



## Palliative care for Parkinson's disease and related disorders: stepping into the future

There has been remarkable growth in the application of palliative care approaches to neurologic illnesses over the past 20 years (1,2), including the emergence of neuropalliative care as a clinical subspecialty and field of research (3-5). Regarding palliative care for Parkinson's disease and related disorders (PDRD), the first set of articles to tackle this topic broadly and articulately advocated for the need for a palliative care approach based on clinical and theoretical considerations but had little in the way of empirical research to support their claims or provide specific guidance for implementation (6-10). When I first began in this field there were only a handful of references that I turned to for inspiration and support for my research program. At the time of the writing of this editorial there are now over 250 articles on PubMed using the search terms of "palliative" and "Parkinson's", over half of which were written in the past 5 years.

This focused issue sheds further light on the exciting work and active research community tackling a broad array of issues tied to palliative care and PDRD. In all of these articles the authors take us past the general question of whether persons living with PDRD would benefit from palliative care to the specific questions of how. While there is significant evidence that the PDRD population has high palliative care needs, the question of which individuals merit more intensive clinical services or inclusion in clinical trials has not been fully addressed. To begin this issue, Richfield and Johnson (11) tackle this important question by reviewing several approaches and tools that have been used for palliative care needs assessment. As they note, this is a complex area and the choice of tool (or tools) will depend on the population to be supported, the services to be offered and the goals of the clinician or researcher.

To better understand what needs are most prevalent in PDRD and how to identify persons needing additional support, Prizer *et al.* (12) examined what factors were most associated with spiritual wellbeing in persons living with PDRD. As a cross-sectional study, one cannot derive causal conclusions, but their results suggest several promising areas for future work, including how to identify patients with higher spiritual needs, how spirituality may improve coping, and where to target spiritual interventions. Macchi *et al.* (13) examines both patient and care partner characteristics associated with caregiver burden in PDRD. Their results importantly extend prior work on caregiver burden into the palliative sphere by examining needs in a population with high needs and examining important factors in a palliative framework, such as spiritual wellbeing, that had not been examined previously. Fox *et al.* (14) also look at the needs of care partners and call attention to the important issue of anticipatory grief, an emerging concept in oncology that merits serious consideration in neurology where care partners are frequently faced with ongoing and anticipated losses from incurable neurodegenerative illness. They report that anticipatory grief is common, distinct from depression and may be more common in persons caring for someone of younger age or with high nonmotor symptom burden.

As PDRD is a chronic and progressive disorder that may span decades, there is a need to develop models of care that can meet the varying needs of persons living with PDRD and their families throughout the disease course. Tarolli and Holloway (15) provide an overview of some of these needs and discuss several broad models of outpatient palliative care for PDRD. These models are complementary and include primary palliative care provided by neurologists, consultative models with referrals to palliative medicine specialists, and a hybrid model led by neuropalliative care specialists. Oliver and Veronese (16) discuss specialist palliative care for PD including the topics of the role of palliative care, framing palliative care needs through different phases of the illness, complex needs meriting specialist care, ethical issues, and the emerging evidence supporting the effectiveness of this approach. Jordan *et al.* (17) tackle the specific issue of future care planning through a patient and care partner-centered approach. Through qualitative interviews and work with a patient and care partner advisory panel, they propose the use of a "roadmap" as a central metaphor to guide conversations with patients, develop shared decision-making resources and inform future research.

As evidence builds to establish the needs of the PDRD population and the efficacy of palliative care approaches to address these needs, the field needs to consider how best to implement and disseminate these approaches. Dr. Katz discusses the potential for telehealth as a means of improving both the access and quality of palliative care available to persons living with PDRD (18). This article includes suggestions for novel models of telehealth, such as the extension for community healthcare

outcomes (ECHO) model, that may empower rural and community providers an opportunity to receive consultative support as well as education in the principles of palliative care (19). Fleisher *et al.* (20) share their experiences using two models of interdisciplinary home-based palliative care for persons living with advanced PD. Both models show evidence of feasibility, acceptability, and effectiveness, with the second model using a hybrid model of in-person and telehealth support to improve efficiency.

While one could argue that the serious and systematic application of palliative care to the clinical care and research program of PDRD is overdue, the articles in this issue point to the current activity and vibrancy of this field. This work may be informed by and benefit from palliative care approaches from other illnesses where palliative care is more developed but will ultimately require novel and nuanced application to meet the unique needs of this population. There is still much work to do (21) but I am happy to state that we have left the starting gates and are laying the foundation for the future of care for people living with this condition.

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## Footnote

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