



Short Communications

Adopting a palliative care mindset is an unmet need in Parkinson's disease

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ABSTRACT

Introduction: Parkinson's disease (PD) affects multiple facets of patients' lives, many of which may not be recognized or addressed by their healthcare team. A growing body of evidence has shown that palliative care improves patients' quality of life with PD; however, little is currently known about how patients with PD perceive palliative care.

Methods: An 8-question multiple choice survey was created and given to patients with established care for PD at a movement disorders clinic in a quaternary care center. Patients with less than two years of follow-up or that had atypical features of PD were excluded from the survey.

Results: There were 106 respondents to the survey. A third of patients reported having never heard of palliative care and an additional 25% had heard of it but did not know what it was. Eighty-eight percent reported being familiar with or very knowledgeable about hospice, though 50% of respondents did not know the difference between hospice and palliative care. 93% had never been offered either service. 37.7% thought their neurologist should discuss advance care planning early in the course of their disease.

Conclusion: Even among established patients with Parkinson's disease in a quaternary center, over half were not familiar with palliative care, and the majority had never been offered palliative or hospice services despite growing evidence that it could improve their quality of life. Additionally, patients would like to be introduced to advanced care planning early in the course of their disease.

1. Introduction

Parkinson's disease (PD) affects 1–2% of adults over the age of 65 and is the 14th leading cause of death in the United States [1–2]. PD results in motor symptoms of tremor, rigidity, and bradykinesia causing significant functional decline over time. It also causes many non-motor symptoms including depression, psychosis, dementia, sleep disturbances, pain, fatigue, dysphagia, urinary difficulties, and slowed gastric motility. Currently, there are no disease-modifying therapies for PD; though many medication options target the symptoms of the disease. As the disease progresses, the symptoms worsen and become more difficult to manage resulting in increasing physical, psychological, and social issues for both patients and their families. Many of these symptoms, particularly non-motor symptoms, may not be recognized or addressed by physicians despite their impact on patients' quality of life [3].

Palliative care, a service aimed at improving quality of life and

reducing suffering in patients with serious illnesses, was traditionally implemented in the care of cancer patients, but it has since become more widely used as an interdisciplinary treatment for a vast array of chronic illnesses with significant benefits for patients and their families. [4–5] Patients with PD have been shown to have numerous palliative care needs, including management of symptom burden, mood, anticipatory grief, spiritual well-being, and advanced care planning, at similar or higher levels than patients with advanced cancer [6]. Palliative care should not be seen as exclusively end-of-life care, but rather a focus on relief of suffering through all stages of the disease [8]. Examples of this include emotional support at time of diagnosis, goals of care discussions and management of nonmotor symptoms during the middle of the disease, and end of life care at the late-stage of the disease [8]. There is now growing evidence that suggests that palliative care may improve quality of life and reduce hospital deaths in patients with PD [7–10]. The importance of palliative care is becoming increasingly recognized and

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the Parkinson's Foundation has since launched a palliative care program initiative across 33 U.S. Parkinson's Disease Centers of Excellence.

Hospice is a service that focuses on care, comfort, and quality of life for patients with a terminal illness. Patients with PD become increasingly disabled throughout their disease course and PD is associated with higher rates of premature death, which makes advanced care planning important. Though not studied specifically within this population, the majority of terminally ill patients prefer to die at home [11]. Studies have shown that most patients with PD do not receive hospice care and die in hospitals or other institutions rather than at home [4,11].

There is little known about patients with PD knowledge or perceptions of palliative care and hospice. Prior studies have primarily focused on identifying palliative care needs of patients with PD and those that have studied patient perceptions were completed in a qualitative interview format [6]. In this study, we analyze patients' perceptions of palliative care by using a standardized survey with the goal of obtaining more uniform data on this topic. A secondary aim is to learn PD patients' preference on how palliative care be presented to them and at what stage of their disease they would like to be introduced to advanced care planning.

2. Methods

An 8-question survey with multiple choice answers was created to assess patients' perceptions of palliative care. Patients filled out questions regarding their own demographics and self-reported length of time since their diagnosis of PD. The survey was offered to consecutive patients with PD with established care in the movement disorders clinic at a large, multi-specialty academic medical center. To be included in the study, patients must have had a diagnosis of PD from a movement disorders fellowship-trained neurologist, and had to have been followed at the movement disorders center for at least 2 years. Patients were excluded if they had significant cognitive impairment which limited their ability to reliably complete the survey or if there was any suspicion that they may have an atypical parkinsonian disorder, as determined by the movement disorder specialist treating the patient. The survey included questions about the patients' familiarity with palliative care and hospice, if they knew the difference between palliative care and hospice, if they knew someone who had utilized these services, who they would prefer to introduce them to palliative care and when advanced care planning should be discussed in their disease course. This survey has not previously been validated in this population.

Descriptive statistics were calculated for the sample to characterize sex, race, ethnicity (Hispanic or non-Hispanic), current age, and time since diagnosis of PD. Survey responses are presented as a count and percent of total respondents per question. Comparisons of survey responses were made between men and women, older and younger respondents, and shorter and longer lengths of disease.

3. Results

There were 106 respondents included in the survey results. The sample was 54% male, 95% white, 97% non-Hispanic with a median age of 71.0 years (SD = 8.4) and a median of 9.8 years since diagnosis (SD = 7.4; n = 92 responses).

More than one third (34.6%) of respondents had never heard of palliative care and an additional 25% had heard of palliative care, but did not know what it was. (Table 1) On the contrary, respondents had some familiarity (55.7%) or were very knowledgeable (32%) about hospice. Half of respondents did not know whether or not there was a difference between palliative care and hospice. Most respondents reported knowing someone who had utilized hospice (78.3%), but fewer reported knowing someone who had utilized palliative care (27.4%), and 93% reported they had never been offered or used either. Half of respondents who reported having some familiarity with or being very knowledgeable about palliative care reported having known someone

Table 1
Survey responses.

Survey Item	n (%)
Familiarity with palliative care*	
“I have never heard of it.”	36 (34.6)
“I have heard the term, but don't know what it is.”	26 (25.0)
“I have some familiarity with palliative care.”	36 (34.6)
“I am very knowledgeable about palliative care.”	6 (5.8)
Familiarity with hospice	
“I have never heard of it.”	4 (3.8)
“I have heard the term, but don't know what it is.”	9 (8.5)
“I have some familiarity with hospice.”	59 (55.7)
“I am very knowledgeable about hospice.”	34 (32.1)
“Is there a difference between palliative care and hospice?”	
Yes	51 (48.1)
No	2 (1.9)
I don't know.	53 (50.0)
Has known someone who has utilized†	
Palliative care	29 (27.4)
Hospice	83 (78.3)
Neither	16 (15.1)
Feelings about more information regarding palliative care†	
Explained by primary care provider	32 (30.2)
Explained by neurologist	51 (48.1)
Explained through online resources	18 (17.0)
Explained through pamphlets	27 (25.5)
Explained by a support group	9 (8.5)
Explained by someone who has had palliative care	18 (17.0)
Not interested in more information	33 (31.1)
Advanced care planning†	
Should be discussed before someone is diagnosed with any disease	22 (20.8)
Should be discussed at the time of diagnosis with Parkinson's disease	20 (18.9)
Should be discussed earlier in the disease course	40 (37.7)
Should be discussed later in the disease course	28 (26.4)
Should be discussed when someone is unable to care for themselves	13 (12.3)

*Two responses incomplete.

†Multiple response or no response allowed.

who used it, while those who reported no or little knowledge about palliative care had very low rates of knowing someone who had used it (12%).

When asked if they were interested in receiving more information about palliative care and if so, who would be the best to explain it to them, respondents preferred their neurologist (48.1%) introduce them to it. A third (37.7%) of respondents also felt that advanced care planning should be discussed early in the disease course.

Knowledge about and preferences regarding palliative care were similar between genders, among patients of different ages, and with different lengths of disease. The only exception was that patients with a longer disease duration were more likely to answer that they did not think there was a difference between palliative care and hospice (Supplementary Material Tables 2–4).

4. Discussion

PD affects numerous aspects of patients' lives, many of which may not be adequately addressed by the current healthcare system. There is increasing evidence that palliative care can have positive impacts on patients with PD quality of life [8–11]. However, there is limited knowledge about how patients with PD perceive palliative care or how they would like to be introduced to palliative care.

Our study has shown that over half of patients with PD, despite their established care in a quaternary center, were not aware of what palliative care medicine is, but the majority reported having at least some familiarity with the term hospice. However, half did not understand the difference between the two, and 93% were never offered either, despite a median disease duration in our study sample of nearly ten years. Furthermore, patients prefer that their neurologist be the provider to introduce them to palliative care and that advance care planning be discussed early in the course of their disease. Interestingly, these results

did not significantly differ based on disease duration or age of the patient. These results demonstrate the need to educate patients and providers about these important services and that these services should be more consistently offered to patients as part of the management of their disease, regardless of their age or duration of their disease.

A limitation of this study was that the vast majority of respondents identified themselves as white and non-Hispanic and all patients were being treated at a quaternary medical center. While our results may not be indicative of the perceptions of the PD population outside these parameters, we calculated that patients with established care for at least 2 years in a Parkinson's center would have the best opportunity of receiving palliative care education. The survey also relied on patients being able to read and comprehend the questions; thus those with significant cognitive impairment and likely further in their disease course and presumably with a higher need of palliative care, were not represented in the results. In addition, further research needs to be done to study providers' perceptions of palliative care for the PD population and the reasons they are or are not consistently offering palliative care services to their patients with PD.

In our study, over half of patients with PD are not familiar with palliative care and the vast majority have never been offered palliative care or hospice services even though it could improve their quality of life. This does not imply that motor and non-motor symptoms of patients were not addressed during their routine care, nor that patients were unsatisfied with the care they received. However, it does highlight the large opportunity to present such interdisciplinary care in a *palliative care mindset*, even among Parkinson's disease centers. Moreover, the results of this study show that patients with PD would like to be introduced to palliative care by their neurologist and discuss advance care planning early in the course of their disease.

5. Disclosures

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Avery Kundrick: Resources, Writing - Original Draft, Writing - review & editing. **Olivia Hogue:** Formal analysis, Writing - review & editing. **Sarah Namrow:** Investigation. **Renato Samala:** Conceptualization, Writing - review & editing. **Ellen Walter:** Writing - review &

editing. **Benjamin Walter:** Writing - review & editing. **Hubert Fernandez:** Supervision, Conceptualization, Writing - review & editing. **Adam Margolius:** Supervision, Conceptualization, Methodology, Investigation, Resources, Writing - review & editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.prdoa.2023.100206>.

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