A neuropalliative care focus on Parkinson’s disease and related disorders

Charles B. Simone II

Department of Radiation Oncology, New York Proton Center, New York, NY, USA

Correspondence to: Charles B. Simone II, MD. Department of Radiation Oncology, New York Proton Center, 225 East 126th Street, New York, NY 10035, USA. Email: csimone@nyproton.com.

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The timing has never been better for a focused issue on Parkinson’s disease, especially considering the recent advances in the field and the relatively recent establishment of neuropalliative care as a clinical subspecialty of neurology and palliative medicine (1). Neuropalliative care principals call for an improved understanding of the broad range of symptoms encountered by patients with neurological disorders, which can inform management approaches and can help alleviate suffering (2). This focused issue builds on the earlier work reported in the July 2018 focused issue in Annals of Palliative Medicine that was dedicated to the more diverse field of neuropalliative care (3).

Parkinson’s disease and related disorders (PDRD) are some of a number of quality-of-life limiting disorders commonly encountered by neurologists and increasingly encountered by palliative care providers. Parkinson’s disease is a progressive neurodegenerative disease with a slight male predominance affecting approximately 100–200 per 100,000 people over age 40 years, equating to over one million people with this condition just in North America (4). In fact, Parkinson’s disease is the fastest growing cause of disability due to neurological reasons, and there are an estimated 6.1 million people affected with the condition globally, up from 2.5 million in 1990 (5). Parkinson’s disease is generally a disease of the elderly, with a mean age at diagnosis is 70.5 years (6). The precise etiology of Parkinson’s disease is incompletely understood but likely involves a multitude of events that include environmental and genetic factors, protein processing abnormalities, oxidative stress, mitochondrial abnormalities, excitotoxicity, inflammatory response, and immune dysregulation (4).

While Parkinson’s disease has long been classified as a motor system disorder, there has been increasing recognition that it is a complex condition with more diverse clinical features like neuropsychiatric and other nonmotor manifestations along with motor symptomatology (7). Common nonmotor symptoms include cognitive dysfunction and dementia, psychosis and hallucinations, mood disorders, fatigue and sleep disturbances, autonomic dysfunction, gastrointestinal dysfunction, olfactory dysfunction, pain and sensory disturbances, rhinorrhea, and dermatologic findings (7,8).

Parkinson’s disease is the most common of the spectrum of parkinsonian neurodegenerative disorders, termed PDRD, in which patients most typically develop progressive tremor, bradykinesia, and rigidity, followed in more advanced stages of disease by postural instability (9). Although the predominant symptoms often evolve over the course of the illness, the major subtypes of Parkinson’s disease and other related disorders are tremor-dominant, akinetic-rigid, and postural instability and gait difficulty (10). Up to 15% of patients with parkinsonism have diseases similar to but distinct from Parkinson’s disease, including dementia with Lewy bodies, progressive supranuclear palsy,
multiple system atrophy, and corticobasal degeneration (11).

Progressive neurological disorders like PDRD have known significant impact on patients, their caregivers, and providers (12). As such, the need to prevent and relieve suffering and improving the quality of life for patients and their families facing PDRD is a critical component of care for these disorders. In fact, basic tents of palliative care—managing medical symptoms, addressing psychosocial problems, and preventing caregiver burnout—are all critical aspects of care for PDRD, particularly as these conditions often have quite a long patient-dependency period over years or even decades (13).

This focused issue of Annals of Palliative Medicine features a preface, five original research articles, and four review articles that discuss active areas of research across a broad spectrum of issues relating to palliative care for PDRD. This issue provides greater clarity in how patients with RDRD can benefit from palliative care, and it addresses which patients can benefit more from which palliative interventions. The issue covers diverse aspects of palliative care related to RDRD, including clinical trial inclusion, spiritual wellbeing, caregiver burden and anticipatory grief, models of care, specialist palliative care, future care planning, access and quality of care, and interdisciplinary home-based palliative care.

This issue on palliative care for PDRD underscores the considerable progress made in the field of neuropalliative care, and it will undoubtedly provide a strong foundation for improving clinical care and advancing future research for patients with Parkinson’s disease and related neurodegenerative disorders.

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Footnote

Conflicts of Interest: The authors have no conflicts of interest to declare.

Ethical Statement: The authors are 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.

References