

A New Day: The Role of Telemedicine in Reshaping Care for Persons With Movement Disorders

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ABSTRACT: The COVID-19 pandemic has demonstrated the fragility of clinic-based care for Parkinson's disease and other movement disorders. In response to the virus, many clinics across the world abruptly closed their doors to persons with Parkinson's disease. Fortunately, a niche care model, telemedicine—first described in this journal a generation ago—emerged as the dominant means of providing care. As we adjust to a new normal, we should focus future care not on clinics but on patients. Their needs, guided by clinicians, should determine how care is delivered, whether in the clinic, at home, remotely, or by some combination. Within this patient-centered approach, telemedicine is an attractive care option but not a complete replacement for in-person consultations, which are valuable for specific problems and for those who have access. Now that many clinicians and patients have gained exposure to

telemedicine, we can better appreciate its advantages (eg, convenience) and disadvantages (eg, restricted examination). We can also create a new future that utilizes the Internet, video conferencing, smartphones, and sensors. This future will bring many clinicians to one patient, connect individual experts to countless patients, use widely available devices to facilitate diagnosis, and apply novel technologies to measure the disease in new ways. These approaches, which extend to education and research, enable a future where we can care for anyone anywhere and will help us stem the tide of Parkinson's disease. © 2020 International Parkinson and Movement Disorder Society

Key Words: telemedicine; Parkinson's disease; movement disorders; patient-centered care; delivery of health care; COVID-19

We, including the authors of this paper, are failing the Parkinson's community. We are failing to prevent the disease. We are failing to treat it adequately. And we are failing to care for all people with the condition. The status quo is simply not working.¹

Against this backdrop, the COVID-19 pandemic has changed clinical care and research for persons living with Parkinson's disease.^{2,3} In their thoughtful

viewpoint, Dr. Mulroy and colleagues highlight how COVID-19 has “obligated a fundamental re-structuring of the way in which care is delivered to patients with movement disorders.” They indicate that telemedicine is a “useful adjunct” but question its utility for establishing relationships, making initial diagnoses, and providing hands-on educational training.

Here, rather than reviewing the benefits and limitations of telemedicine^{4,5} or responding to all the valuable points that our colleagues make, we take a step back. We first evaluate the state of Parkinson's care before the arrival of the novel coronavirus. We then critique the dominant clinic-centered approach to care, provide a new lens on patient-centered care, and discuss how technology may also reshape clinical research. We hope that this discussion motivates a long overdue “fundamental restructuring” of clinical care and clinical trials.

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Current Clinical Care

The state of Parkinson's care is, for most, poor. Many individuals with Parkinson's disease are diagnosed too late or not at all. In door-to-door studies around the world, the proportion of individuals with Parkinson's disease who have not been previously diagnosed range from 12% (Rotterdam) to 100% (rural Bolivia) (Fig. 1).^{6,7} In Tyrol, Italy, it is 78%⁸ and in Beijing 48%.⁹ Even when diagnosed, most do not receive appropriate care. In the United States, which spends more on health care than any country, over 40% with the disease do not see a neurologist of any kind within 4 years.¹⁰ In Europe, over 40% do not see a Parkinson's specialist in the 2 years after diagnosis, even though such care is the first right expressed in the European Parkinson's Disease Association Charter.^{11,12}

For many, care in specialty clinics is simply inaccessible. For rural populations, where Parkinson's disease is more common, the distance and costs are often too great. In addition, many doctors and major medical centers have yet to earn the trust of some populations.¹³ For others, the disease burden is too large, and social support is too little. Dr. Allison Willis and colleagues have found that in some rural areas in the United States, care for Parkinson's disease from a neurologist is essentially absent.¹⁴ African-Americans, women, and older individuals are all less likely to receive such care.¹⁴ Our dominant care model (pre-COVID-19) in which patients travel to clinics or to medical centers to see a specialist can provide great care but only for a select few. And even in countries where

neurology services are readily available, they are not typically offered to individuals living in nursing homes, resulting in suboptimal care.¹⁵ In other words, those with the greatest need often receive the least care. We must do better.

Clinic-Centered Care

Mulroy and colleagues argue, "Just like other interventions, telemedicine and health technologies should be critically evaluated ... before becoming part of routine practice."¹⁶ No care model has been less studied, more accepted with less critical evaluation than our "routine practice."¹⁶

To our knowledge, no studies have examined the optimal frequency of visits, their duration, content, participants, or location. Similarly, no one has investigated the therapeutic benefits of the parking lot or waiting room. Most have not even asked why we provide the care we do. In designing a Parkinson's care model from scratch, few would create one that requires individuals with impaired driving ability to be driven by overburdened caregivers to complex urban centers that are difficult to navigate.¹² Yet that is exactly what we do.

Moreover, clinic-centered care is not always best for progressive disorders. Mulroy and colleagues write that "co-operative camaraderie which develops between doctor and patient may be of great solace" and that "[maintaining] this connection is therefore paramount."¹⁶ In-person encounters are valuable for establishing a relationship. But such consultations remain a

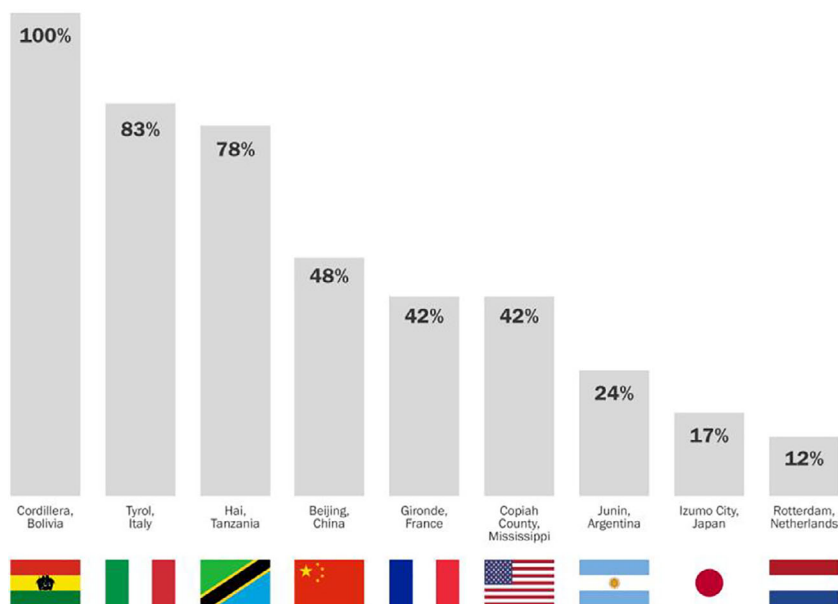


FIG. 1. Proportion of individuals with undiagnosed Parkinson's disease by region.¹ Reproduced courtesy of Dorsey R, Sherer T, Okun MS, Bloem BR. *Ending Parkinson's Disease*. All rights reserved. [Color figure can be viewed at wileyonlinelibrary.com]

luxury for a small proportion of patients. And even for the fortunate few who receive this personal care, the connection is frequently not maintained. As Parkinson's disease progresses, we often leave our patients to fend for themselves. In some of the world's top Parkinson's clinics, less than 10% of patients have stage IV or V disease.¹⁷ Where are they? At home or in nursing homes and often invisible to us. In the United States, 2 million Medicare beneficiaries, some with Parkinson's disease, are homebound.¹⁸ Another 100,000 reside in long-term care facilities, where the much-desired connection to their neurologist and other regular providers is typically lost.¹⁹

Because of these and many other disadvantages with routine care, the National Academy of Medicine wrote in 2001, "Between the health care we have and the care we could have lies not a gap, but a chasm."²⁰ To cross the chasm, health care should be safe, effective, patient-centered, timely, efficient, and equitable. Yet current Parkinson's care frequently fails to meet any of these aims.^{12,21}

Patient-Centered Care

In Parkinson's care, the patient is the sun, not the physician and certainly not the clinic. Services should revolve around the patient's needs.²² Patient-centered care is "respectful of, and responsive to, individual patient preferences, needs and values, and [ensures] that patient values guide all clinical decisions."²⁰

This care could be provided in the clinic, and some patients prefer and need such care. The clinic is excellent for evaluating patients with uncertain diagnoses, conducting a detailed physical examination, and providing immediate access to diagnostic testing. Similarly, care in major medical centers is well suited for advanced treatments of Parkinson's disease where substantial surgical experience²³ and co-location of multiple specialists are paramount.²⁴

For some patients, care could be delivered in their own home.²⁵ In the 1930s, the house call was the primary means of providing care, and 40% of patient-physician encounters occurred there.²⁶ Dr. Jori Fleisher and colleagues have demonstrated the feasibility and value of providing such care from a Parkinson's specialist, nurse, and social worker.²⁷ House calls are the gold standard of patient-centered care but are time- and resource intense. Indeed, a recent study in Germany found that many patients with Parkinson's disease were ineligible to receive a house call by a Parkinson's nurse specialist simply because travel distances were too long.²⁸

An attractive alternative is to offer such house calls via telemedicine. Telemedicine uses the Internet and video conferencing software as tools (like a car) to

extend the reach of Parkinson's specialists and other clinicians. In *Movement Disorders* 27 years ago, Dr. Jean Hubble and colleagues demonstrated that telemedicine can provide care to rural residents in Kansas.²⁹ Since then, numerous studies have found that patients value the care, convenience, and comfort that telemedicine offers.³⁰⁻³³ In a randomized controlled trial of "virtual house calls," some even found it offered more personal care than the clinic.³² The near-universal finding across all telemedicine studies is that patients like it.^{34,35} As Mulroy and colleagues indicate, some patients still appreciate and need an in-person assessment to create an intimate doctor-patient relationship, establish a new diagnosis, or identify reasons for changes in the disease course. The key point is that telemedicine should be a standard part of our clinical armamentarium of services available for optimal patient care (Fig. 2).

COVID-19

Yet, despite mounting evidence for its feasibility and benefits, especially to patients, telemedicine for Parkinson's disease has remained a niche.⁴ It took a contagion to demonstrate the value of telemedicine to patients, physicians, and insurers. With vastly expanded (temporary) insurance coverage in the United States, telemedicine use increased 10- to 100-fold and temporarily became the dominant means of providing care for many clinicians and medical centers.

Although initial experiences with any new technology can be frustrating, many clinicians and patients in a short time span have rapidly adopted a new care model. Although published studies of this rapid transition are lacking, presumably hundreds, if not thousands, of individuals in the past few months have been diagnosed with Parkinson's disease by telemedicine. At the height of the pandemic in Italy, free phone consultations with nurses provided camaraderie and solace to nearly 400 Italians with Parkinson's disease.³⁶ Based on triage, over 100 of these subsequently underwent remote video consultations with neurologists, physiotherapists, psychologists, speech therapists, occupational therapists, or some combination of these. Over two-thirds of patients provided positive feedback.³⁶

As Mulroy and colleagues rightly point out, the in-person neurological examination is superior to video, in terms of both accuracy and comprehensiveness, although creative means of assessing rigidity and other parkinsonian features remotely are emerging.^{16,33} That said, 80% of diagnoses are based on history alone.³⁷ Another proportion can be gathered from remote examination. Three of Dr. James Parkinson's seminal descriptions were based on observing individuals walk the streets of London.³⁸ Sir William Osler wrote in 1892, "When well characterized, Parkinson's disease

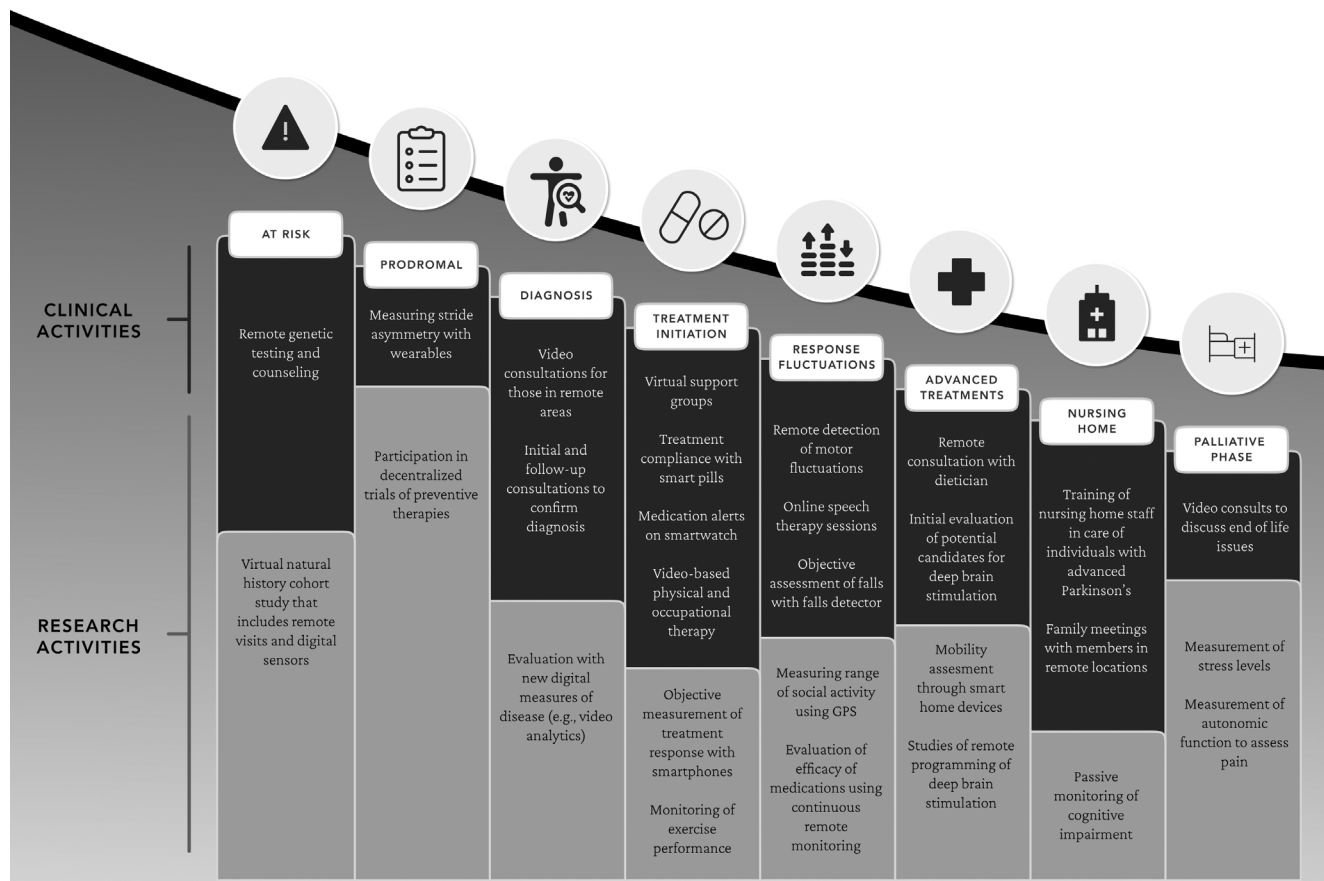


FIG. 2. Map of potential applications of telemedicine to care and research.

can be diagnosed at a glance.”³⁹ More than possibly any other field in medicine and certainly in neurology, we often rely on home-based videos for diagnosis, education, and even competition. But when a diagnosis remains uncertain by video, we can ask patients to come to the clinic (or we can conduct house calls) for further evaluation.³⁷ Classically, modern medicine has embraced the concept that a Parkinson’s diagnosis can and should be made on a single visit. This need not be the case. A differential diagnosis could be constructed in the first encounter and followed up with additional telemedicine visits or, if needed, an in-person appointment. In many cases, telemedicine, if used properly, can make and confirm the diagnosis.

Telemedicine visits are qualitatively different from traditional in-clinic appointments. Seeing patients in their own living environment offers insights into the lives of patients that are missed in the clinic. We have seen patients with their families, friends, and pets in their kitchens, bedrooms, living rooms, offices, and neighborhoods. We have observed patients have terrible bouts of freezing navigating their crowded living rooms while they walk with ease in our clinics, much to everyone’s frustration. We have also seen individuals at their happiest and their saddest. Once when we asked a

patient to stand up to see her walk, the patient’s daughter adjusted the camera and revealed a ring of tissue around her mother’s chair. The mother had spent the entire morning crying.

Digital Measures and Virtual Research Studies

The COVID-19 pandemic has halted the vast majority of clinical research studies and postponed countless others.⁴⁰ This situation has highlighted the need for new measures of Parkinson’s disease. Our most commonly used scale, the MDS-UPDRS, was not designed for remote administration.⁴¹ The time for objective, sensitive, frequent real-world assessments has arrived to unmask or quantify features previously invisible to or underappreciated by clinicians.⁴² Various approaches are available. Smartphones can objectively record a patient’s performance on a series of self-completed tasks (eg, finger tapping) generating an objective “mobile Parkinson disease score” or can detect tremor not appreciated by clinicians.⁴³ Body-worn sensors can measure gait or detect falls; some have been cleared by regulatory authorities for use in clinical practice.⁴⁴⁻⁴⁶

Passive in-home sensors can also provide novel insights into the disease.

Some of these digital outcome measures are ready for use. But we agree with Mulroy and colleagues that more work remains to develop reliable algorithms and to validate their use in a patient's home.⁴⁷ In the short term, remote (or home) visits can enable current studies to resume. In the long term, virtual visits and digital measures can enable a broader geographic reach, capture objective real-world data, and foster participant-centered research studies.

A New Day

We are glimpsing what is possible when we use new technology to improve clinical care and enhance research. One of our patients in rural upstate New York sees a physical therapist for exercise training twice weekly. The only differences now are that the physical therapist is located 300 miles (500 km) away in Boston, Massachusetts, and that he is part of a class with 100 patients. In Zimbabwe, a new phone app has capitalized on the latest dance craze and coupled it to machine learning to diagnose individuals with Parkinson's disease in areas where clinicians are scarce.⁴⁸ These innovations are just the beginning.

In addition, although the focus of this paper has been on Parkinson's disease, the lessons and experiences from this field likely apply to a wide range of other movement disorders.⁴⁹ Additional research is needed to outline the benefits and limitations of telemedicine and alternative care models to individuals with other parkinsonian disorders, ataxia, Huntington's disease, and many other diseases. In addition to exploring additional conditions, considerable work remains to reach the least well served. Many lack access to the technologies that enable telemedicine. For example, in the United States, 20% of households lack broadband access, and a similar number do not have smartphones.⁵⁰ This digital divide should be bridged by expanding efforts to make such access universal.

Mulroy and his colleagues conclude, "This is a critical time when, as physicians, we are charged with shaping our future clinical practice."¹⁶ We agree. We know that clinic-based practice, valuable as it may be, meets the needs of only a select few. COVID-19 has demonstrated its fragility and caught many of us and our patients flat-footed. As we regain our balance, we should embrace a new future—a future that (1) facilitates timely diagnoses and better care of Parkinson's disease, (2) embraces new approaches to clinical research, and (3) welcomes new technologies and models of clinical care.

Charcot, the father of modern neurology, said, "To me, the practice of medicine has no real autonomy: it

exists by borrowing and making new application of ideas from other disciplines. Without a constant reinfusion from other scientific domains, the practice of medicine would soon become an outmoded routine."⁵¹ Our routines are outmoded. We, like Charcot, need to borrow and apply ideas from other disciplines and extend our expertise and care to all. ■

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