REVIEW

The Past, Present, and Future of Telemedicine for Parkinson's Disease

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ABSTRACT: Travel distance, growing disability, and uneven distribution of doctors limit access to care for most Parkinson's disease (PD) patients worldwide. Telemedicine, the use of telecommunications technology to deliver care at a distance, can help overcome these barriers. In this report, we describe the past, present, and likely future applications of telemedicine to PD. Historically, telemedicine has relied on expensive equipment to connect single patients to a specialist in pilot programs in wealthy nations. As the cost of video conferencing has plummeted, these efforts have expanded in scale and scope, now reaching larger parts of the world and extending the focus from care to training of remote providers. Policy, especially limited reimbursement, currently hinders the growth and adoption of these new care models. As these policies change and technology advances and spreads, the following will likely develop: integrated care networks that connect patients to a wide range of providers; education programs that support patients and health care

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providers; and new research applications that include remote monitoring and remote visits. Together, these developments will enable more individuals with PD to connect to care, increase access to expertise for patients and providers, and allow more-extensive, less-expensive participation in research.

Key Words: telemedicine; Parkinson's disease

Telemedicine or "healing at a distance"[1] involves remote delivery of health care services using telecommunications technology, and its primary purpose is to increase access to care. Currently, the majority of individuals with Parkinson's disease (PD) have very limited access to care.[2] In wealthy nations such as the United States, over 40% of individuals over 65 years old who have been diagnosed with PD do not see a neurologist and are approximately 20% more likely to fracture their hip, be placed in a skilled nursing facility, and die.[3] In less wealthy nations such as Bolivia, door-to-door prevalence studies have found that none of the individuals identified with PD have sought, much less received, care for their condition.[4]

As populations age globally, the burden of PD will increase rapidly. Between 2005 and 2030, the number of individuals with PD globally will more than double,[5] and most of that growth will occur in developing economies where care is very limited or absent (Fig. 1). For example, in China, 68% of rural and 37% of urban cases of PD are not diagnosed,[6] and the country has few neurologists and less than 100 movement disorders specialists[7] to care for over 2 million individuals with PD.[5] The rising numbers of individuals with PD in China and most of the world will far outstrip the ability to develop more neurologists, so technology-enabled solutions will be required to increase access to available providers.

With technology, more individuals can connect directly to care or indirectly to the expertise that they need. Fueled by falling telecommunications costs,[8] the global market for telemedicine services is growing rapidly.[9,10] In some fields, such as radiology, the remote transmission of clinical data is longstanding and an inherent part of practice.[11,12] Within neurology,[13] telestroke is rapidly increasing[14] and has brought access to stroke specialists and therapeutics to millions of individuals.[15]

Movement disorders such as PD are well suited to telemedicine because they are primarily visually assessed, generally limit mobility, and require ongoing multidisciplinary care.[16] Movement disorders expertise is associated with greater adherence to quality indicators,[17] higher patient satisfaction,[18] and improved health outcomes, including lower mortality in PD.[3] Internet-enabled communications, especially interactive audio and video conferencing, can increase access to that expertise. This report examines the past, present, and future applications of telemedicine to PD.

Past: Pioneering Efforts

Two decades ago, Hubble et al. found that valid motor assessments of PD could be conducted remotely and that "virtually all patients viewed [interactive video conferencing] as a means of accessing better

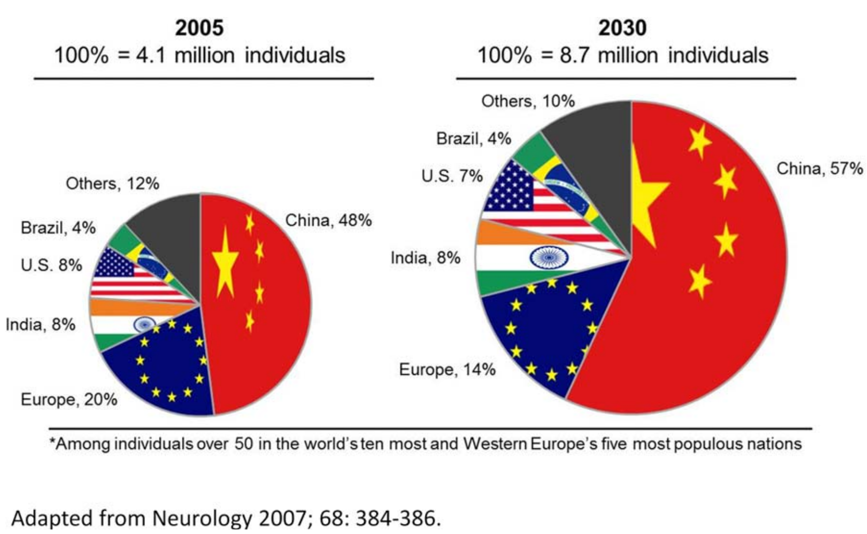

FIG. 1. Projected number of people with PD in the world's and Europe's most populous countries, 2005-2030.

health care."[19] Subsequent studies confirmed the validity of remote assessments[20-22] and reported on Internet-enabled communications in Germany,[23] Italy,[24] and the United States.[25] However, the literature published to date on telemedicine and PD is quite limited. For example, a PubMed search of "telemedicine" and "Parkinson disease" returns 53 articles, of which only nine report on actual care delivery.[21,23,25-31] These studies plus a recent case series[32] have all been small (n = 1-78 patients) and primarily aimed at establishing the feasibility of providing specialty care from either a neurologist or speech therapist to remote patients (Table 1).

In addition to improving care, the published literature actually has many reports on novel remote monitoring devices, beginning with a published report from 2002 on computer exercises that support the diagnosis of PD.[33] Additional remote monitoring devices that have been evaluated include wearable step counter[34] and gait sensors,[35] computer-based assessments of motor tasks (e.g., rapid alternating movements),[36-38] continuous electromyography,[39] noninvasive speech assessments,[40] and, more recently, smart phone applications that measure tremor,[41] among other symptoms. These studies have primarily assessed the validity and performance of remote assessments and have only recently linked remote monitoring to changes in care or in assessments of therapeutics for PD.[42,43]

In the past, available technology limited applications of telemedicine. Visits typically had to be conducted over interactive video conferencing "units" that were expensive (in excess of $10,000) to purchase and maintain. Such units were based in dedicated centers that both patients and providers had to access and usually required another individual to provide technological support to both the provider and the patient. In addition to the high cost, the quality of the connection was frequently poor, such that common portions of the UPDRS could not be performed consistently.[25] Today, those limitations are rapidly disappearing for many parts of the world. Currently, 2.7 billion people, or 39% of the world's population,[44] have broadband access, and 1.4 billion smart phones can enable video conferencing.[45]

Remote encounters are also inherently limited by difficulty with some parts of standard assessments and the lack of physical interaction. From an examination standpoint, neither rigidity nor balance (using the pull test) can be assessed remotely. In addition, other potentially key components of the neurological exam, such as eye movements and reflexes, are harder or impossible to assess. Even components that can be visually assessed (e.g., tremor) are harder to evaluate on a video call, which focuses on the face and shoulders at the expense of the extremities. These concerns are especially important for new patient encounters. Perhaps more important, many worry about the quality of the doctor-patient relationship. In general, older systematic reviews have found that the effect of telemedicine on doctor-patient communication is favorable among published studies[46] and that patient satisfaction is good.[47] In PD, telemedicine studies report high degrees of patient satisfaction[21,25,29] and preference for remote visits,[21,27] suggesting that either the relationship quality is not adversely affected, is qualitatively different,[32] or is offset by gains in other factors (e.g., reduced travel).

Present: Increasing Access to Care

Although published studies of telemedicine in PD are limited, current telemedicine programs are increasing and growing rapidly in many parts of the world. A 2012 survey of leading U.S. neurology departments, for example, found that over 85% have or planned to implement telemedicine programs within the next year and that, next to stroke, movement disorders was the most common application.[48] As detailed by members of the International Parkinson and Movement Disorder Society (MDS) Task Force on Telemedicine in the Appendix, telemedicine programs for PD of various stages of maturity are operating globally and focus on both care and educational activities.

Some of the most mature telemedicine programs are found in Canada, the Netherlands, and parts of the United States. In Canada, the largest provider of telemedicine services is the Ontario Telemedicine Network,[49] which is funded primarily by the Ministry of Health and Long-Term Care. Last year, over 300,000 total patients and over 600 with movement disorders received care by telemedicine. Patients receive care by going to local studios in hospitals, clinics, or offices in their community and connecting remotely to movement disorder specialists. Telemedicine visits are reimbursed at the same rate as face-to-face care in addition to a telemedicine premium to encourage use. Malpractice insurance covers telemedicine, and, generally, physicians may see patients in different provinces.

In the Netherlands, the ParkinsonNet infrastructure,[50-52] a nation-wide network of specialized health care professionals in regional multidisciplinary teams, use different e-health solutions to improve communication and quality of care.[53] The technological applications are diverse and allow patients to access care from providers from their homes. Among the applications are self-monitoring programs for exercise, interactive medication adherence programs, and self-care portals. A telehealth video system allows patients to communicate securely with single professionals or even a multidisciplinary team. Creating a sustainable economic model through either self-pay or health

TABLE 1. Published telemedicine studies on care delivery

Authors	Year	Country	Sample Size (No. of Patients)	Intervention	Design	Results
Samii et al.[25]	2006	United States	34	Video visits into eight satellite clinics over 3 years	Longitudinal observational study	Patients and providers satisfied with the technology; visits saved 1,500 attendant travel hours, 100,000 kilometers in travel, and $37,000 in travel and lodging
Biglan et al.[28]	2009	United States	1	Video visits with a nursing home resident	Case report	Visits resulted in improved motor and cognitive symptoms
Howell et al.[30]	2009	United Kingdom	3	Online speech therapy with the Lee Silverman Voice Treatment	Case series	Broadly similar treatment gains between those treated over the internet and those treated in person
Constantinescu et al.[26]	2010	Australia	1	Online speech therapy with the Lee Silverman Voice Treatment	Case report	Patient was very satisfied and preferred online sessions for future treatment.
Dorsey et al.[21]	2010	United States	14	Video visits into a nursing home	Randomized, controlled trial of video visits versus usual care	Thirteen of fourteen participants opted to receive care by telemedicine in the future. Quality of life and motor performance improved in those randomized to telemedicine.
Constantinescu et al.[29]	2011	Australia	34	Online speech therapy with the Lee Silverman Voice Treatment	Randomized, controlled trial of online versus face-to-face speech therapy	Online speech therapy was noninferior to face-to-face therapy on mean change in sound pressure level. Online participants were highly satisfied.
Dobkin et al.[31]	2011	United States	20	Telephone-based cognitive-behavioral therapy for 10 weeks	Observational study of phone-based cognitive behavioral therapy	Phone-based therapy improved depression, anxiety, negative thoughts, and coping and may be a feasible and helpful approach.
Marzinzik et al.[23]	2012	Germany	78	Patient-recorded videos of their symptoms sent online to treating team for 30 days	Observational study	Patients and a blind rater rated their PD as improved at the end of the study.
Dorsey et al.[27]	2013	United States	20	Video visits into the home	Randomized, controlled trial of video visits versus in-person care	Home video visits are feasible, save patients 100 miles of travel and 3 hours of time per visit, and may offer similar clinical benefit to in-person care.
Venkataraman et al.[32]	2013	United States	55	Video visits into the home	Case series	Virtual visits into the home for new patients are feasible, results in changes to care, and are well received.

insurance reimbursement for these solutions remains a challenge.

Telemedicine is growing in the United States, especially where the financing and delivery of health care are integrated. For example, telehealth began in the Department of Veterans Affairs (VA) in 1968 and has recently expanded. The 2013 VA Performance and Accountability Report indicates that in 2013, "VA's provision of telehealth-based clinical services has grown by 24 percent, thereby increasing access to care for rural Veteran patients and reducing avoidable travel."[54] Telehealth in the VA is divided into three modalities: home telehealth for transmission of data, such as vital signs from veterans' homes to the VA; store and forward for transmitting stored images for interpretation; and clinical video telehealth for live video encounters from remote VA sites or directly from veterans' homes. These programs span clinical medicine, education, and research, and 603,532 of 5.5 million veterans receive VA care by telehealth.[54] Currently, over 400 veterans with PD receive some form of care by telehealth, and one of the largest randomized, controlled trials of telemedicine for PD (n = 87) is currently underway at the Philadelphia VA.

As with the VA, Kaiser Permanente, a large, prepaid integrated delivery system in the United States, has widely adopted telehealth programs into its care model. Kaiser Permanente in northern California makes wide use of virtual visits, including e-mail, phone, and, more recently, video visits. Overall, the number of these virtual visits has increased from 4.1 million in 2008 to 10.5 million in 2013. In the past 2 years, several hundred video-based consultations for both new and follow-up patients—which can take place from the home—have occurred for neurological disorders, including movement disorders, pediatric neurology, and neuro-oncology. By 2016, the chief executive officer of Kaiser Permanente in northern California projects that the number of virtual (email, phone, and video) visits will surpass the total number of office visits.[55]

Medicare, the United States' universal health insurance program for individuals older than 65, considers telemedicine a cost-effective alternative to traditional delivery of medical care in rural areas,[56,57] but only reimburses for telemedicine services delivered in health professional shortage areas.[58] Some providers, such as the Gundersen Health System in Wisconsin, have successfully developed telemedicine programs for PD that provide care to satellite clinics, but such programs are generally rare and relatively small.

Where the distribution, but not the number, of neurologists is the issue, telemedicine programs focus on direct care provision to patients. However, for many parts of the world, the absolute number of neurologists, especially movement disorders specialists, is insufficient to care for the population with PD. In these areas, including Cameroon and China, for example, nascent telehealth programs—supported by the MDS—seek to increase the ability of local providers, including neurologists, internists, and other health professionals. These programs make use of interactive video lectures and, in some cases, provide remote access to a PD specialist to assist in the care of a patient.

Policy issues, especially reimbursement, currently represent the primary limitation to current telemedicine programs. Where virtual visits are reimbursed, either in Canada or the United States, they flourish. However, in the Netherlands and most of the United States, limited or absent reimbursement hinders their broader adoption. Medicare policies, in particular, incent care to be provided in high-cost centers. For example, Medicare reimbursement for a follow-up visit for PD is approximately \$200 in a hospital-based clinic, \$100 in a community-based clinic, and \$0 for a virtual visit into the home.[56,59] Such policies act to ensure that many of those with the least access (e.g., live in nonurban environments) and greatest need (e.g., have the greatest disability) go without care from a specialist. Other policy barriers include the requirement to be licensed in the state where the patient is located, which has limited effect in large states (e.g., Texas), but profound effect in smaller states that do not have any PD specialists (e.g., Delaware).

Future: Emergence of Telehealth

Potential applications of telemedicine will expand as the pace of technological innovation and adoption accelerates. In the future (Fig. 2), "telehealth" applications will expand to include care, education, and research. For care, as the experience in Canada and Kaiser Permanente suggests, the scale of virtual visits will expand rapidly as reimbursement policy, which lags innovation, catches up. Once reimbursed, virtual visits will likely become more attractive as a result of the care, convenience, and comfort[32] they offer. They will also be viewed as a lower-cost alternative in place of expensive clinic space for providing chronic care management. Integrated delivery networks, such as ParkinsonNet and the VA, will also develop and offer a broader range of services from a diverse set of providers, such as therapists, exercise trainers, and dieticians, that will extend well beyond the traditional doctor-patient relationship. In addition, the technology will permit the delivery of care at scale (one exercise trainer coaching many patients) and enable asynchronous means of communication, such as forwarding of video clips of abnormal movements for subsequent review.[23]

The biggest technological change will be the rapid ascent of smart phones and other mobile computing

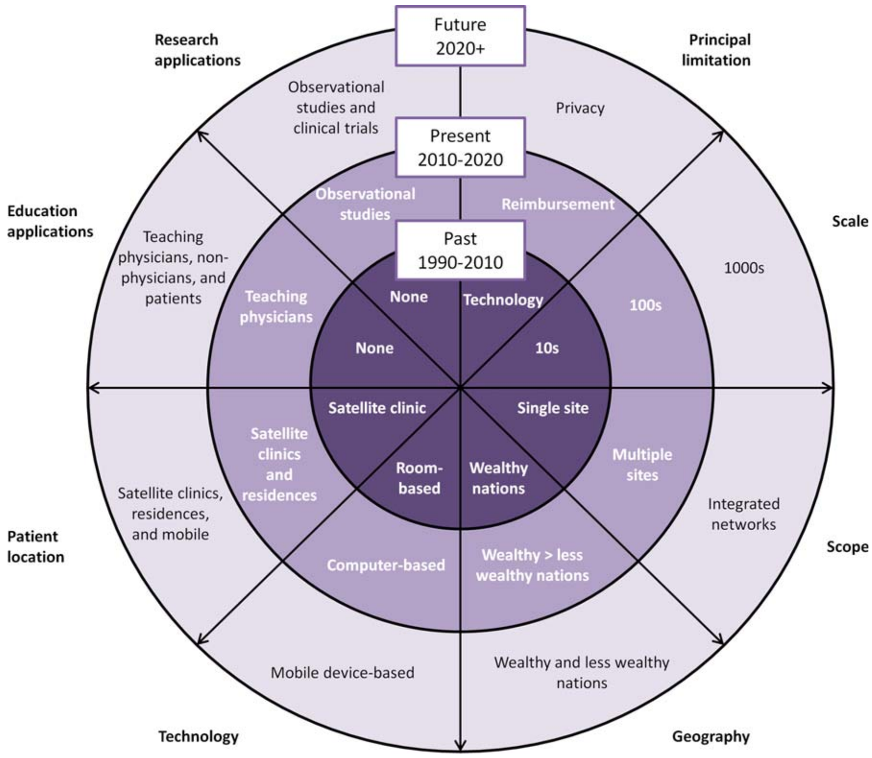

FIG. 2. Expanding dimensions of telemedicine for PD.

devices that will exceed 3 billion, or nearly half the world's population, by 2017.[60] Such devices will be instrumental in providing care in developing economies, such as China, which has the world's largest number of mobile phone users,[61] but where the traditional medical infrastructure (hospitals, clinics, and physicians) is underdeveloped. In these areas, care will likely be delivered to individuals with PD by less-trained health professionals supported by point-of-care or other mobile solutions.

These technology-enabled solutions will also support the education and training of health professionals. In the United States, one prominent model is called the Extension for Community Healthcare Organizations, which uses video conferencing technology to train local primary care providers to provide specialized chronic care (e.g., hepatitis C) management for remote populations.[62] With interest of local providers and financial support, such models could be extended to PD in the United States and globally. These models will be especially important in areas of the world where neurologists will have to oversee or support the care of the majority of individuals with PD who do not see a specialist.

To date, telemedicine has had limited effect on the conduct of research in PD, but that will change. Participation in clinical trials in neurodegenerative conditions is currently limited to a small proportion of the population. In Alzheimer's disease, home visits would increase the participation of caregivers and individuals with the condition.[63] Increasingly, home visits can and will take place virtually. Their initial application could be to confirm self-reported diagnoses of PD in registries or to follow the natural history of genetically defined subpopulations of individuals with PD (e.g., LRRK2 carriers) who may be geographically dispersed or located in areas of the world where neurological expertise is limited. Such models could save substantial time and travel costs, allow for centralized assessments that reduce variability, and reduce the need and cost for multiple sites. Over time, video research visits could be incorporated into clinical trials to assess eligibility for trial participation, conduct interim safety assessments (akin to audio calls currently), or follow participants longitudinally post–final efficacy assessments (e.g., in open-label follow-up). Such remote assessments could pave the way for entirely, or nearly entirely, virtual clinical trials that have been piloted for other conditions,[64,65] and may be particularly valuable for trials targeting patients with advanced disease or PD dementia.

Perhaps the greatest change in the future will be the application of technology to remote monitoring of patients or study participants.[66] Current outcomes measures in PD are subjective, episodic, and generally insensitive to change over short periods of time, leading to the need for expensive, large-scale, long-duration studies to see whether a particular intervention works.[67] The number of devices designed to measure the symptoms of PD is increasing rapidly. Whether assessing motor activity, gait, or voice, such measures promise more objective, frequent, and sensitive assessments of the disease.[22,68] These assessments will increasingly be incorporated into care and research for individuals with PD. Early adoption is likely to occur in advanced cases that are managed with more expensive technologies, such as DBS or levodopa continuous intestinal gel.[69] As with pacemakers and defibrillators, deep brain stimulators can gather either data on stimulation[70] or—through built-in accelerometers—data on activity. Such data can be captured remotely and guide optimization of stimulation parameters, pharmacological, or nonpharmacological management. Labor-intensive therapies, such as L-dopa infusions, could benefit from remote monitoring to adjust medication or support patients and their families. In fact, AbbVie, which markets L-dopa continuous intestinal gel, is conducting a pilot study to determine the utilization of health professionals when provided by telemedicine.[71]

These new technological innovations will bring their own concerns, chief of which is likely to be privacy. With time, individuals may be increasingly concerned about data captured regarding their activity or their location. Whereas such data could be helpful in understanding the effect of PD on individuals or for gauging response to therapy, deidentifying such data, restricting its use, and protecting it from others will be challenges. The monitored life may lead to better health outcomes, but the downside of potential privacy breaches may become increasingly real and common. In addition to privacy, the future will require rigorous evaluation of the new devices to determine their feasibility as sensors, correlation with current measures, and ability to detect subclinical signals. Enhanced understanding of the disease, its fluctuations, and additional sources of disability could lead to better care and quicker evaluation of novel therapies for PD.

Telemedicine has tremendous promise and potential for PD. Realizing this potential will take time, enabling policies, and a willingness to experiment with new care and research models by patients, a wide range of providers, and sponsors. Such experimentation could greatly expand access to care, facilitate participation in research, and enhance our understanding of PD.

Appendix

Members of the International Parkinson and Movement Disorder Society (MDS) Task Force on Telemedicine described the following telemedicine programs operating around the world. Whereas they represent a convenience sample of programs, they highlight both mature and new programs focused on care, education, and specialized programs on DBS.

Mature Programs

Canada

In Canada, telemedicine programs are mature and supported by provincially funded universal health care systems. The largest system is the Ontario

Courtesy of Ontario Telemedicine network, http://otn.ca/en

APPENDIX FIG. 1. The area served by the Ontario Telemedicine Network and its partners.

Telemedicine Network (OTN),[49] a nonprofit corporation funded primarily by the Ministry of Health and Long-Term Care. Last year, over 300,000 patients received care by telemedicine at more than 1,600 sites (Appendix Fig. 1). Over 900 physicians regularly use the network, with more than 50% growth in the number of patients served in the last year. Visits for mental health and addictions comprise over 60% of all visits, but the OTN serves all of medicine, including an active 24-hour telestroke program.

The government-funded health care system reimburses physicians at the same rate as face-to-face care plus an additional telemedicine premium to encourage use (Appendix Table 1). Malpractice insurance supports telemedicine, and there are no major licensing issues for physicians seeing patients in different provinces. The network comprises both expensive, room-based video systems and newer, personal computer-based solutions, enabling physicians to connect from their homes, offices, or institutions. Educational programming is vast and is well integrated into medical education.

The Center for Movement Disorders in Markham, Ontario, Canada, began seeing patients with PD, Huntington's disease, and other movement disorders in 2001. Currently, over 600 patient visits utilize telemedicine each year, and the numbers are growing. Initial face-to-face visits establish patients in the practice, and follow-up assessments take place by videoconferencing. Patients go to studios located in hospitals, community health clinics, physician offices, and nursing outposts in their communities, staffed largely by nurses and other health care professionals. The local telemedicine coordinator interviews patients 15-30 minutes before their appointment and then faxes the information to the Center for Movement Disorders for the visit. With the community-based locations, technical problems and interruptions in service remain rare. An electronic medical record system generates reports and prescriptions, and the telemedicine coordinator may set up referrals for local services, such as physiotherapy, social work, and occupational therapy, during the visit. The primary care physician manages imaging and lab testing. The providers advise patients to contact the neurologist between assessments if changes occur or questions arise. If a patient is hospitalized locally, videoconferencing assessments can be performed with the local physician present to manage the patient's PD.

Patients are highly satisfied with telemedicine. Of 73 patients surveyed at satellite clinics who had been assessed in person and then followed by telemedicine, 90% reported that the telemedicine experience was the same or better than face-to-face visits. They cited proximity to home, reduced travel time, and lower travel risks as advantages. However, a minority did find the visit impersonal and missed having more intimate physician contact. Some reported difficulties communicating sensitive problems in this setting, and some have chosen to come to at least one assessment in person on an annual basis as part of their ongoing care. Despite these limitations, however, telemedicine has become an integral and mainstream part of Canada's health care system.

Netherlands

In the Netherlands, the ParkinsonNet infrastructure,[50-52] a nation-wide network of specialized health care professionals who work together in regional multidisciplinary teams, uses various e-health solutions to improve communication and quality of care.[53] ParkinsonNet includes a limited number of specialized professionals, and various telehealth solutions have been developed to provide access to high-quality care from these providers in patients' homes.

Technology applications have focused on supporting self-monitoring with Web applications, stimulating physical activity using devices such as activity monitors, which display workouts on Web-based portals,[72,73] home trainers fitted with interactive computer screens, and increasing medication adherence with interactive medication dispensers and Web applications, empowering patients using Web-based self-care portals that give patients insight into their current medical situation and progression,[74] and facilitating knowledge exchange through Web-based communities.[75] A customized telehealth video system allows patients to communicate securely with single professionals or even a multidisciplinary team. Some of these solutions are in place and widely adopted, whereas others remain in development; however, generating a sustainable economic model for these products through purchase by patients or doctors or reimbursement by health insurers remains a challenge.

Because patients benefit from multidisciplinary care,[16] ParkinsonNet has a widely used, public, online tool called Parkinson Healthcare Finder,[76] which allows the public to find and self-refer to professional PD experts, who display their previous training and caseload on the Healthcare Finder. A national registry of health care claims by Dutch patients with PD allows health care professionals to benchmark products while giving patients insights into quality of care and clinical outcomes.[77]

United States

Health care delivery in the United States is expensive, largely decentralized, and complex.[78] Various health care programs include the Department of Veterans Affairs (VA), prepaid health plans, such as Kaiser Permanente, private health insurers, and Medicare, the universal health program for individuals older than 65. The aims and economics of each program differ, and telemedicine applications in the United States reflect this diversity.

APPENDIX TABLE 1. Telemedicine models for PD in Canada and the United States

Country/model	Location of patient	Visit type	Reimbursement
Canada			
• Ontario Telemedicine Network	Satellite clinic	Follow-up	Yes, and above in-person encounter
United States			
• Veterans Health Administration	Satellite clinic and home	New and follow-up	Yes
• Kaiser Permanente	Home	New and follow-up	Yes, covered as part of prepaid health plan
• Nursing homes	Nursing home	New and follow-up	Yes, in limited geographies
• Rural clinics	Satellite clinic	Follow-up	Yes, in limited geographies
• Homes	Home	New and follow-up	No

Veterans Health Administration

Telehealth in the United States was developed and implemented by the VA in 1968 and has recently expanded rapidly. The 2013 VA Performance and Accountability Report indicates that in 2013, "VA's provision of telehealth-based clinical services has grown by 24 percent, thereby increasing access to care for rural Veteran patients and reducing avoidable travel."[54] Telehealth is divided into three modalities: home telehealth, for transmission of data such as vital signs from veterans' homes to the VA; store and forward for transmitting stored images for interpretation; and clinical video telehealth for live video encounters from remote VA sites or directly from veterans' homes (Appendix Fig. 2). These programs span clinical medicine, education, and research, and 603,532 of 5.5 million veterans receive their VA care through telehealth.[54]

The six nation-wide VA Parkinson's Disease Research, Education, and Clinical Centers (PADRECCs), which are multidisciplinary centers of excellence for veterans with PD,[79] are uniquely positioned to implement and study telehealth in PD. Within PADRECCs, video telehealth programs have existed for over 10 years.[25,80] Services include new patient consultations and follow-up care, DBS pre- and postoperative evaluations, patient and caregiver educational programs, and provider-to-provider consultations. These programs have largely utilized live video encounters with local VA outpatient centers, but, more recently, have included video visits with patients in their homes. VA policies allow provider consultation across state lines without additional licensure and credentialing. Currently, over 400 veterans with PD receive some care through telehealth. One of the largest randomized, controlled trials of telehealth in PD ($n = 87$) is underway at the Philadelphia VA PADRECC. Results are expected to guide future development as implementation success and other outcomes are measured. Additionally, home monitoring of motor symptoms using quantitative assessment tools,[38] such as the Great Lakes NeuroTechnologies' Kinesia system,[81] will be piloted soon.

Future program development includes mental health, physical and speech rehabilitation, social work, palliative care services, and education programs, and challenges include organizing and implementing these programs in ways that are effective, standardized, and sustainable.

Kaiser Permanente

Kaiser Permanente is a large, prepaid, integrated U.S. health care delivery system. Kaiser Permanente in northern California has nearly 8,000 patients with PD as well as five movement disorders specialists. To improve access, Kaiser Permanente has leveraged its integration and universal electronic medical record to utilize telemedicine, including telephone calls, secure e-mails, and video appointments.

Virtual visits use videoconferencing, for which patients must complete an online consent form. The treating physician creates an encounter note for the visit in the patient's medical record. Patients connect with providers at designated times from home. In the past 2 years, several hundred video-based patient consultations for both new patients and follow-ups have been registered in the system, covering movement disorders, pediatric neurology, and neurological oncology.

Kaiser Permanente in northern California has also successfully incorporated videoconferencing to facilitate virtual meetings between providers, including general neurologists and movement disorders specialists who "prescreen" remote patients who may be eligible candidates for DBS. Within 5 years, up to 50% of all movement disorders visits could be virtual.

Nursing Homes

Approximately 40% of patients with PD will require care in a skilled nursing facility at some point, and up to 7% of nursing home residents have PD.[82-84] Individuals with PD requiring nursing home care are more likely to have cognitive impairment, behavioral manifestations including psychosis, and other nonmotor symptoms that reduce quality of life.[85,86] Despite the increasing needs of patients in nursing homes, specialized neurological care in nursing homes is lacking and less than half are receiving optimal care.[82]

Telemedicine improves access to care for such patients. In a randomized trial of telemedicine versus usual care for nursing home residents with PD, telemedicine increased access to specialist care and improved outcomes.[21,28] This study has led to increased access to specialty care for approximately 200 patients observed in nursing homes throughout New York

APPENDIX FIG. 2. A example of telehealth technology used in the home by the Department of Veterans Affairs.

State. This program benefits nursing homes through possibilities for higher reimbursement, differentiation of services offered, and training of nurses and staff.

Barriers to widespread implementation of telemedicine in nursing homes include reimbursement, credentialing, and varying requirements for in-person evaluations before providing care. In the United States, Medicare reimburses telemedicine originating in nursing homes in sufficiently rural locations.[56] However, many nursing homes with limited specialty access do not satisfy these criteria. Nursing homes also require that remote providers be credentialed at each facility, introducing another hurdle. Finally, state mandates requiring an initial in-person evaluation before providing telemedicine care, especially for prescribing medications, could effectively ensure that those with the greatest need for specialty care have the least access.

Rural Clinics

In much of the United States, populations are sparse and dispersed with limited access to medical care. Medicare considers telemedicine a cost-effective alternative to traditional delivery of medical care in rural areas[56,57] and reimburses only telemedicine services delivered in health professional shortage areas[58] and outside of metropolitan statistical areas.[87] Health systems in these areas may turn to telemedicine to improve access to care.

Gundersen Health System is an integrated, multispecialty, 700-provider network based in La Crosse, Wisconsin, with a 100-mile radius serving 585,000 individuals in Wisconsin, Minnesota, and Iowa. Currently, 62 physicians at 21 sites perform telemedicine. A telemedicine program began in 2003, and PD was added in 2010. Gundersen's Parkinson's Disease and Movement Disorders Center consists of a movement disorders neurologist and specialty nurse practitioner, licensed in the three states where transmissions occur. Between June 2010 and May 2013, 114 telemedicine encounters for 73 patients (61% parkinsonism, 4% essential tremor, and 35% other movement disorders) took place. Through the telemedicine program, patients in remote areas can now receive care from their primary care physicians' offices. In a typical visit, an on-site nurse records vitals and muscle tone, then the patient sees the specialist for approximately 25 minutes by videoconferencing. Coordination of care occurs through a shared electronic medical record, and prescription changes are automatically faxed to a local pharmacy.

Telemedicine in the Gundersen Health System has been limited by several factors, including patient acceptance, physician adoption, and maintenance and cost of equipment. Future efforts to broaden the acceptance and reimbursement of telemedicine services, including to the home, would greatly improve access to care in this growing population.[5]

Homes

Over 40% of Medicare beneficiaries with PD do not see a neurologist for care.[3] Distance, disability, and the distribution of neurologists limit access. Telemedicine delivered directly into the home can reduce these barriers. A small, randomized, controlled trial compared follow-up care delivered by telemedicine into patients' homes versus in clinic follow-up care.[27] The study found that virtual visits were feasible (93% of virtual visits completed as scheduled), may offer comparable clinical benefit to in-person care, and saved patients and caregivers 100 miles of travel and 3 hours of time per visit. At the study's conclusion, 85% of participants expressed interest in continuing their care virtually rather than in person.

A recent case series evaluated virtual visits to over 50 individuals in five states who had not been previously evaluated by a remote PD specialist.[32] This case series again demonstrated that virtual visits are feasible, result in changes to recommended care, and are well received by patients (100% were likely to recommend to a friend). Patients cited access to specialty care, convenience, and comfort of having visits at home as benefits.

This approach requires patients or families to be familiar with the Internet, and licensure laws require physicians to be licensed in the state where patients are physically located. Finally, neither Medicare[56] nor private insurers currently reimburse for medical care delivered virtually in the home. As technology improves and regulatory barriers diminish, this care model has the potential to deliver highly patient-centered care.

Developing Programs

Cameroon

As life expectancy increases in sub-Saharan Africa, the prevalence of PD is also increasing.[88] With specialist shortages, most patients remain undiagnosed,[89] and those diagnosed may have suboptimal treatment and increased mortality. The World Health Organization,[10] telecommunications companies, and medical associations are increasingly interested in telemedicine in developing countries, but information and communication technology infrastructure are often inadequate.

To help increase access to care and train providers using technology, the MDS has sponsored pilot projects in care and education through the African Task Force, including one in Cameroon. The telemedicine program in Cameroon aims to create a regional Web-based movement disorders educational program. The 12-month program consists of 12 lectures designed for doctors and other health professionals, connecting participants with movement disorders experts using live video, slides, chat, and audio conferencing. Participants have the opportunity to receive MDS membership and benefits, including special education to certify them to use MDS rating scales.

Networking can spread the telemedicine infrastructure costs among local governments, businesses, foreign education providers, and health sectors to ensure long term sustainability. Telemedicine can remove, or at least mitigate, the barriers that society and physical geography impose, especially in rural areas of sub-Saharan Africa. Challenges to broader adoption include developing reliable broadband access throughout the region, ensuring that programs are culturally appropriate, and perhaps most challenging, providing affordable and sustainable access to medications.

China

Improved economic conditions in China have helped increase longevity and, consequently, those at risk for PD. China currently has at least 2 million citizens with PD,[90] and because as many as 68% of rural and 37% of urban cases are not diagnosed,[6] this may be a significant underestimate. Between 2005 and 2030, the number of cases is expected to at least double,[5] and by 2030, more than 50% of persons with PD in the world's most populous nations will reside in China.

Despite this increasing burden, China has few neurologists and less than 100 movement disorders experts.[7] A PD expert in a university center may see as many as 80 patients per day, limiting in-depth management. For the majority of patients, significant barriers limit access to care, including distance, overcrowded specialty clinics, and transportation.

The MDS has recently funded a project that will assess whether supporting and training neurologists without movement disorders expertise through telemedicine can improve patient outcomes. Between August and October 2013, neurologists were randomly assigned to a telemedicine or no telemedicine arm, and each neurologist will follow 10 patients with PD for 12 months. Neurologists assigned to the telemedicine intervention will have regular consulting visits with a movement disorder specialist, including televideo presentations of patients. In addition, neurologists, patients, and caregivers will receive educational seminars to help create a virtual PD center. Many more neurologists volunteered to participate than could be accommodated, indicating the strong desire for additional training among Chinese neurologists. Patient enrollment is in progress, and results will be analyzed in 2015 after the last patient assessment has been completed.

Remote training and consultation with movement disorder specialists provides a first step to improving PD care in China. Future steps include extending the program to additional facilities and using mobile technologies—China already has the world's largest number of mobile phone users[61]—including Web-based applications for providers and patients.

Specialized Applications

DBS

The geographical mismatch between patients and providers is especially acute for DBS, which requires advanced infrastructure and highly specialized skills.

Telemetry monitoring and remote care for device-based therapies are well-established for cardiac pacemakers.[91] Controlled studies have demonstrated that remote monitoring is beneficial[92] and offers patient convenience, non-inferior safety compared with in-person evaluation, shorter detection time to actionable events (e.g., arrhythmias), reduced length of hospitalizations and fewer office visits, reduced inappropriate shocks, increased battery longevity, and a relative reduction in risk of death.

With recent technological breakthroughs, such as the "brain radio"[93] and the Activa PC+S,[94] reading, remotely storing, and sharing certain DBS parameters off the implanted device are now technically feasible. At a minimum, usage information, battery status, and hardware integrity can be monitored remotely. Many patients travel long distances for DBS "checkups," which could be largely eliminated through telemetry. Such technology may be available for clinical testing of safety and efficacy soon. Subsequently, more advanced remote options could be evaluated. With the growing variety of ambulatory motor and electrophysiological tracking devices, changes in continuously monitored clinically relevant measures could autotune DBS devices across a range of possible values until optimal settings are established. Such DBS telemedicine approaches could minimize travel burden and potentially produce better results than periodic brief programming sessions.

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