Parkinson disease patients' perspectives on palliative care needs

What are they telling us?

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Abstract

Background: A growing body of literature suggests that patients with Parkinson disease (PD) have many unmet needs under current models of care that may be addressed through palliative care approaches. A first step in improving care for patients with PD through palliative care principles is to better understand patient perspectives on their perceived needs and care preferences. **Methods:** A total of 30 in-depth individual interviews and 4 focus groups were held to elicit the perspectives of patients with PD on unmet palliative care needs and preferences for addressing these needs. We used ATLAS.ti and inductive qualitative data analysis techniques to interpret responses. **Results:** Patients articulated major challenges in living with a diverse and complex set of motor and nonmotor symptoms; feelings of loss; changes in roles, relationships, and concept of self; and expressed concerns about the future. Participants discussed gaps in their care, including support at the time of diagnosis, education about the disease, and advance care planning. There was an expressed interest in and openness of participants to interdisciplinary approaches for addressing these needs. **Conclusions:** PD has a profound effect on multiple domains of a person's life starting at diagnosis. Patients desired individualized care and identified several areas where care from their primary neurologist could be improved. Patients were receptive to outpatient team-based palliative care services to address psychosocial issues, adjustment to illness (particularly at diagnosis and with progression), nonmotor symptom control, and advance care planning as an adjunct to usual care. Future research is needed to develop and test the effectiveness of palliative approaches to improve the care of patients with PD. *Neurol Clin Pract* 2016;6:209-219

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Parkinson disease (PD) is traditionally viewed as a movement disorder with characteristic motor symptoms that affect quality of life (QOL) but not mortality. However, it is now recognized that nonmotor symptoms affect the majority of patients with PD, decreasing QOL and increasing nursing home placement.¹ There is also increasing

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recognition of PD's effect on mortality.² Despite these advances, clinical care for PD continues under a chronic illness model focused on motor symptoms through a patient–physician dyad.³ Gaps in this model include management of nonmotor symptoms, grief, spiritual needs, advance care planning, caregiver support, and appropriate hospice referrals.^{4–7}

Palliative care is an approach to the care of patients and families affected by life-threatening illness that aims to relieve suffering through management of medical symptoms, psychosocial issues, and spiritual well-being. Although traditionally associated with hospice and cancer, palliative approaches have been successfully applied to several chronic illnesses, may be appropriate at any stage of an illness, and may be applied by primary care physicians and neurologists.^{5,8,9} A fundamental first step in improving services for patients with PD is to identify their palliative care needs. To this end, we conducted a qualitative study eliciting patient perspectives on potential palliative care issues.

METHODS

Standard protocol approvals, registrations, and patient consents

All study procedures were approved by our institutional review board and written informed consent was obtained from all participants in the study. Authorization to disclose the names of patient reviewers of this article was acquired.

Recruitment

To maximize diversity, we recruited participants from an academic tertiary care center, a Veterans Affairs Medical Center, an inner city clinic, and community support groups. We initially used a convenience sample; however, as the study progressed, we used maximum variance sampling to ensure diversity in terms of sex, age, home environment (e.g., urban, rural), PD severity, and cognitive status.¹⁰ Eligible patients were English-speaking, over age 40 years, and met UK Brain Bank Criteria¹¹ for probable PD. We included patients with Hoehn & Yahr¹² stage I or higher. We specifically included patients with dementia. For these patients, we simplified questions and used caregivers as informants when needed. Patients who were unable to meaningfully answer questions, as determined by a movement disorders specialist, were excluded from this study.

Data collection

Interviews were conducted in clinic or patient homes. Interviews averaged 60 minutes, and were digitally recorded, transcribed, and entered into ATLAS.ti¹³ for coding and analysis. An interview guide (table 1) was used and revised during the study to probe emerging themes. Initial domains were based on studies of palliative care in heart failure and proposed models of PD palliative care.^{14,15} Patients were asked their opinions regarding palliative care at the end of interviews; the term palliative was not used earlier to avoid potential biases.

Analysis

Analysis goals included probing unmet needs, salient concerns, and care preferences. We used inductive qualitative data analysis techniques to interpret patient responses to interview questions as described below.^{10,16} A code list was developed by 3 members of our team (I.B., J.J., and B.K.) to track salient quotations and ideas and revised with continued data collection and

Table 1 Interview domains and sample questions

Interview domains	Sample questions/probes
Communication	Think back to when a health care professional first told you that you had PD. What should they have done differently?
	What would you recommend about how and what to tell patients about the diagnosis?
Symptoms	What symptoms of your PD are most difficult for you to deal with?
	What is it about [previously mentioned symptom] that is difficult to manage?
Psychological	When you think about your PD, what are the strongest emotions that come to mind?
	What aspects of your PD are most worrisome to you?
	Has your PD changed how you view yourself as a person?
	Where do you find strength?
Social	Who do you turn to when you are feeling [previously mentioned emotion]?
	How would you describe your social life since being diagnosed with PD?
Quality of life	How would you describe your quality of life?
	What things are important to you in terms of quality of life?
Advance care planning	Have you talked to someone about what you would want done if you could no longer make decisions for yourself?
	Do you have your wishes in writing and who knows about them?
	When do you think it would be appropriate to talk about planning for the future?
	Who would you want to talk to about advance care planning?
Palliative care	Have you ever heard of the term palliative care? If yes, what does that mean to you?
	Would you be interested in outpatient palliative care and if so when do you think these services might be helpful to you?

Abbreviation: PD = Parkinson disease.

input from the multidisciplinary team. Text within and between codes was compared to develop broader themes. We employed several methods to increase the validity of our results, including the following: (1) observer triangulation (utilizing multiple analysts to review data); (2) data triangulation (obtaining data from multiple sources); and (3) member checking (eliciting feedback from a subsample of participants).^{10,17} Data triangulation involved the use of varied data collection strategies including interviews and focus groups.¹⁰ In terms of member checking, we returned a draft of the findings to a subsample of participants in order to ascertain their sense of agreement with the findings.

RESULTS

Participant characteristics and overview

A total of 30 individuals with varying stages of PD and 4 focus groups (a distinct group of 4–7 patients each) completed interviews. Table 2 summarizes demographic and disease characteristics. The following themes emerged: (1) challenges of living with motor and nonmotor symptoms; (2) loss, grief, and identity; (3) worries about the future; (4) spiritual well-being; (5) gaps in care; (6) impressions of physicians; and (7) responses to palliative care. The results presented reflect these themes with additional descriptive examples presented in table 3.

Challenges of living with motor and nonmotor symptoms

In addition to the effect of motor symptoms on daily function, patients described how social embarrassment and the unpredictable nature of symptoms led to restriction of activities and social withdrawal. Tremor and gait issues were particularly difficult for patients. Participants

Table 2 Participant characteristics

	Patients	Informal caregivers
Sample size, n	30	11
Sex, n (%)		
Female	11 (36.7)	9 (81.8)
Male	19 (63.3)	2 (18.2)
Age, y, mean (SD)	68.1 (7.1)	65 (8.2)
Years of education, mean (SD)	16.7 (2.6)	16.8 (1.8)
Disease duration, mo, mean (SD)	136.4 (77.4)	—
UPDRS III, ³⁶ mean (SD)	28.2 (15.4)	—
Hoehn & Yahr, ¹² n (%)		—
Stage I	2 (6.7)	
Stage I.5	1 (3.3)	
Stage II	13 (43.3)	
Stage II.5	6 (20.0)	
Stage III	3 (10.0)	
Stage IV	5 (16.7)	
Levodopa equivalent dose, mean (SD)	704.8 (478.8)	—
MoCA, ³⁷ mean (SD), range	25.1 (4.1), 14-30	—
Dementia, n (%)	5 (16.7)	
Deep brain stimulation surgery, n (%)	6 (20.7)	
Abbreviations: MoCA = Montreal Cognitive Assessment; UPDRS = Unified Parkinson's Disease Rating Scale.		

reported multiple nonmotor symptoms, including fatigue, cognitive dysfunction, speech/communication issues, anxiety, depression, and pain, and these were often cited as being more challenging than motor symptoms. While these problems were common across patients with both early and advanced disease, deep brain stimulation appeared to result in more complaints regarding speech and communication. Patients described avoiding social interactions, interference with passions/hobbies, and inability to complete daily tasks. Fatigue was the most commonly cited most difficult nonmotor symptom. Fatigue often came on unexpectedly, leading patients to cancel plans and miss important events. Cognitive dysfunction was also common, limited function, and related to fears about being a burden and losing identity.

Loss, grief, and identity

Patients struggled with a sense of loss, changing roles, relationship changes, and concept of self. Some patients discussed PD's effect on their sex life in terms of both motor and nonmotor symptoms. One of the most pervasive themes was grief attributable to cognitive decline, which affected patients' sense of self. Participants discussed the loss of former roles in terms of family and partners. Some patients also talked about their identification and involvement with the larger PD community as a meaningful source of friendship and support (table 3).

Worries about the future

Patients described difficulty in living with uncertainties regarding how their PD would progress and future needs. This included fears regarding dementia, being a burden to loved ones, the loss of independence, and deterioration of personal appearance. Some patients discussed

Table 3 Core themes with descriptive examples

Core themes	Descriptive examples
Core theme 1: Challenges of living with motor and nonmotor symptoms	"It makes me feel like a fool...we are walking along the docks of the harbor one day and I heard these guys say 'she is drunk.'"—Female, 68, referring to issues with balance
	"Because by um...sometimes 5:00 I'm in so much pain I can hardly see straight. So I go to bed like at 7:30. Just to knock out the pain. And then I get up at 3:30 in the morning. I start the day early, because the early part is the best. The pain hasn't started yet."—Female, 69
	"I'm self-conscious about that in public. I don't want anybody to notice that or for it to be a distraction if I'm having a conversation with somebody. I mean I was in business for years and I know what physical distractions can be when you are trying to communicate with someone."—Male, 69, referring to tremor
	"A lot of issues with anxiety...I can't really go in a crowd. It's just too much. Just data overload. It just makes me sick, cause I used to thrive on that stuff."—Female, 66
	"I was very high energy. Physically, psychologically...I mean I was used to waking up with a Boom! And go, go, going. No limitations. I've been healthy all my life. This fatigue isn't like you take a nap and you feel better. It's just this lack of stamina that I find incredibly frustrating."—Female, 57
Core theme 2: Loss, grief, and identity changes	The easy overriding issue for me is the cognitive. I mean it is just the elephant in the room. The problem is that you keep looking for answers to understand it and to be able to categorize it. To say I know it's not normal. Is it normal for Parkinson's? If it is not normal, what is it? And what are the prospects?"—Male, 65
	"I agree in terms of cognition. It makes me feel like I'm not myself anymore. Because I can't count on my brain to come back with that response, or to be insightful for all the things I've relied on for my whole life, they are no longer there at my access. So it makes me feel sometimes, a little bit lesser."—Focus group 4
	"My engagement with other patients, and with the PD world in general, has just taken me to a different place. And that is what I latch on to and it makes me feel much more positive about things. One of the interesting things is that you learn—or I've learned—pretty quickly, that I feel extremely comfortable around other people with Parkinson's. There is no guile. And that is the only place where that happens. It is like brothers and sisters who are sharing something. It is like we are brothers in arms."—Male, 65
	"It makes me sad that I can't do what I used to do...It's like something died. I can't play tennis. I can't run. I only sit and eat and get fat. And I have to watch everything I eat. Because if I eat any protein the medicines don't work."—Female, 67
	"Parkinson's is a journey in grief."—Female, 59
Core theme 3: Worries about the future	"There was a time when I was the king of the house. I ruled the roost. I made the major decisions. Now I turned over the bookkeeping to her."—Male, 72
	"I don't have as many friends and when early in my career, I was a school teacher, college placement director and the Director of Admissions. A training officer, a school superintendent. I was somebody in the community. And now I'm nobody."—Male, 72
	"Everybody has a future self. You may not consciously always be thinking of it. But you think of what am I going to be doing in 5 years or 10 years. It's something you carry around. And when you have Parkinson's, your future self is eliminated."—Female, 57
	"But the biggest one is just that becoming disabled and not being independent. I hate the thought of that. And when I try to talk to Joe [spouse] about that, he just laughed at me. What if I get disabled and have to use a cane and then I got all this movement? And the grandkids all laugh at me? Or they don't want their friends to be with me? I just can't stand the thought of that."—Female, 64
	"I'm afraid I'm going to lose my mind. I'm afraid I'm going to be demented on top of everything. My dad had dementia terribly...I've seen what it does. It's horrible."—Female, 66

Continued

Table 3 Continued

Core themes	Descriptive examples
	"I worry about the progressive part of it. ...we were at the conference and I saw some people that were further along. And their hands were moving a whole lot more than mine. Both of them. They never sat still. And I worry about that. How far is mine going to go? So I worry about the future, financially too."—Male, 56
	Patient: "Um...whether I'll have dementia. Whether I will be able to negotiate the house without hurting myself. Or somebody else." Interviewer: "What worries you about the possibility of dementia?"
	Patient: "Oh, just being a burden. To my family. And not be able to be who I am with people. People won't remember me the way I was."—Male, 72
	"I think it is never knowing how I am going to feel to plan something. And you just got an invitation to dinner or something and you just think I hope I'll feel good because sometimes I don't feel like I can even get up and go and walk around."—Focus group 3
Core theme 4: Spiritual well-being	"I have always had it [religion] and I used it to help me cope with life. And enhance life. Not cope with it as much as enhance it."—Female, 69
	"I do have spirituality, but I am not a religious person. So my spirituality really is a very internal belief that is very wrapped up in my own moral code. I think it is evolving and becoming more present in my life because of Parkinson's."—Female, 58
	"And that helps a lot. Because I guess if you thought this was it, you would be very disappointed. Now I'm wasting the last days I have and that's it. And we are Catholic and we go to church. And we try to be good Christians."—Male, 78, referring to religion
Core theme 5: Gaps in care	"I think it would really be nice, if after that diagnosis, you could debrief with a mental health person...I just remember going into this crowded exit area and just collapsing. I went into the women's bathroom and called my family. And I just sat on the floor. But it would have been nice, in an ideal situation, if there had been the option to meet with a social worker or somebody who could support you."—Female, 57
	"People who are being told for the first time, it would be really ideal if they were handed off, either with information or to someone, you know, just to... and it wasn't Dr. X's fault, but go home and come back in 3 months. Well, I don't think anybody would do particularly well under those circumstances. So it gives you too much room to imagine the worst."—Male, 65
	"My diagnosis was very perfunctory. My appointment was fit into a 20 minute time slot, you know? And I didn't leave with anything other than a prescription. No real advice on how to go forward..."—Focus group 4
	"I felt like I had to pull and pull and pull to get information. I still feel like that...I'd like to know what to expect down the road. And I know they said it is different for everybody, but let's talk about it"—Female, 65
	"It would be nice to have some guidance on it. Right now we don't know. Go to the hospital or the doctors? Is it on the computer? But they need to offer some guidance. Everybody says you need to do it, you need to do it, you need to do it, but nobody says what is the first step to doing it? Just write it out and sign it and get it notarized? Is that legal? Or do I have to use a special form and file it with the government? Nobody knows."—Male, 60, referring to advance directives
	"So we need to be told the resources. We can do the research, but we have doctors to tell us what is going on right? Like it would be nice if someone would say, here are some of the things you could expect. Here ...come to this workshop or whatever."—Male, 69
Core theme 6: Impressions of physicians	"I am concerned about saying anything to her, cause I'm afraid she will increase my meds... And I don't really want to take any more meds."—Female, 64
	[Question: Do you think your doctor should be involved in advance care planning?] "I wouldn't know that he would really care, one way or the other."—Female, 66
	"They think so much into the medicines and that type of stuff, I never thought of them talking about that."—Female, 64, referring to advance care planning

Continued

Table 3 Continued

Core themes	Descriptive examples
	"Dr. X hasn't been that much helpful as far as she just keeps prescribing medication. She even asked me what do I want to try? I said I have no idea. You know? You tell me. So it kind of upsets me that hospital X doesn't know more about it than just the medication part of it."—Male, 56
	Interviewer: "Would you want to talk to anyone in health care about this [referring to advance care planning]?" Patient: "No, because I don't see what they could tell me."—Female, 73
Core theme 7: Responses to palliative care	"What I think patients need is the ability to interact at different stages based on their needs at that point."—Male, 60
	"But I think for the number of people that are getting diagnosed earlier, it is critical to form that environment that makes it easy to learn, easy to get information, and is supportive. You know? Kind of that one-stop shopping mentality, but it is outside of that traditional clinical box."—Female, 57
	"I mean I can see some benefit to starting now, so to speak...fatigue...planning for the future...hospice and end of life care. Cause right now I think I'm far enough away from it that I'm not so emotionally wrapped up in it that I think I could be more receptive than when I am, let's say, 6 months away from death or something like that."—Male, 69
	"All your services in one place. And they could interact with each other...and I can see the benefit of that."—Focus group 3
	"I like the idea. The concept. I've learned all pretty much on my own, cause I haven't had anybody to talk to...how to deal with it. How to get over the bumps in the road."—Male, 60
	"And I said you know what I would love? Cause there are so many components to this illness, I wish there was one stop shopping. And that really you could have a care team under one roof and that it wouldn't be me who was always responsible for making sure everybody worked together"—Female, 57

medication costs and the financial consequences of living with advanced PD. Falls were a source of fear and anxiety for both patients with and without current balance issues. Patients had concerns about planning for the future and advanced directives and often did not know to whom to turn for answers.

Spiritual well-being

Religion and spirituality were important for many patients, including helping with the acceptance of PD and for moving forwards in their new life with PD. Some patients used meditation and prayer as a source of strength. Others stated that they did not have religious or spiritual beliefs and often obtained support from other sources (i.e., family, friends, and nature).

Gaps in care

Patients discussed several areas in which they believed their neurologic care was inadequate. Patients appreciated the difficulties physicians face when giving a serious diagnosis, but emphasized the importance of individual variation in terms of how much information should be presented and the manner in which the diagnosis is given. Many patients described a sense of abandonment by their medical team after diagnosis due to the lack of support offered for dealing with its repercussions. Participants desired earlier follow-up, access to immediate emotional support, and improved connections to PD resources. Participants articulated the need for more education, particularly on what to expect in the future. Many patients were dissatisfied with the information they had received from their medical team and used online resources to fill in gaps, often with less than satisfactory results. Many participants did not have or were unsure if they had an advance directive. Patients often said they knew what it was and that it needed to be

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done, but did not know how. Several participants who had completed an advanced directive did not include their physician in the process and believed it should be done by the family or a lawyer. Some patients also wanted more information about nutrition, research, clinical trials, and exercise.

Impressions of physicians

In general, patients believed their neurologists were primarily interested in managing their medications and even withheld information about worsening symptoms due to the fear of being prescribed another drug. Some patients held the belief that their neurologist was not interested in advance care planning. Further, some patients did not understand how their neurologist or health care team could assist them with future planning and did not consider including their doctor in the process.

Responses to palliative care

The majority of participants did not have an accurate knowledge of palliative care and often equated palliative care with hospice, advanced cancer, and end of life. However, when educated on palliative care concepts, patients responded positively. Overall, patients were supportive of team-based care and enthusiastic about early palliative care, particularly at the time of diagnosis and with disease progression. Some patients believed that it might be more helpful later in their disease course. Several patients used the term “one-stop shop” and liked the idea of addressing multiple issues during a single visit and individualized care based on patient-specific needs.

DISCUSSION

This study supports recent literature that patients with PD have many unmet needs under current models of care and we propose that many of these needs may be addressed through a palliative care model.^{4,5,18–20} The experiences described by participants suggests that the effect of symptoms goes well beyond what clinicians and researchers typically consider, including concerns about the future, finances, personal appearance, identity, and social relationships. This study has implications that extend beyond the realm of PD as there are many similarities with our findings and comments made in other neurology patient populations such as multiple sclerosis.²¹

Patients were receptive to the idea of an outpatient palliative care clinic for PD even early in the course of disease, which is similar to reports from qualitative studies in some but not all chronic illnesses.^{14,22} It should be noted that patients with PD are more generally interested in increasing patient-centered care and multidisciplinary care and that our results may be reflective of these broader needs and that many of the needs identified (e.g., educational) may be met in other models of multidisciplinary care.²³ Palliative care may have overlap with other patient-centered models of multidisciplinary care but is distinct in its approach to reducing suffering for the patient and family, incorporation of spiritual and psychosocial well-being, and emphasis on advance care planning. One aspect of our results that echoes our experience in providing outpatient palliative care for patients with PD is that patients are more receptive to palliative care when presented in terms of the actual services provided than when using the term palliative care and many clinics use the term supportive care or complex symptom management to mitigate these biases.

Many patients identified nonmotor symptoms as being their greatest challenges, consistent with multiple prior studies.^{24–28} This underscores the need for clinicians to actively screen and manage nonmotor symptoms.²⁹ Notably, a recent case series suggests that a team-based outpatient palliative care program for PD may be efficacious in managing patients with advanced disease with high nonmotor symptom burden.¹⁸

Diagnosis is a particularly traumatic event for many patients and this emotional effect appears to be frequently underestimated by clinicians.³⁰ Similarly, it appears that we are not meeting patients' needs when it comes to education and planning for the future, including advance directives. Several patients also expressed the view that their physician was primarily interested in pushing medications and not in discussing alternative approaches, emotions, future planning, or treating them as individuals.

This study has several limitations. Our intention in conducting this relatively small qualitative study was to generate hypotheses and future studies are needed to fully understand the importance of these findings on a population level. While standard qualitative methods were used for this study, it should be recognized that biases of the research team may influence the results through biases at the level of participant selection, interviews, choice of themes, and presentation of results.

Overall, these results suggest several areas for future research as well as more immediate ways in which to improve care. We do not believe that a single solution can hope to address all issues. For community clinicians, focused education in primary palliative care (skills appropriate to all clinicians including communication of bad news, basic symptom management, and completing advance directives) may result in considerable gains for a large number of patients.³¹ Community-based resources, group classes, patient mentoring programs, and Internet-based materials should be considered to meet educational needs.³² Finally, secondary (community-based) and tertiary (academic) palliative care programs should be developed to address the needs of patients with advanced disease and those with more complex symptom management, psychosocial, and spiritual issues.³¹ Further research is needed to determine the most effective approaches to addressing these needs and prior work in both neurologic and non-neurologic populations may provide a basis for future interventions dependent on the target need(s), the target population (e.g., advanced disease, time of diagnosis), and setting (e.g., rural vs urban).^{33–35}

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I.B.: interpretation of the data, writing of the initial draft, and revision of subsequent drafts. J.J.: interpretation of the data, assistance with revision of subsequent drafts, design and conceptualization of the

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