary to fully address the imbalance of supply and demand [25]. Some solutions to this issue have already emerged during this pandemic, as many exercise classes and e-learning endeavors are being delivered to large groups in their homes.

Despite the limitations of telemedicine, the future holds many possibilities. Video visits will expand beyond neurologists to include many other clinicians on the multidisciplinary care team, including physical-, occupational-, and speech-language therapists, nurses, dietitians, and genetic counselors [12].

Video visits can also include family members who are in different cities or even different countries. As such, multidisciplinary care may be easier to deliver remotely and in the future can become much more family-centric. Many teams in the world now have the positive experience of performing multidisciplinary team meetings remotely, as video visits no longer require all team members to be present in the same room at the same time. Some of these telemedicine efforts will involve group visits, non-clinicians (e.g., exercise coaches), and even digital therapies (e.g., for speech-language therapy). A trial is ongoing to now formally evaluate the merits of remote speech therapy for individuals with Parkinson's disease. As telemedicine gains greater adoption, additional groups that are currently underserved may be better equipped to utilize the technology [26]. Telemedicine will also eventually merge more with traditional care where infrequent in-person visits may be combined with more frequent telemedicine visits. Clinical research, including both observational and interventional studies, will also rapidly adopt remote visits, if only out of necessity [27]. Currently, during the COVID-19 pandemic, virtually all clinical trials for Parkinson's disease worldwide are on hold, a situation that delays the promise of novel therapies for the disease.

While telemedicine may be enjoying its finest hour, its future is not entirely certain. Many of the changes in the United States (e.g., insurance coverage by Medicare, reduction of licensing restrictions) that have enabled telemedicine use during this time of crisis are only temporary [28]. In many cases, telemedicine is less financially attractive to medical centers than in-person care. Ensuring that the policy changes that have supported the rise of telemedicine become permanent will likely require political action

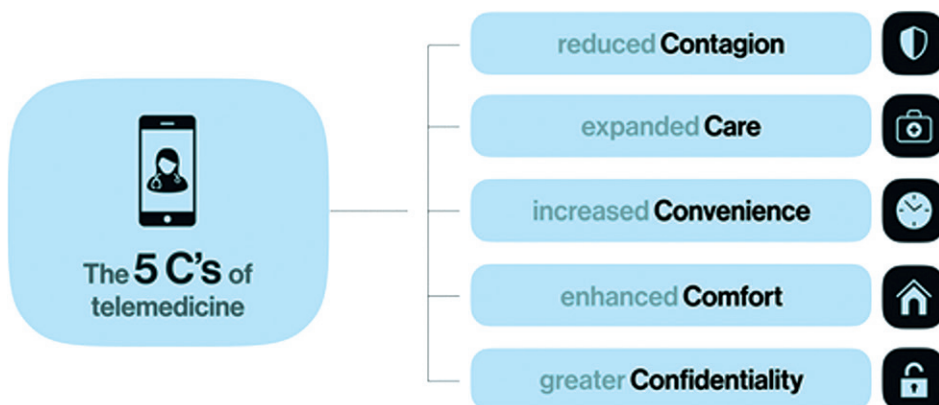


Fig. 1. The 5 C's of telemedicine.

and overcoming objections from those vested in a pre-COVID model of care. Until then, thousands of patients and hundreds of clinicians will be gaining increasing experience with telemedicine. Their experiences and needs will, to a large extent, shape the future of health care delivery. In just weeks, telemedicine has become the dominant means of care for Parkinson's disease and for most medical conditions. This radical transformation will re-shape the way we deliver care for years to come. We are just beginning to see the immense possibilities that it can offer.

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## CONFLICTS OF INTEREST

Dr. Dorsey has served as a consultant to 23andMe, Abbott, Abbvie, Amwell, Biogen, Clintrex, CuraSen, DeciBio, Denali Therapeutics, GlaxoSmithKline, Grand Rounds, Huntington Study Group, Informa Pharma Consulting, medical-legal services, Mednick Associates, Medopad, Olson Research Group, Origent Data Sciences, Inc., Pear Therapeutics, Prilenia, Roche, Sanofi, Shire, Spark Therapeutics, Sunovion Pharmaceuticals, Voyager Therapeutics, and ZS Consulting. He has received honoraria from the Alzheimer's Drug Discovery Foundation, American Academy of Neurology, American Neurological Association, California Pacific Medical Center, Excellus BlueCross BlueShield, Food and Drug Administration, MCM Education, Michael J. Fox Foundation, Stanford University, UC Irvine, and University of Michigan. He has received research support from Abbvie, Acadia Pharmaceuticals, AMC Health, BioSensics, Burroughs Wellcome Fund, Greater Rochester Health Foundation, Huntington Study Group, Michael J. Fox Foundation, National Institutes of Health, Nuredis, Inc., Patient-Centered

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Dr. Okun serves as a consultant for the Parkinson's Foundation, and has received research grants from NIH, Parkinson's Foundation, the Michael J. Fox Foundation, the Parkinson Alliance, Smallwood Foundation, the Bachmann-Strauss Foundation, the Tourette Syndrome Association, and the UF Foundation. Dr. Okun's DBS research is supported by: R01 NR014852 and R01NS096008. Dr. Okun has received royalties for publications with Demos, Manson, Amazon, Smashwords, Books4Patients, Perseus, Robert Rose, Oxford and Cambridge (movement disorders books). Dr. Okun is an associate editor for New England Journal of Medicine Journal Watch Neurology. Dr. Okun has participated in CME and educational activities on movement disorders sponsored by the Academy for Healthcare Learning, PeerView, Prime, QuantiaMD, WebMD/Medscape, Medicus, MedNet, Einstein, MedNet, Henry Stewart, American Academy of Neurology, Movement Disorders Society and by Vanderbilt University. The institution and not Dr. Okun receives grants from Medtronic, Abbvie, Abbott and Allergan and the PI has no financial interest in these grants. Dr. Okun has participated as a site PI and/or co-I for several NIH, foundation, and industry sponsored trials over the years but has not received honoraria. Research projects at the University of Florida receive device and drug donations.

Prof. Bloem currently serves as co-Editor in Chief for the *Journal of Parkinson's Disease*, serves on the editorial of *Practical Neurology* and *Digital Biomarkers*, has received honoraria from serving on the scientific advisory board for Abbvie, Biogen and UCB, has received fees for speaking at conferences from AbbVie, Zambon, Roche, GE Healthcare and Bial, and has received research support from the Netherlands Organization for Scientific Research, the Michael J Fox Foundation, UCB, Abbvie, the Stichting Parkinson Fonds, the Hersenstichting Nederland, the Parkinson's Foundation, Verily Life Sciences, Horizon 2020 and the Parkinson Vereniging.

## SUPPLEMENTARY MATERIAL

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