

Outpatient Palliative Care for Parkinson's Disease: Results from a National Survey

Kei Sugiura, MD; Umer Akbar, MD; Sandhya Seshadri, PhD, MA, MS; Megan Dini, MA; Peggy Auinger, MS; Sally A. Norton, PhD, RN; Jodi Summers Holtrop, PhD; Benzi M. Kluger, MD, MS

Background

- Palliative care (PC) is an approach to address the multidimensional suffering of people with serious illness including medical symptoms, emotional and spiritual distress, future care planning, and family support.
- People living with Parkinson's Disease (PWP) and their care-partners have significant PC needs.¹
- Motor symptoms remain central to the diagnosis of Parkinson's disease (PD), but neuropsychiatric signs and symptoms are gaining recognition as being of similar relevance in many cases, and PD can now be conceptualized as a complex neuropsychiatric disorder.²
- PC approaches improve patient and family-centered outcomes.³
- Little is known about the availability of resources and current practices among physicians in addressing PC needs in outpatient neurology clinics.

Objective

To describe the current availability of outpatient PC for PWP and their CP.

Methods

- A cross-sectional survey was sent to 661 healthcare professionals (including 288 physicians) at the 33 Parkinson's Foundation US centers of excellence (COE).
- This study was part of a larger study on implementing outpatient PC at the COE. For this project we operationalized PC to include 5 key pillars:
 - (1) **Systematic management of non-motor symptoms,**
 - (2) **Management of patient grief and psychosocial issues,**
 - (3) **Care-partner support,**
 - (4) **Annual advance care planning,**
 - (5) **Timely referrals to PC specialist and hospice when needed.**

Results

- We present results related to **physicians' responses.**
- Response rate: 56.9%

Demographics	Physicians (n = 164)
Female, %	48.2
Age, y, mean (SD)	43.6 (11.1)
Time Working in Health Care (Post Training) y, mean (SD)	11.5 (11.4)

Results cont'd

PC pillar elements	Physician providing to >75% of patients, %
Screening of nonmotor symptoms	58
Management of nearly all nonmotor symptoms	69
Pain management	6
Screening of grief/guilt/demoralization/spiritual concerns	15
Direct support for difficult but normal emotions	15
Management of depression/anxiety	44
Referrals to chaplain/counselor	4
Use of scale/checklist to screen care-partners for burnout/other services	2
Direct support for family care-partners	13
Referrals of care-partners to outside services	15
A review/discussion of advance care planning	4
Completion of advance care planning documents	2
Referring end-stage patients to hospice services	8
Referring high need patients to a PC specialist	16

Conclusions & Recommendations

- More physicians assess and manage nonmotor symptoms.
- Patient emotions and CP needs are not adequately addressed.
- Few PWP get timely referrals to PC specialist and Hospice.
- To improve PC approach for PD and address patient and family PC needs, more PC Education and Training for PD providers is recommended.⁴
- PC approach integration into traditional biomedical model is recommended through improved access and support from institutional resources to national policies.⁵

References:

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