

# Defining Palliative Care Needs in Parkinson's Disease

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**ABSTRACT:** Objectives: Palliative care addresses the suffering of patients and families affected by progressive illness through the management of medical symptoms, psychosocial issues, and spiritual concerns. Although there is an emerging interest in applying palliative care to Parkinson's disease (PD), potential palliative care needs have not been systematically investigated in PD patients. Our primary objective was to determine the prevalence of clinically significant symptomatic, psychosocial, and spiritual issues in PD and understand their impact on health-related quality of life (HRQOL). Secondary objectives included comparing the level of palliative care needs of PD patients to advanced cancer patients and assessing preferences for advance care planning. Methods: Ninety PD patients and 47 patients with advanced cancer were surveyed regarding potential palliative care needs, including symptom burden, mood, anticipatory grief, and spiritual well-being. PD patients completed additional scales regarding HRQOL, motor symptoms, cognitive impairment, and preferences regarding advance care planning.

Results: Potential palliative care needs, including high symptom burden and grief, were common in PD patients and contributed to HRQOL even when controlling for depression and motor severity. In all domains investigated, PD patients had similar or higher levels of palliative care needs as patients with advanced cancer. PD patients expressed a desire to complete advance directives early in the disease course and with a physician.

Conclusions: Palliative care needs contribute to HRQOL in PD and are of similar severity as cancer patients. This study supports and helps focus efforts to integrate palliative care principles in PD care across the spectrum of the disease.

Although Parkinson's disease (PD) is traditionally viewed as a movement disorder, our understanding of PD has shifted markedly over the past 20 years. Nonmotor symptoms are now recognized as intrinsic features of PD with a significant impact on quality of life (QOL) and disability.<sup>1-3</sup> There is increasing recognition of the impact of PD on mortality, with recent Centers for Disease Control and Prevention statistics ranking PD as the 14th leading cause of death.<sup>4</sup> Palliative care (PC) is an approach to improving the QOL of patients and families focused on the relief of suffering through the management of physical, psychosocial, and spiritual issues.<sup>5</sup> Although traditionally associated with cancer, PC has been successfully applied to several chronic illnesses, including heart

failure and pulmonary disease.<sup>6,7</sup> There is an emerging interest in applying PC to neurological illnesses, including PD.<sup>8</sup> A fundamental first step in moving this field forward is to systematically identify and define the PC needs of PD patients. Our primary objective was thus to understand the range of symptomatic, psychosocial, and spiritual issues in PD and understand how they impact QOL. Secondary objectives included comparing the severity and distribution of PC needs of PD and advanced cancer patients, a population where PC needs are well established,<sup>9</sup> and assessing PD patient preferences for advance care planning. We hypothesized that PC needs would independently contribute to QOL in PD and be of similar magnitude as cancer patients.

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## Materials and Methods

### Standard Protocol Approvals, Registrations, and Patient Consents

This cross-sectional observational study was approved by institutional review boards at the University of Colorado and the Denver Veterans Affairs Medical Center (VAMC). All participants provided written informed consent.

### Participants

PD and cancer patients were recruited from clinics at the University of Colorado Hospital and Denver VAMC between January 2014 and July 2014. Patients were recruited from general clinics and were not specifically recruited from palliative care clinics or programs. Eligible study participants were aged >45 years, English speaking, and either (1) diagnosed with idiopathic PD by a movement disorder fellowship-trained neurologist using UK Brain Bank Criteria<sup>10</sup> or (2) diagnosed with locally advanced or metastatic head and neck, lung, pancreatic, gastric, esophageal, or biliary cancer. Patients were excluded if they had dementia severe enough to preclude meaningful survey completion as determined by the patient's primary neurologist or research staff. Our goal was to be as inclusive as possible for the full range of PD severity while maintaining reliable and valid reporting outcomes.

### Outcome Measures

#### Health-Related Quality of Life and Functional Status

Health-related quality of life (HRQOL) was assessed in PD patients using the Parkinson's Disease Questionnaire-39 (PDQ-39), a 39-item survey which assesses overall HRQOL and includes eight validated subscores (mobility, activities of daily living, emotional well-being, social stigma, social support, cognition, communication, and bodily discomfort).<sup>11</sup> For each item, patients are asked how frequently they have experienced certain events (e.g., "Had difficulty getting around in public") on a 5-point scale ranging from "never" to "always." Functional status was assessed in PD and cancer patients using both the Eastern Cooperative Oncology Group Performance Status score (ECOG; 5-point scale ranging from Asymptomatic to Death)<sup>12</sup> and the Schwab and England (S&E) activities of daily living scale, which assesses a person's independence ranging from 100% indicating total independence to 0% indicating a state of complete dependence.<sup>13</sup>

#### Global Symptom Burden

Global symptom burden was measured using the Memorial Symptom Assessment Scale Short Form (MSAS), a 32-item survey of global symptom burden which provides a total score, global

distress index (combines four psychological symptoms [sadness, worry, irritability, and nervousness] and six physical symptoms [lack of energy, pain, appetite, drowsiness, constipation, and dry mouth]), physical symptom subscale, and psychological symptom subscale.<sup>14</sup> Ranges for total score and all subscores are 0 to 4. Items are symptoms (e.g., "pain") which are rated on either a 5-point scale of severity ranging from "not at all" to "very much" or a 4-point scale of frequency ranging from "rarely" to "almost constantly." As a secondary outcome, we created a modified version of the MSAS (MSAS-PD) with five additional symptoms commonly observed in PD ("hallucinations," "confusion," "muscle stiffness," "uncontrollable movements," and "problems with motivation") rated using the 5-point scale of severity.

#### Mood, Grief, and Spiritual Well-Being

Mood was measured using the depression and anxiety subscores of the Hospital Anxiety and Depression Scale (HADS), a 14-item scale which rates symptoms of depression and anxiety on a scale of 0 to 3, with some items related to frequency and others to severity; a cut-off score of  $\geq 11$  has been suggested to indicate clinically significant anxiety or depression for either subscore.<sup>15</sup> Anticipatory grief refers to feelings of loss associated with illness, which are distinct from depression, and was measured using the Prolonged Grief Questionnaire 12 (PG-12), a 12-item scale that rates symptoms of grief in terms of either frequency (5-point scale from "not at all" to "several times a day") or intensity of feelings (5-point scale from "not at all" to "overwhelmingly").<sup>16</sup> The presence of prolonged grief disorder was based on the presence of daily symptoms of distress and impairment in function as per suggested Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition criteria using responses from this scale.<sup>17</sup> Spiritual well-being was assessed using the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale (FACIT-Sp), a 12-item scale that rates symptoms of spiritual well-being on a 5-point scale from "not at all" to "very much" and includes meaning, peace, and faith subscores.<sup>18</sup> High spirituality was defined by a score of  $\geq 36$  and poor spiritual well-being by a score  $\leq 12$ .<sup>19</sup>

#### Medical Comorbidities

Medical comorbidities were measured using the Charlson Comorbidity Index, which assigns a single score based on 22 medical conditions, each of which is weighted based on mortality risk and by age with 1 point assigned for every decade above age 50.<sup>20</sup>

#### PD Stage, Motor Symptoms, and Cognitive Function

PD disease stage was rated using the H & Y scale, a single 5-point investigator rating based on extent of motor symptoms and balance impairment.<sup>21</sup> Motor symptoms were assessed by a trained rater using the motor subscore of the UPDRS.<sup>22</sup> Cognitive function was assessed using the Montreal Cognitive Assessment (MOCA).<sup>23</sup>

## Preferences and Use of Advance Care Planning

Preferences, knowledge, and use of advance care planning was assessed with selected and modified items from the Lyon Advance Care Planning Survey, including items regarding whether they had heard about and completed a Health Care Power of Attorney or Advance Directive, when is the best time to bring up end-of-life decisions, and who on a treatment team are/is the best people/person to bring up advanced care planning.<sup>24</sup>

## Statistical Analyses

Statistical analysis was performed using SAS software (Version 9.4; SAS Institute Inc., Cary, NC). All data were checked for outliers, distributions, and missing values. *P* values <0.05 were considered significant. Descriptive statistics, including means and standard deviations for continuous variables, and percentages for categorical variables are presented for characteristics of PD and cancer patients. *t* tests were used for bivariate or group comparisons, and mean differences were adjusted for age, sex, years of education, and marital status when comparing PD and cancer groups. Pearson correlations were used to measure associations between continuous variables. To better understand the relationship between explanatory variables and HRQOL, regression models were selected from variables having a significant Pearson correlation with HRQOL using backward elimination. If there were more than nine significant explanatory variables, separate models were created based on clinical domains, and then the selected explanatory variables were combined and backward elimination was performed again to obtain the final model. The threshold for removal from the model was a *P* value >0.10.

With a sample size of 90 PD patients and 45 cancer patients, we have 86% power to exclude a clinically significant difference on the MSAS Global Distress Index (range, 0.0–3.2) of >0.45 points<sup>25</sup> between PD and cancer patients with a two-tailed alpha of 0.05, assuming that our PD and cancer patients have similar standard deviations as previously published cohorts (approximately 0.8).<sup>14</sup> The difference of 0.45 points on the Global Distress Index is clinically significant<sup>25</sup> and is less than the change detected in advanced cancer patients from 6 to 6 months preceding death.<sup>26</sup> For other aims, we are powered to detect correlations of  $\geq 0.3$  with over 80% power at 0.05 significance, and in regression models with five covariates we can detect an effect size of 0.15 ( $f^2$ ) with 80% power at 0.05 significance.

## Results

### Demographic and Disease Characteristics of PD and Cancer Patients

Ninety PD patients with a wide range of disease severity and 47 patients with advanced cancer were recruited. Table 1

summarizes their demographic, disease severity, and cognitive features.

### Impact of Palliative Care Issues on HRQOL in PD

To better understand the relationship of the explanatory variables with HRQOL, we first performed Pearson correlations for continuous variables and *t* tests or analysis of variance for categorical variables with the total PDQ-39 (see Supporting Information Table S1 for details).

Because there were more than nine significant predictors of the PDQ-39, we performed separate regression models for non-palliative (e.g., demographic, motor) and palliative predictors, and then combined the winners of these models into a single model (Table 3). We followed a similar strategy to determine what variables were the best predictors of the PDQ-39 subscales (Supporting Information Table S2).

### Comparison of PD and Cancer Patients' PC Needs

On average, PD patients were older ( $67.6 \pm 9.1$  vs.  $62.9 \pm 11.8$  years;  $P = 0.02$ ), had longer disease duration ( $107.5 \pm 71.1$  vs.  $29.7 \pm 28.7$  months;  $P < 0.0001$ ), and were more educated ( $16.1 \pm 2.9$  vs.  $14.8 \pm 2.9$ ;  $P = 0.01$ ) than cancer patients, but did not significantly differ in terms of income, sex, or race/ethnicity (see Table 1). PD patients reported similar common symptoms (lack of energy, feeling drowsy, pain, muscle stiffness, and difficulty concentrating), uncommon symptoms (vomiting, diarrhea, and mouth sores), but differed in having lower reported hair loss and higher reported severity of urinary and sexual problems (see Supporting Information Table S3 for full results). Notably, PD patients did not differ significantly from patients with advanced cancer, except for having significantly higher psychological symptom burden on the MSAS (PD  $0.71 \pm 0.61$  vs. cancer  $0.43 \pm 0.48$ ;  $P = 0.0036$ ). There were no significant differences in the proportion of patients in each group meeting HADS cutoff for depression (9 of 90 for PD and 2 of 47 for cancer;  $P = 0.33$ ), anxiety (7 of 90 for PD and 1 of 47 for cancer;  $P = 0.26$ ), FACIT-sp cutoff for poor spiritual well-being (41 of 90 for PD and 14 of 47 for cancer;  $P = 0.07$ ), or PG-12 criteria for prolonged grief disorder (1 of 88 for PD and 0 of 46 for cancer;  $P = 1.0$ ).

### Patient Preferences and Use of Advance Care Planning

Table 3 summarizes PD and cancer patients' preferences, knowledge, and use of advance care planning. Notably, a significantly higher proportion of PD patients reported completing medical power of attorney paperwork (76% vs. 53%;  $P = 0.018$ ) and reporting a preference for completion of this paperwork before or at the time of diagnosis (92% vs. 78%;  $P = 0.048$ ). The majority of patients reported a preference for discussing these issues

**TABLE 1** Demographic and Disease Characteristics of Parkinson's disease and cancer patients

	PD	Cancer	P Value
Age (mean ± SD, range)	67.6 ± 9.1 (38–87)	62.9 ± 11.8 (26–79)	0.02
Gender (N; % male)	64 male (71.1)	31 male (66.0)	0.53
Level of education (years; mean ± SD)	16.1 ± 2.9	14.8 ± 2.9	0.01
Income: <			0.29
\$10,000/year (N; %)	14 (15.6)	7 (14.9)	
\$10–20,000/year	9 (10.0)	11 (23.4)	
\$20–35,000/year	10 (11.1)	6 (12.8)	
\$35–50,000/year	16 (17.8)	6 (12.8)	
\$50–100,000/year	28 (31.1)	9 (19.2)	
>\$100,000/year	13 (14.4)	8 (17.0)	
Married (N; %)	71 (78.9)	30 (63.8)	0.057
Disease duration (months; mean ± SD, range)	107.5 ± 71.1 (12–336)	29.7 ± 28.7 (1–108)	<0.0001
Cancer types	NA		NA
Pancreatic		16 (34.0)	
Lung		15 (31.2)	
Head and neck		6 (12.8)	
Biliary		4 (8.51)	
Esophageal		3 (6.38)	
Gastric		3 (6.38)	
H & Y (mean ± SD)	2.49 ± 0.82	NA	NA
Stage 1 (N; %)	5 (5.6)		
Stage 1.5	1 (1.1)		
Stage 2	36 (40.5)		
Stage 2.5	23 (25.8)		
Stage 3	12 (13.5)		
Stage 4	10 (11.2)		
Stage 5	2 (2.3)		
ECOG	1.17 ± 0.85	1.04 ± 0.81	0.40
S & E	80.1 ± 16.5	83.0 ± 16.5	0.34
UPDRS Motor Score (mean ± SD)	30.9 ± 14.6	NA	NA
L-dopa equivalent dose (mean + SD)	703.9 ± 482	NA	NA
Presence of DBS (N; %)	10 (11.4)	NA	NA
MOCA (mean ± SD, range)	24.9 ± 4.0 (7–30)	NA	NA

Abbreviation: NA, not applicable.

with a physician (either primary care physician, oncologist, or neurologist).

## Discussion

The goals of this study were to better understand the range and impact of palliative care issues affecting individuals with PD with

secondary objectives, including comparing these needs to persons with advanced cancer and furthering our understanding of preferences for advance care planning. Our results support current efforts to integrate a PC approach for this population across the full spectrum of the illness.<sup>27</sup> Specifically, we found that PC issues, including high symptom burden, poor spiritual well-being, and grief, were common across the disease spectrum and similar in prevalence and severity to patients with advanced

**TABLE 2** Predictors of Overall HRQOL in PD Patients

PDQ Subscales	Pearson Variables Used in Model (r, P Value for Continuous Items)	Significant Results From Stepwise Linear Regression Model (Partial r, P Value)
PDQ-total	Sex (male) (−0.3, 0.02) Income (−0.4, 0.002) Education (−0.5, <0.0001) H & Y (0.6, <0.0001) UPDRS (0.4, 0.0001) MOCA (−0.3, 0.004) Prolonged grief 12 (0.7, <0.0001) MSAS:physical (0.6, <0.0001) MSAS:psychological (0.6, <0.0001) FACIT:meaning (−0.5, <0.0001) FACIT:peace (−0.5, <0.0001) HADS:depression (0.6, <0.0001) HADS:anxiety (0.6, <0.0001)	Education (−0.3, 0.007) H & Y (0.47, <0.0001) Grief (0.52, <0.0001) MSAS:physical (0.3, 0.003)

Grief = Prolonged Grief Questionnaire 12 item.

**TABLE 3** PD Patient Use and Preferences for Advance Care Planning

Item	Potential Responses	PD Responses (N; %)	Cancer Responses (N; %)	P Value
Have you ever written down any thoughts about your future health plans?	Yes, definitely	43% (N = 38)	30% (N = 14)	0.32
	Very probably	1% (N = 1)	2% (N = 1)	
	Probably	3% (N = 2)	2% (N = 1)	
	Probably not	0% (N = 0)	2% (N = 1)	
	Definite no	48% (N = 43)	62% (N = 29)	
Have you ever heard about and completed a Health Care Power of Attorney, in which you name someone to make decisions about your health care in case you could not?	Don't know	6% (N = 5)	2% (N = 1)	0.018
	Have heard about and completed	76% (N = 68)	53% (N = 25)	
	Have heard about but not completed	18% (N = 16)	38% (N = 18)	
	Have not heard about	4% (N = 4)	9% (N = 4)	
Have you ever heard about and completed an Advance Directive, such as the Five Wishes?	Don't know	2% (N = 2)	0% (N = 0)	0.32
	Have heard about and completed	56% (N = 50)	40% (N = 19)	
	Have heard about but not completed	23% (N = 21)	32% (N = 15)	
	Have not heard about	16% (N = 14)	23% (N = 11)	
When do you think it is the best time to bring up end-of-life decisions?	Don't know	6% (N = 5)	4% (N = 2)	0.048
	Before getting sick, while healthy	80% (N = 72)	58% (N = 26)	
	When first diagnosed with a life-threatening or progressive illness	12% (N = 11)	20% (N = 9)	
	When first sick with a life-threatening or progressive illness	2% (N = 2)	9% (N = 4)	
When do you think it is the best time to bring up end-of-life decisions?	When first hospitalized with a life-threatening or progressive illness	3% (N = 3)	7% (N = 3)	P > 0.05 for all comparisons
	If dying	2% (N = 2)	7% (N = 3)	
	Primary care physician	58% (N = 52)	45% (N = 21)	
	Neurologist	54% (N = 49)	38% (N = 18)	
	Nurse practitioner	21% (N = 19)	19% (N = 9)	
	Nurse	9% (N = 8)	11% (N = 5)	
	Social worker	11% (N = 10)	15% (N = 7)	
Who are the best people/person on the treatment team to bring it (end-of-life decisions) up with you? (Could select more than one)	Psychologist	9% (N = 8)	9% (N = 4)	
	Case manager	6% (N = 5)	9% (N = 4)	
	Chaplain	20% (N = 18)	17% (N = 8)	
	Patient advocate	11% (N = 10)	11% (N = 5)	
	Other	37% (N = 33)	36% (N = 17)	

cancer. Importantly, these issues contributed to HRQOL even when controlling for motor disease severity and depression, suggesting that models of care to optimize HRQOL in this population need to address these issues. Patients also overwhelmingly indicated a desire to complete advance directives early in their disease course, and the majority expressed an interest in doing this with a neurologist or other physician.

PC is an approach to care that focuses on improving quality of life and reducing suffering through management of medical and psychiatric symptoms, psychosocial issues, and spiritual well-being, as well as through planning for the future.<sup>28</sup> The PC approach encompasses both primary palliative care (defined as skills appropriate to any clinician, including general neurologists and movement disorders specialists)<sup>29</sup> and specialist PC (defined as care provided by persons with additional training and certification in PC). Regarding physical and psychiatric symptom burden in PD patients, both were similar to or higher than patients with cancer and significantly contributed to many aspects of HRQOL. This is not surprising given the growing body of literature on the prevalence and impact of nonmotor symptoms in PD.<sup>30</sup> Despite the growing recognition of these symptoms in the research literature, evidence suggests that these symptoms are often under-

recognized in clinical practice, and our data would suggest that efforts moving toward comprehensive care for PD, whether using a palliative model or otherwise, must include routine assessment for these symptoms.<sup>31</sup> From a specialty PC perspective, it is important to note that the distribution of symptoms is somewhat different across these populations and that even shared symptoms, such as pain, may originate from different causes and merit different treatment strategies.<sup>32</sup>

From an emotional standpoint, grief, defined as the response to any kind of significant loss including the losses associated with chronic disease, was commonly present and also contributed to many aspects of QOL even when controlling for symptoms of depression and anxiety. We think it is important to point out that difficult emotions are not necessarily a pathological reaction to chronic illness and should be distinguished from the well-described mood complications of PD. In our clinic, we find that grief, guilt, worry, frustration, and other difficult emotions are common and may respond to counseling with our chaplain or referrals to community psychotherapists. Evidence from other populations suggests that grief can be distinguished from depression and merits distinct treatment and therapies.<sup>33</sup> Our data also suggest that it is less common for patients to meet criteria for

prolonged grief disorder, although further study in larger samples and possibly focusing on more-advanced disease should be undertaken to better understand this issue.

Aspects of spiritual well-being contributed to HRQOL, and there was a strong trend for more patients with PD to have poor spiritual well-being compared to cancer patients. We found that both “meaning” and “peace” subscores of the FACIT-sp scale contributed to HRQOL, and these represent two important issues for people with PD. There is a growing body of literature on the importance of meaning in coping with chronic illnesses, and a loss of meaning may contribute to demoralization and even requests for medical aid in dying.<sup>34,35</sup> Regarding peace, there is evidence that prayer, meditation, deep-breathing, and other spiritual practices may be useful aids to coping and are commonly used by PD patients.<sup>36</sup> We hypothesize that the chronic, progressive, and incurable nature of PD, combined with its effects on cognition and mood, may contribute to spiritual challenges, and this suggests a need for both quantitative and qualitative studies to better understand the challenges and opportunities of spirituality in PD.

An additional objective in this research was to look more closely at preferences for advanced care planning in PD. In patients aged  $\geq 65$  years, advanced care planning has been found to increase patient satisfaction with their provider.<sup>37</sup> Similar to one previous publication on this issue, PD patients in our study were found to prefer end-of-life discussions before they were acutely ill.<sup>38</sup> Earlier discussions have been found to lead to end-of-life care that is more concordant with patient preferences and earlier use of PC, which was shown to be beneficial to quality of life and mood in patients with cancer.<sup>39</sup>

This study has several important limitations. The study represented a convenience sample of patients coming largely from a single university-based clinic. It is possible that different factors may be more or less important in patients coming from different settings or communities and at different disease severities, duration, and cognitive abilities. Another limitation is that research questionnaires were administered at one point in time and thus reflect associations, but cannot be used to draw causal inferences such as may be drawn from longitudinal or intervention studies. Caregiver support and strain is another important PC issue that we plan to explore in a subsequent article.

In conclusion, PC issues contribute to HRQOL in PD and are of similar severity as cancer patients. Notably, PC needs appeared to differ in several important aspects between these populations, including a greater burden of psychological symptoms. This study supports efforts to develop and integrate PC approaches in PD care across the spectrum of the disease.

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## Author Roles

(1) Research Project: A. Conception and Design; B. Acquisition of Data; C. Analysis and Interpretation of Data; (2) Manuscript: A. Writing of the First Draft, B. Review and Critique; (3) Other: A. Literature Search and Review; B. Obtaining Funding; C. Statistical Analysis.

B.M.K.: 1A, 2B, 3B

J.S.: 1B, 1C, 2C

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F.B.: 1B, 3A

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D.W.B.: 1A, 2B

S.S.: 3C

D.B.B.: 1A, 2B

## Disclosures

**Ethical Compliance Statement:** This cross-sectional observational study was approved by institutional review boards at the University of Colorado and the Denver Veterans Affairs Medical Center (VAMC). All participants provided written informed consent. All authors confirm that they have read the Journal's position on issues involved in ethical publication and affirm that this work is consistent with those guidelines.

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## Supporting Information

Supporting information may be found in the online version of this article.

**Table S1.** Predictors of Health-Related Quality of Life in Parkinson's Disease Patients

**Table S2.** Impact of Palliative and Nonpalliative Variables on PDQ-39 Subscores in Parkinson's Disease Patients

**Table S3.** Comparison of Palliative Care Needs Between Parkinson's Disease and Cancer Patients