Palliative Care for Parkinson's Spectrum Disorders: an Emerging Approach

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Abstract

Parkinson's spectrum disorders (PSD) are neurodegenerative parkinsonian conditions that carry a tremendous symptom burden. Palliative care is an interdisciplinary medical specialty that focuses on improving quality of life for patients and caregivers affected by serious life-limiting illnesses, at any stage of disease. Research and clinical programs into this emerging therapeutic approach remain limited. This review focuses on the role of palliative care in the treatment of patients with PSD. Gaps in knowledge and recommendations for future research are discussed.

Key Words Palliative care · Parkinson disease · parkinsonian disorders · caregivers · interdisciplinary communication

Introduction

Parkinson's spectrum disorders (PSD) are a group of neurodegenerative, life-limiting movement disorders that cause progressive parkinsonism, as well as disabling cognitive, and psychiatric symptoms [1–8]. In addition, these disorders isolate those afflicted by impairing mobility and communication. The tremendous symptom burden caused by PSD significantly diminishes quality of life for both patients and caregivers [5, 9]. PSD includes Parkinson's disease (PD), progressive supranuclear palsy (PSP), multiple system atrophy (MSA), corticobasal degeneration (CBD), and dementia with Lewy bodies (DLB).

Palliative care is specialized medical care for patients and caregivers affected by serious illness. It focuses on treating the physical, emotional, psychosocial, and spiritual suffering caused by serious illness in order to improve quality of life. Palliative care also helps people plan and prepare for the future using serious illness communication skills to optimize advance care planning and align treatment recommendations to

goals of care [10]. Given the comprehensive scope of palliative care's mission, it requires an interdisciplinary team that includes a palliative care physician, a social worker, a nurse, and a chaplain. Interdisciplinary teams work interdependently, in contrast to multidisciplinary teams, where roles are clearly defined and expertise is contributed in relative isolation from other team members [11].

Palliative care is a relatively new medical specialty, and its integration into neurology has been limited. This review focuses on research that evaluates the role of palliative care for the treatment of patients with PSD. Gaps in knowledge and future directions for research are discussed.

Methods

A literature search was performed using the electronic databases: PubMed, MEDLINE (Ovid), Google Scholar, and the Cochrane Library, to identify studies published from January 2000 to February 2020. Reference lists of original publications were reviewed to ensure that the literature search was complete. Randomized clinical trials, prospective cohort studies, retrospective studies, case series, and expert reviews were included. The key search terms were “symptom burden,” “advance care planning,” “palliative care,” “Parkinson's disease,” “corticobasal degeneration,” “progressive supranuclear palsy,” “multiple system atrophy,” “corticobasal degeneration,” “dementia with Lewy bodies,” and “caregivers.” Studies were excluded if they were not available in English or had limited

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details regarding methodology. Findings from this review are grouped by themes.

Results

Palliative Care Needs in Parkinson's Spectrum Disorders

Symptom Burden in Parkinson's Spectrum Disorders

Total pain is a palliative care concept that has evolved to describe all of the physical, emotional, social, practical, and spiritual distress caused by serious illness for patients and their families [12]. The total symptom burden measured in PD has been found to be similar to the total symptom burden reported in metastatic cancer [6]. While a similar study assessing symptom burden has not been done in patients with atypical parkinsonian syndromes, these disorders typically cause a more rapid functional decline than PD, and standard PD therapies are usually ineffective or poorly tolerated [13]. While the motor symptoms of PSD severely impair mobility and independence [13–15], the nonmotor symptoms (e.g., depression, insomnia, fatigue, psychosis, dementia) [1–8, 16–19] have been shown to have a greater impact on quality of life [1, 20, 21]. Furthermore, there is evidence that nonmotor symptoms are under-recognized and undertreated in PSD [8, 22–27]. For example, depression occurs in about 40% of people with PD [28] and is associated with worse functional disability, quality of life, and caregiver distress [29]. There is evidence indicating that the majority of people with PD who meet the criteria for a depressive disorder are not receiving antidepressant treatment, and among the patients with PD and depression who are receiving treatment, almost half are receiving treatment that is inadequate or ineffective [30, 31]. Suicidal ideation and suicide-specific mortality is higher in people with PD compared to healthy controls [32, 33].

Psychosocial and Spiritual Distress in Parkinson's Spectrum Disorders

Changing roles in relationships, progressive loss of independence, and increased economic burden often cause severe emotional and psychosocial strain for patients with PSD [8, 27, 34, 35]. Spiritual distress in PSD includes demoralization, grief, existential distress, and death anxiety [18, 27, 36–38]. The loss of ability to communicate due to dementia, hypophonia, bradyphrenia, and fine motor impairment contributes to the isolation often experienced by patients with PSD [4, 8, 24, 25, 27, 36, 38–40].

End-of-Life Care in Parkinson Spectrum Disorders

People with PD are significantly less likely to die at home and with hospice services than the general population [41–43]. Only 4% of patients with PD in the United States (US) die at home with hospice [41], even though the majority of patients with serious life-limiting illnesses report that they would want to die at home [44].

The symptom burden at the end-of-life for patients with PSD increases significantly [22, 27, 45, 46]. Patients are usually functional quadriplegics and are wheelchair-bound and then bedridden in advanced stages of PSD [5, 8, 15, 27]. Difficulty communicating and pain were rated by caregivers of people with PD as the most bothersome symptoms at the end-of-life [47]. Paranoid delusions and hallucinations often become severe, frightening, and difficult to control in the terminal stage of PD dementia (PDD) and DLB [45, 46]. In the last weeks to days of life, patients usually suffer from cachexia, severe physical pain, and dyspnea [4]. Ultimately, the majority of people with PSD will die of their underlying neurodegenerative diseases [2, 22, 27, 45, 48].

Advance Care Planning in Parkinson's Spectrum Disorders

Advance care planning is a major component of palliative care which includes discussions to identify patient and caregiver goals, values, and priorities; provide anticipatory guidance to help patients and caregivers plan and prepare for the future; identify surrogate decision makers; and document preferences for medical care [49, 50]. The high rates of dementia and communication difficulties found in patients with more advanced stages of PSD make it critical to discuss advance care planning early in the course of PSD [51, 52]. There is evidence that people with PSD do not have adequate advance care planning, although studies have shown that a majority of people with PD and atypical parkinsonism want to talk to their doctors about what to expect in the future to help with preparing and planning for the future [45, 53–56]. For patients with PSD, and their caregivers, anticipatory guidance and early advance care planning has been shown to be a priority [27, 45, 53, 55, 57]. In one survey of several hundred patients with PD, 94% wanted prognostic information early in the course of their disease [55].

Caregiver Distress in Parkinson Spectrum Disorders

Caregiver burnout is common in those caring for people with PSD [58–61]. Predictors of caregiver burden in PD include poor patient spiritual well-being, as well as caregiver anxiety and depression [62]. Embarrassment, anger, lack of privacy, and guilt are commonly described [63]. Many PSD patients have sleep disturbances, and this adversely affects the sleep quality of their caregivers [64]. Caregivers can also experience

physical and sexual aggression directed against them by the person with a PSD who they are caring for, particularly if psychosis and dementia are present [65]. Anticipatory grief (also called predeath grief) is common in caregivers, particularly in caregivers of patients with PSD who have a higher symptom burden and advanced dementia. Caregivers with higher rates of burnout and depression scores have more anticipatory grief symptoms [23, 66, 67]. Caregivers of people with PD have reported significant concerns about the future relating to finances, living situation, and caregiving in advanced disease [66, 68].

Benefits of Palliative Care in Parkinson's Spectrum Disorders

Palliative Care for Parkinson's Spectrum Disorders: Intensive Symptom Management

Intensive symptom management is a core principle of palliative care [69]. Many PSD-related symptoms have been shown to significantly improve with palliative care [6, 18]. Results from the first randomized clinical trial comparing palliative care to usual care for patients with PSD found that palliative care significantly improved quality of life, symptom burden, and spiritual distress at 6 months and 12 months, while reducing caregiver distress at 12 months [18]. There were no significant reported side effects from palliative care. Patients with PSD and their caregivers were eligible for the study as long as there was at least one moderate to severe unmet palliative care need (i.e., physical symptoms, psychosocial distress, spiritual distress, or need for advance care planning) using a validated Palliative Care Needs Assessment Tool (PC-NAT) modified for PD [70, 71]. An earlier single-site prospective study showed significant improvement in the modified Edmonton Symptom Assessment System Scale for PD (ESAS-PD) in a palliative clinic for people with PD [6]. Constipation, dysphagia, anxiety, pain, and drowsiness were the symptoms found to be the most responsive to palliative care.

Palliative Care for Parkinson's Spectrum Disorders: Advance Care Planning

Palliative care has been shown to significantly increase advance care planning in patients with PD [18, 42, 72], and patients with PD are much more likely to die at home if they have a documented advance care planning discussion [42]. Unfortunately, many older adults get caught in a cycle of being “rehabbed to death” [73], where they move between the hospital and the skilled nursing facility/nursing home. Invasive and aggressive medical care at end of life is often medically futile and is counter to the goals of care expressed by the majority of patients with serious life-limiting illnesses [44, 74]. Anticipatory guidance can help patients with

advanced PSD avoid medically futile treatments, such as high-calorie supplements, feeding tubes, and thickened liquids [75–77].

There is concern among clinicians that discussing disease progression may cause patients and caregivers to lose hope or overwhelm them with difficult news they are not ready to hear [49]. Palliative care addresses this concern by providing a framework for assessing patients' and caregivers' preferences for receiving serious illness information. Advance care planning conversations using palliative care serious illness communication skills have been shown to reduce anxiety and improve quality of life in patients and caregivers [78]. The importance of advance care planning was recognized by the American Academy of Neurology (AAN) as a quality metric for people with PD [79].

Palliative Care for Parkinson's Spectrum Disorders: Caregiver Support

In palliative care, the interdisciplinary team helps the caregiver cope with difficult emotions (e.g., isolation, grief, guilt) and addresses their psychosocial, practical, and spiritual distress [69]. Palliative care shifts the unit of care to the family since serious illness affects the entire family [5]. Qualitative research indicates that caregivers are requesting more anticipatory guidance to help them plan and prepare for the future [53, 68]. For example, many caregivers with DLB report that the providers did not give them the information they needed to be prepared for end-of-life process and care of their loved one [45]. Anticipatory guidance has been shown to reduce the risk of complicated grief in caregivers during bereavement [80].

Palliative Care for Parkinson's Spectrum Disorders: Reducing Clinician Burnout

Another area where palliative care provides benefit is by reducing clinician burnout and improving clinician resilience. This is a major focus in all palliative care programs and is based on the principle that a clinician suffering from burnout, or at risk of burnout, will find it challenging to provide empathic person-centered care [81, 82]. Palliative care interventions to reduce clinician burnout are primarily focused on building resilience using evidence-based methods [83].

Timing of Palliative Care Interventions for Parkinson's Spectrum Disorders

According to the World Health Organization (WHO), palliative care is “applicable early in the course of illness, in conjunction with other therapies” [10], yet despite this, many clinicians equate palliative care to end-of-life care [84]. The majority of PSD patients enrolled in the only randomized controlled trial of a palliative care intervention in

Parkinson's disease [18] had mild severity disease (Hoehn & Yahr stage 2) [15] and still significantly benefited from palliative care, although patients with a higher palliative care need had a more significant benefit from the intervention [18]. Palliative care may even be appropriate for many patients and care partners at the time of diagnosis, given qualitative research indicating that many patients with PSD experience significant psychosocial and spiritual distress when they receive their diagnosis [85].

Accessibility of Palliative Care for Parkinson's Spectrum Disorders

There is growing evidence supporting the significant benefit of palliative care in improving quality of life for patients and caregivers affected by PSD [6, 18]. Unfortunately, there are only a handful of outpatient neuropalliative care programs in the US, and less than 5% of people with PD die with hospice services [43].

There are various modalities of potential palliative care delivery for people with PSD, including 1) interdisciplinary specialty palliative care consultations; 2) palliative care specialists integrated into an interdisciplinary movement disorders clinic; 3) neurologist-delivered primary palliative care; and 4) the emerging specialty of neuropalliative care (neurologists who have palliative medicine fellowship training) [86, 87]. Interdisciplinary specialty palliative care consultations are the traditional delivery method for palliative care. This model is resource intensive and may be disconnected from neurological expertise that can help optimize symptom control and anticipatory guidance. Integrating a palliative care specialist into an interdisciplinary movement disorders clinic has been shown to significantly improve quality of life for patients with PSD and reduce caregiver burnout [18], but it is also resource intensive, with a nurse, social worker, chaplain, movement disorder specialist, and palliative care physician all on the same team, with only two of these clinicians able to bill for services. The other limitation with both of these models is that access to specialty palliative care physicians is limited [88].

Primary palliative care can be practiced by nonpalliative specialists within their own discipline [89], significantly expanding access to palliative care for patients with serious illness. These primary palliative care skills include understanding 1) intensive symptom management approaches; 2) basic psychosocial and spiritual health assessments; and 3) basic advance care planning communication skills. Every clinician who cares for patients with a PSD can incorporate primary palliative care skills into daily practice [27, 89]. Palliative care serious illness communication skills help ensure that patients are getting goal-concordant care [90]. Adequate education of neurologists in primary palliative care skills during neurology residency and movement disorder

fellowships is currently lacking [91]. Integrating a primary palliative care curriculum into neurology residency training and movement disorder fellowship training is essential to improving palliative care access to people with PSD [86]. Primary neuropalliative care providers are supported by specialty interdisciplinary palliative care when needed for issues such as complex symptom management, significant psychosocial distress, existential distress, and/or challenging advance care planning discussions. With the emerging field of neuropalliative care, neurologists who also get specialty training in palliative care can then deliver highly specialized person-centered care that merges expertise across these two disciplines [86, 92].

Even in advanced stages of PSD when most patients are homebound, palliative care can still be offered through telehealth [5, 8, 15, 27, 93]. Neurological care of PD patients by telehealth has been shown to be equivalent to in-person neurological care [94, 95]. Telehealth is also an important tool to increase access to neurological and palliative specialty care in many under-resourced areas of the US [91, 96].

For any outpatient neuropalliative care clinic or primary neuropalliative care provider practice to be sustainable, appropriate understanding of medical billing coding is needed [87]. For example, an advance care planning procedure is billable under Current Procedural Terminology (CPT) code 99497. Philanthropy and research funding may be needed to start and build such a clinical program. Despite the initial investment in starting a neuropalliative care program, palliative care has been shown to reduce overall healthcare costs [97–99]. For example, one study of Medicaid costs in New York state showed that a matched group of patients who received palliative care incurred \$6900 less in healthcare costs compared to those who received usual care alone [99].

Palliative Care for Parkinson's Spectrum Disorders: Gaps in Knowledge

Research evaluating palliative care for the treatment of PSD is limited. Palliative care itself is a relatively new medical specialty, and its important role in the treatment of neurodegenerative disorders is only starting to be recognized [9, 18, 45, 86]. The gaps in our understanding of neuropalliative care for patients with PSD include identifying best practices for primary neuropalliative care, reliable triggers for palliative care interventions, accurate and responsive needs assessment tools, and the optimal model of neuropalliative care that is feasible, effective, and scalable. Much of the current research in neuropalliative care for PSD only includes patients with PD. Additional research should investigate how palliative care interventions can be optimized for patients with atypical parkinsonian syndromes, who often have a more severe symptom burden, and shorter life expectancy compared to PD [4, 46].

To further demonstrate the feasibility and utility of telemedicine in the provision of palliative care to people with PSD, telemedicine was incorporated as an option for visits in the recently published randomized clinical trial comparing palliative care *versus* usual care for PSD, funded by PCORI [18, 100]. Understanding the optimal way to incorporate telemedicine using comparative effectiveness models, while working on policy advocacy to increase insurance coverage of telemedicine, should be a priority given that this approach increases access to high-quality care for patients with PSD [94, 95].

Awareness of the need to increase the number of primary neuropalliative care providers is growing [88, 90]. In 1997, the Institute of Medicine (IOM) reported that end-of-life care and palliative care education was lacking in medical and nursing training programs; the IOM update to this report in 2014 found that this issue persists [101]. Several studies highlight the lack of training in neurology residency programs in palliative care and end-of-life care [89, 91]. An ongoing National Institutes of Health (NIH) National Institute of Nursing Research (NINR)-funded randomized clinical trial is exploring the feasibility and effectiveness of a primary neuropalliative care training program with access to an interdisciplinary specialty palliative care team by telehealth to increase access to palliative care in the community neurology setting for patients with PSD. This study is using a primary palliative care education program designed with Northwestern University's Education for Palliative and End-of-Life Care (EPEC) program, EPEC-Neurology [86], and will include an evaluation of this training program. EPEC-Neurology covers serious illness communication skills, clinician wellness, and basic spiritual and caregiver assessment. Efficacy will be determined by improved palliative care knowledge and attitudes towards palliative care pre- and post-training, as well as clinician burnout, and clinical measures of quality of life in patients and caregivers.

One area where there is particularly limited research and education is in end-of-life care for patients with PSD [4, 9, 18, 22, 45, 86]. Specialized neuropalliative care is essential to controlling the severe symptom burden found in end-stage PSD [18], but would benefit from greater integration with neurological expertise to reduce the risk of medication errors. For example, haloperidol and metoclopramide are commonly found in hospice comfort kits that are provided to patients and caregivers to ease symptoms, but these are contraindicated in PSD due to the high risk of worsening motor and nonmotor symptoms with these medications. Research into various treatment modalities for refractory symptoms at the end of life for people with PSD (e.g., paranoid psychosis, agitation) is needed to identify the best treatment strategies.

Traditionally, palliative care has been perceived as a treatment reserved for end-of-life care [54] and a decision between quantity of life and quality of life [102]. Challenging this is

evidence that earlier palliative care extends and improves quality of life in serious illness, at least in metastatic cancer [103]. Evaluating whether life expectancy in PSD can be prolonged by palliative care would require a large clinical trial powered to detect such a difference.

There is evidence that palliative care increases use of home hospice services [42], which is likely to reduce healthcare costs in patients with PSD who receive palliative care. Investigating whether palliative care for PSD provides cost savings would be helpful in supporting the dissemination of palliative care into routine outpatient neurological care [97–99].

Conclusions

The symptom burden in PSD is severe. There is growing evidence that palliative care significantly improves quality of life and symptom burden for patients with PSD, and their caregivers, while improving advance care planning to better align medical care with patient values and treatment preferences [18]. Access to palliative care for patients with PSD and research into the most effective, sustainable, and scalable neuropalliative care program for these patients and caregivers is currently limited. Given the benefits of palliative care in the treatment of PSD, comparative effectiveness studies that seek to optimize neuropalliative care interventions and evaluate methods of dissemination should be a priority. An effective and scalable palliative care program for PSD will need to utilize telemedicine to gain access to patients who are geographically isolated or homebound. Additional research, education, advocacy, and clinical efforts to optimize and increase access to palliative care in neurologic disease should be a public health and health economics priority.

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Compliance with Ethical Standards

Disclosures The author declares that she has no competing interests.

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