

Telehealth increases access to palliative care for people with Parkinson's disease and related disorders

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Abstract: The purpose of this review is to describe the role that telehealth has in the delivery of palliative care to people with Parkinson's disease and related disorders (PDRDs), particularly as their disease advances, and they become homebound. A review of the Cochrane database, PubMed, and the American Academy of Neurology (AAN) guidelines was conducted to identify peer-reviewed publications on this topic. Telehealth has been found to increase access to neurological specialty care for people with PDRDs who live in more under-resourced areas or are homebound due to their advancing neurodegenerative disease. Given the benefits of palliative care for people with PDRDs and their caregivers, increasing access via telehealth to palliative care through research, education and policy efforts has the potential to significantly improve the landscape of care for those with PDRDs.

Keywords: Palliative care; telemedicine; Parkinson's disease (PD)

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Introduction

Parkinson's disease (PD) affects 1–2% of adults over age 65, representing approximately 1.5 million Americans (1). Parkinson's disease and related disorders (PDRDs) are a group of incurable and life-limiting neurodegenerative movement disorders with a tremendous symptom burden that severely diminish quality of life (QOL) and cause significant distress for caregivers (2,3). PDRDs have traditionally been seen as diseases of motor impairment. In reality, non-motor symptoms, psychosocial, and spiritual challenges impair QOL much more so than motor symptoms do in these disorders (4). Unfortunately, many of the needs most important to people with PD and their caregivers are poorly addressed under current models of chronic medical care (5). Palliative Care is medical care focused on improving QOL for people with serious illness that addresses medical symptoms, psychosocial needs, spiritual wellbeing and advance care planning (6). Palliative care has been shown to significantly improve QOL in PDRDs for both patients and caregivers, while improving

communication to better align medical care with personal values and treatment preferences (6–8).

Neurodegenerative movement disorders isolate those afflicted by impairing mobility and communication. Ultimately, most will become homebound, reducing and ultimately preventing their access to more traditional outpatient medical care (9). Those with atypical parkinsonian disorders are so often non-ambulatory within 5 years of diagnosis, that a “5-year wheelchair sign” is a red flag for one of these neurodegenerative disorders (10). In this review, we describe the important role of telemedicine as an emerging health care delivery method of palliative care for people with PDRDs who are homebound or live in under-resourced areas.

Methods

Evidence for this review was obtained from a search of the Cochrane database, PubMed, and the American Academy of Neurology (AAN) guidelines.

Results

Limited access to outpatient providers for people with PDRDs

People with PDRDs currently have limited access to outpatient neurologists under the current chronic care model, which is based on in-person visits, with one retrospective 3-year study showing that 42% of 138,000 incident PD cases did not see a neurologist over the course of the study (11). Those individuals who saw a neurologist in this study had a lower risk of hip fracture, were less likely to be in a skilled nursing facility (SNF), and had a lower adjusted likelihood of death. Lack of access to neurological care in more rural areas, in addition to the patient and caregiver travel burden in the setting of advancing neurodegenerative movement disorders lead visits with an outpatient neurologist to be out of reach for many (12).

Unfortunately, the majority of people with PDRDs will eventually become homebound due to progression of their motor symptoms; with wheelchair/bedridden status being the common functional endpoint seen in the most advanced stages of these neurodegenerative movement disorders (9,10). Ultimately, most of those suffering from these neurodegenerative movement disorders will become functional quadriplegics, and will need full care. In addition to homebound status preventing access to outpatient providers, non-motor symptoms caused by PDRDs can also limit access to outpatient providers (e.g., fatigue, apathy, mood disorders, psychosis, autonomic dysfunction, and dementia).

Given the risk of becoming homebound, there is a high likelihood that people with PDRDs will lose access to their neurologists and other outpatient providers (including outpatient palliative care providers). Research shows that many older and disabled adults get caught in a cycle termed “rehabbed to death” (13), where they move between the hospital and the skilled nursing facility/nursing home. All of this represents a need to improve access to tele-neuropalliative care for homebound patients as well as geographically isolated patients.

Palliative care needs in people with advanced PDRDs

The symptom burden seen in PD has been shown to be equivalent to that found in metastatic cancer (14). While motor symptoms such as tremor, shuffling gait, and imbalance are often disabling (9), non-motor symptoms (e.g., anxiety, depression, autonomic dysfunction, insomnia, fatigue, psychosis, cognitive impairment) have been shown

to have the greatest impact on QOL (15). As PDRDs progress, dysphagia, shortness of breath, pain, cachexia, existential distress, dementia, psychosis and caregiver burnout are often severe (16,17). Many PDRD-related symptoms are fortunately highly amenable to palliative care treatment. A single site prospective study showed that the modified Edmonton Symptom Assessment System Scale for PD (ESAS-PD) found a significant improvement in symptom burden in a palliative clinic for people with PD (14). Constipation, dysphagia, anxiety, pain and drowsiness were the symptoms found to be the best controlled. Results from the first randomized clinical trial comparing palliative care to usual care for PDRD found that palliative care significantly improved QOL, symptom burden, and grief, while reducing caregiver stress at 6 months (18). This makes access to an interdisciplinary neuropalliative care team essential for optimizing QOL for both patients with PDRDs and their caregivers.

In the current chronic care model, the majority of those with PD die during a hospitalization or shortly following a hospitalization in a SNF, and only a small number of patients (4%) die with hospice (19,20). For those with PD who die in the hospital, 97% have never had an advance care planning discussion documented (20). AAN guidelines published in 2015 list annual advance care planning discussions in people with advanced PD as a quality measure (21). Palliative care has been shown to significantly increase advance care planning and use of home hospice services in people with PD (8). Many people with PD and their caregivers are told by their healthcare providers that, “*You won’t die from Parkinson’s disease; You’ll die with Parkinson’s disease*” (16,22). Unfortunately, PDRDs are a terminal diagnosis for the majority of those afflicted (23). All of this represents a need to improve advance care planning for those with PD and their loved ones. Given the significant symptom burden of PDRDs, and the fact that they are incurable, progressive and life-limiting (24,25), afflicted individuals and their caregivers are ideal candidates to receive neuropalliative care, which encompasses physical, psychosocial and spiritual care, as well as anticipatory guidance and advance care planning (3).

Telehealth for people with PDRDs: clinical outcomes and patient preferences

Neurologists, especially movement disorder specialists, are scarce in certain areas of the country, and travel to these outpatient clinics presents a major burden for patients and

caregivers (26). Even people with PDRDs who are local to their neurologist may choose to be seen using telehealth intermittently if they have motor (e.g., freezing of gait) or non-motor symptoms (e.g., pain, fatigue) that make leaving their home difficult at the time of their visit. The flexibility of being able to turn an in-person outpatient visit into a telehealth visit provides reassurance to patients with significant symptom burden that they will continue to have the same access to the neuropalliative care team despite having symptoms that impair mobility and travel. As PDRDs progress, most patients will become homebound, making telehealth an even more important way to provide neurological specialty care for these serious, life-limiting neurodegenerative illnesses (12). Validation of a modified version of the internationally recognized Unified Parkinson's Disease Rating Scale (UPDRS) (27) and the Montreal Cognitive Assessment (MoCA) (28) that can be administered remotely allows for standardized assessments to be used in remote clinical and research visits. Two recently published randomized controlled clinical trials (RACE-PD and PD-Connect) showed that outpatient care for people with PD provided via telemedicine was equivalent to the care provided in-person for people with PD, but telemedicine was significantly preferred to in-person visits, saving a median of 88 minutes and 38 miles per visit (29,30).

To further demonstrate the feasibility and utility of integrating telemedicine to provide palliative care to people with PDRDs, we incorporated telemedicine as an option for visits in the world's first randomized clinical trial comparing palliative care versus usual care for PDRDs, funded by the Patient-Centered Outcomes Research Institute (PCORI) (31). The neuropalliative care team consisted of a nurse, chaplain, social worker, movement disorders specialist, and palliative care doctor.

Telehealth can increase access to neurospecialty care for serious neurological illnesses on an international level as well. The International Parkinson and Movement Disorders Society Africa Section has funded a program for the last 5 years that has provided movement disorder specialty care to under-resourced areas of Africa using WhatsApp, providing asynchronous consultations. Whether telehealth consultations are asynchronous largely depends on the consistency of access in the area for electricity and the internet.

Future directions for telehealth and palliative care for people with PDRDs

Telehealth can increase access to specialty neurological

care for people with PD (29,30). and neuropalliative care for people with PDRDs has been shown to improve QOL and reduce caregiver stress, compared with usual chronic neurological care (14,18). Therefore, the author hopes that Medicare will continue to expand coverage of telehealth for older and disabled adults to include people who are homebound and therefore lack access to specialty neurological care (i.e., neuropalliative care and a movement disorders specialist), regardless of whether or not their actual home is located in a rural setting.

Future research efforts should also include a comparative effectiveness study with the goal of optimizing care at the end of life for people with PDRDs. This is an understudied area, and currently there are no prospective studies of care at the end of life for people with PDRDs. For example, usual chronic neurological care could be compared with specialized telehealth neuropalliative care (home hospice and a tele-health movement disorder neurologist) at the end of life for people with PDRDs and their caregivers. Additional research can include understanding barriers to telemedicine and optimizing feasibility.

The International Parkinson and Movement Disorders Society Telemedicine Task Force has been accepted as a permanent Study Group in the Society in 2018, and will therefore be able to continue efforts to build access to care for people with PDRDs in under-resourced areas, this includes an interest to study tele-neuropalliative care for this patient population. In addition, a synchronous WhatsApp-based clinical program is being started by the Telemedicine Study Group, connecting patients seeing local clinicians in more rural areas of Nigeria to movement disorder neurologists in Nigeria's main medical centers. The goal is to create a synchronous consultation system to increase access to neurology specialists who are available in that particular country, for people who would not otherwise get this care due to the tremendous financial and caregiver burden of travelling with serious illness to the main medical center from a more rural area.

Since there are not enough neuropalliative care teams to see everyone with a PDRD, it is important that neurologists and primary care providers caring for these patients become primary palliative care providers. An ongoing National Institutes of Health (NIH) clinical trial that the author is an investigator on is exploring the feasibility of a primary palliative care education program and tele-health specialty primary palliative care resources as a model of increasing access to palliative care in the community neurology setting.

The project ECHO tele-education model is another

potential approach to teach and mentor neurologists to become primary palliative care providers for people with neurodegenerative movement disorders (32). This provider-provider telehealth program is an evidence-based approach that was initially developed to address disparities in hepatitis C treatment in rural New Mexico (33). The project ECHO model has been duplicated in other settings to increase access to specialty level care. In our proposed study, general neurologists and movement disorder neurologists will link simultaneously to neuropalliative care team members using this case-based approach to teach providers how to practice primary neuropalliative care.

Conclusions

QOL is significantly improved with the addition of palliative care for people with PDRDs and their caregivers (14,18), yet access to palliative care for people with these disorders is currently very limited. An outpatient tele-neuropalliative care team that continues to follow patients with PDRDs as they become homebound enables continued intensive symptom management and advance care planning to make sure that care aligns with patients' goals and values. Additional research, education, advocacy and clinical efforts are needed to help increase access to neuropalliative care using telemedicine.

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Footnote

Conflicts of Interest: The author has no conflicts of interest to declare.

Ethical Statement: The author is accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are

appropriately investigated and resolved.

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