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Moving Parkinson care to the home

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Current care models do not meet the needs of individuals with Parkinson disease (PD).[1–3] Many have limited access to proper care and that care, when delivered, is institution-based rather than patient-centered (Table). In this viewpoint, we examine the shortcomings in current care, the need for home-based care, the emerging models, and the barriers to overcome. While written from the perspective of the United States and Europe, the piece will hopefully have broader applications.

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The shortcomings of current care

In 2001, the Institute of Medicine (now the Health and Medicine Division of the National Academy of Sciences, Engineering, and Medicine), a U.S. non-profit that provides independent, objective analysis, issued its landmark report *Crossing the Quality Chasm*. The report opens, "The American health care delivery system is in need of fundamental change." It further states, "Quality problems are everywhere, affecting many patients. Between the health care we have and the care we could have lies not just a gap, but a chasm."[4] The report lists six aims to cross this chasm, proposing that health care should be safe, effective, patient-centered, timely, efficient, and equitable.

However, current care for PD, in the U.S., Europe, and likely the majority of the world, frequently does not meet these six aims. First, Parkinson disease care is often not safe. Individuals with PD who are hospitalized are often subjected to delayed treatment, contra-indicated medications, prolonged immobility, lengthy stays, and high mortality.[5,6] Second, while some comprehensive and distributed PD care models[3,7] are quite effective, few patients receive such care, and many PD-related hospitalizations are likely preventable.[8] Third and fourth, providing patient-centered care that is timely has been studied little.[9] Despite the limited evidence, focus groups and surveys suggest that individuals with PD want more personalized information from multiple disciplines that is delivered remotely in a timely manner.[9,10] Fifth, PD care is very inefficient. Patients and their caregivers spend hours travelling and waiting in the clinic for routine follow-up appointments.[11] Outside the clinic, nearly 25% of Americans over 65 with PD reside in expensive nursing homes that cost more than $200 per day[12] – money than could be devoted to preventing the need for institutional care for many.

Finally, perhaps most concerning is the inequity of current PD care. A primary determinant of care received remains where you live. In the U.S., 42% of individuals with PD over 65 and up to 100% of individuals in some rural areas do not see a neurologist soon after diagnosis.[2] In Europe, the first right expressed in the European Parkinson's Disease Association Charter is care from a physician with a special interest in PD,[13] yet 44% of Europeans do not see a PD specialist in the first two years after diagnosis.[1] Beyond neurological care, access to specialist nurses, occupational therapists, and counselors is often more limited.[14] In less wealthy countries, the situation is even worse. China only has approximately 50 movement disorder specialists to care for over two million individuals with PD.[15] In Bolivia, a door to door epidemiology study found that none of the individuals identified with PD had ever seen a physician, much less received treatment.[16]

New, comprehensive PD care models are emerging that seek to deliver care that is aligned with the aims articulated by the Institute of Medicine.[3,17] For example, ParkinsonNet, a comprehensive, multi-disciplinary care model in the Netherlands, can enhance care, improve health, and lower costs.[3,17] Still, these models are resource intensive and demanding of patients and their caregivers. For example, integrated multi-disciplinary care models require individuals with limited mobility and driving ability to visit physical therapists and speech therapists three times per week for several weeks. Surgical treatments, such as deep brain stimulation, make similar requirements – often lifelong ones – for follow-up care for individuals with more advanced disease.

Need for home-based care

To improve PD care, more of it must be delivered at home. Home care is not new. In the early part of the 20th century, the house call was a dominant means of providing care, with 40% of physician-patient encounters in 1930 occurring in the home.[18] However, advances in transportation and diagnostics that had to be delivered in medical centers (e.g., x-ray, EKG) contributed to the house call's decline. Early in the 21st century, house calls are returning. They are available through home-based chronic care models,[19] on-demand house calls by physicians for episodic care,[20] and a "hospital at home" model.[21] The latter model provides hospital-level care, including physician and nurse visits and intravenous medications, for acute conditions like pneumonia directly in the home. These models can generate equal or better clinical outcomes, improve patient satisfaction, and lower costs,[21] yet few have been applied to PD. In addition to in-person care at home, the next generation house call, enabled by advances in telecommunications, is also emerging.[11,22] Through video visits, these virtual house calls enable frequent consultations and provide specialty care to patients independent of geography.

The demand for in-home care is likely to grow due to demographic, social, and technological factors. Both the absolute number and proportion of older individuals with PD will increase. Due to aging populations, the prevalence of PD in the world's most populous nations will rise to over 8.7 million patients, twice as much as it was in 2005.[23] Similarly, rising life expectancies (four years in the U.S. and six years globally in the last two decades)[24] along with new therapies for advanced PD[25] may increase the survival of individuals with the condition, leading to more individuals with advanced disease.

Social shifts are also driving home care. The splintering of the extended family, the increased mobility of the nuclear family, and the strong desire of older individuals to remain in their own homes[26] lead to geographically separated children caring for aging parents. These children will increasingly demand technology solutions that enable them to care for their parents, monitor their health, and connect to their parents' clinicians conveniently. In addition, more older individuals are discovering the internet, tablets, and smartphones for themselves.[27]

Lastly, technological advances are enabling individuals with PD and other chronic conditions[28] to access specialists in satellite clinics or in their homes.[22] Preliminary evidence suggests that web-based video conferencing may offer similar clinical benefits to that of in-person care while saving patients and caregivers 100 miles of travel and 3 hours of time per visit.[11] Multidisciplinary care, including speech therapy,[29] mental health care, and "tele-rehabilitation"[30] can also be delivered remotely.

Emerging home-based care models

Emerging care models will combine remote monitoring, self-monitoring, and multi-disciplinary care to enable the provision of patient-centered care at home and decrease the need for in-clinic assessments. Remote monitoring from devices, such as wearable sensors,[31] smart beds, wall-mounted cameras, smart glasses, and even utensils, can monitor a patient's symptoms and function objectively in their environment, facilitating the delivery of highly personalized care.[32,33] These devices increasingly form the "Internet of Things,"[34] a network of objects that can collect and exchange data, and can measure relevant outcomes (e.g., physical activity, sleep, falls) that are hard to assess using traditional questionnaires or personal interviews.

Issues such as feasibility (can patients manage these new devices?), compliance (can patients handle prolonged use of wearable sensors?), and validity (do the devices capture clinically relevant information that inform care?) remain to be addressed, but the initial experience is positive, provided that patients are fully informed and engaged from the outset.[31] Wearable devices will also shift current snapshot measurements in the clinic into a more constant flow of measurements in the comfort of the patient's own surroundings, allowing for more ecologically valid observations.

In addition, the increasing ubiquity of smartphones is enabling self-management by patients through self-monitoring apps.[35] These apps allow patients to record symptoms and signs, track progression, and identify warning signals that may necessitate a clinical follow-up. When integrated with the hospital-based electronic health record, these data will provide feedback to the clinician to guide treatment decisions and improve health outcomes. When combined with online education, such as a web-based, informative, and interactive television program (e.g., www.ParkinsonTV.nl) or social media-based community building,[3] remote monitoring tools can increase the ability of individuals with PD "to adapt and self-manage," a new definition of health.[36]

Finally, multidisciplinary care both in-person and remotely can be delivered into the home. The combination of in-person consultations in the home (e.g., to develop personal relationships or to conduct detailed examinations) and remote consultations in the home (e.g., to provide ongoing care) could meet the needs of patients.[37] Such a combination of in-person and virtual house calls can reveal information that is not easily observed in clinic, where patients often perform very differently compared to their usual behavior at home. These house calls can also provide valuable insights into a patient's domestic circumstances (e.g., safety of physical environment, level of social support). Specialized Parkinson's nurses, who have a broad perspective and can act as liaison to other healthcare professionals within the team, have already begun offering house calls.[20] In an ideal situation, such Parkinson's nurses could leave the clinic as agents of integrated regional networks of professionals specialized in PD. House calls are also important for other PD professionals, including physiotherapists (e.g., to help patients learn to transfer from their own beds) and occupational therapists (e.g., to remove domestic hazards). Current professional guidelines, for example, recommend that certain assessments (e.g., transfers) are best done at home.[38] Finally, some remote care could be delivered asynchronously with information flowing from patients to clinicians and advice being delivered from clinicians to patients or other clinicians.[39,40]

Overcoming barriers

Several barriers, including reimbursement, access to technology, and limited evidence, can slow the migration of care to the home. Currently, major insurers, including Medicare (the universal health insurer for older Americans), incent institution-based care by paying more for care rendered in institutions than in the home. Organizations that have integrated delivery and financing of health care can benefit from cost savings from home-based care and thus are likely to be early adopters of this patient-centered model. In the U.S., the Department of Veterans Affairs[28] and Medicare Advantage programs[41] have implemented home-based care models. Kaiser Permanente, a large integrated health system in the U.S., uses internet, mobile, and, more recently, video technology to improve outcomes and increase convenience for its patients.[42,43] In the Netherlands, ParkinsonNet is developing an integrated reimbursement system to assist their network approach of care delivery, which includes many telehealth solutions as video consultations and online platforms for patients. Countries with single payer health systems, like Canada, Norway, or Luxemburg, are also poised to realize the advantages of home-based care for PD. Likewise, across Europe, consumer choice and flexibility have become a major goal of modern home-based care systems.[44] However, funding for these systems remains a challenge because hospitals lose income in a “fee-for-service” model by facilitating care outside the hospital.

The digital divide,[45] the differential access to internet and telecommunication technologies based on economic and social factors, prevents the use of technology to receive care at home. Individuals who are older and have more chronic conditions are less likely to use the internet,[46,47] and the digital divide has hampered efforts to use technology to deliver PD care at home.[48] The divide can be overcome by delivering in-person home care to individuals with PD,[49] providing remote care via satellite clinics close to one’s home as is done in Canada,[22,37] engaging children in the care of their parents, and increasing access to telecommunication technologies. The digital divide is narrowing and the increasing ubiquity of smartphones, which are projected to be in the hands of 90% of individuals over age 6 by 2020,[50] provides a promising avenue to increase access to care, especially in resource limited countries like China and India.[51]

Despite its promise, evidence for these new, home-based care programs is needed. Some of that evidence is being gathered currently,[48] and some is being generated in other chronic conditions.[19,52] Preliminary interest in these models for PD is robust. For example, over 11,000 individuals from 80 countries and all 50 U.S. states visited a recruitment website for a randomized controlled trial of virtual house calls for PD.[48]

Notwithstanding the barriers, “[it] seems inevitable that health care is going home.”[19] Ushering in the next generation of home care will require collective efforts from patients, families, clinicians, advocates, philanthropists, insurers, technology firms, and policy makers. Unless these models gain more visibility, these stakeholders will remain ignorant of opportunities to develop, fund, evaluate, and advocate for models to improve care. To bridge the chasm identified by the Institute of Medicine, we need to be more critical of our current care models, more willing to experiment with disruptive ones, and more prepared to refine them. The more clearly we envision and adopt these future models, the sooner the growing number of individuals with PD will realize their benefits.

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Table

How different care models meet the needs of individuals with Parkinson disease

Feature	**Individuals with Parkinson disease**	**Current care models**	**Home-based care**
Location	Primarily suburban and rural areas[53]	Primarily urban centers	Where the individual is located
Driving	Impaired ability[54,55]	Usually requires driving	Little or no driving required[37]
Mobility	Limited[56]	Generally required to access care	Not required to access care
Cognition	Frequently impaired[57]	Often demanding to navigate	Less demanding to receive
Disease course	Progressive[56]	Least accessible for those with the most advanced disease	Accessible to those with greatest need[58]
Caregivers	Burdened[59]	Increases the burden	Can reduce the burden