



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.

Submitted Feb 10, 2020. Accepted for publication Feb 11, 2020.

doi: 10.21037/apm.2020.02.15

View this article at: <http://dx.doi.org/10.21037/apm.2020.02.15>

The February 2020 supplemental issue of *Annals of Palliative Medicine* is a focused issue entitled, “Palliative care for Parkinson’s disease and related disorders” that is guest edited by Dr. Benzi M. Kluger from the Departments of Neurology and Medicine at the University of Rochester Medical Center in New York. Dr. Kluger’s clinical and research focus is on movement disorders, behavioral neurology, and the overlap of these two fields, with a particular interest in the non-motor symptoms of Parkinson’s disease.

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 tenets 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.

Acknowledgments

None.

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.

References

1. Robinson MT, Barrett KM. Emerging subspecialties in neurology: neuropalliative care. *Neurology* 2014;82:e180-2.
2. Palliative care in neurology. The American Academy of Neurology Ethics and Humanities Subcommittee. *Neurology* 1996;46:870-2.
3. Simone CB 2nd. The current state of neuro-palliative care. *Ann Palliat Med* 2018;7:284-5.
4. Lang AE, Lozano AM. Parkinson's disease. First of two parts. *N Engl J Med* 1998;339:1044-53.
5. GBD 2016 Parkinson's Disease Collaborators. Global, regional, and national burden of Parkinson's disease, 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet Neurol* 2018;17:939-53.
6. Van Den Eeden SK, Tanner CM, Bernstein AL, et al. Incidence of Parkinson's disease: variation by age, gender, and race/ethnicity. *Am J Epidemiol* 2003;157:1015-22.
7. Langston JW. The Parkinson's complex: parkinsonism is just the tip of the iceberg. *Ann Neurol* 2006;59:591-6.
8. Hüssl A, Seppi K, Poewe W. Nonmotor symptoms in Parkinson's disease. *Expert Rev Neurother* 2013;13:581-3.
9. Gelb DJ, Oliver E, Gilman S. Diagnostic criteria for Parkinson disease. *Arch Neurol* 1999;56:33-9.
10. Alves G, Larsen JP, Emre M, Wentzel-Larsen T, Aarsland D. Changes in motor subtype and risk for incident dementia in Parkinson's disease. *Mov Disord* 2006;21:1123-30.
11. Hirschbichler ST, Erro R, Ganos C, et al. "Atypical" atypical parkinsonism: Critical appraisal of a cohort. *Parkinsonism Relat Disord* 2017;37:36-42.
12. Simone CB 2nd. The growing challenge of dementia and its impact on patients, their caregivers, and providers. *Ann Palliat Med* 2017;6:299-301.
13. Kluger BM, Fox S, Timmons S, et al. Palliative care and Parkinson's disease: Meeting summary and recommendations for clinical research. *Parkinsonism Relat Disord* 2017;37:19-26.

Cite this article as: Simone CB 2nd. A neuropalliative care focus on Parkinson's disease and related disorders. *Ann Palliat Med* 2020;9(Suppl 1):S1-S2. doi: 10.21037/apm.2020.02.15