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# Palliative Care and Parkinson's Disease: Caregiver Perspectives

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## Abstract

***Background:*** Palliative care for Parkinson's disease (PD) is an emerging area of interest for clinicians, patients and families. Identifying the palliative care needs of caregivers is central to developing and implementing palliative services for families affected by PD. The objective of this paper was to elicit PD caregiver needs, salient concerns, and preferences for care using a palliative care framework.
***Materials and Methods:*** 11 PD caregivers and one non-overlapping focus group ($n = 4$) recruited from an academic medical center and community support groups participated in qualitative semi-structured interviews. Interviews and focus group discussion were digitally recorded, transcribed and entered into ATLAS.ti for coding and analysis. We used inductive qualitative data analysis techniques to interpret responses.
***Results:*** Caregivers desired access to emotional support and education regarding the course of PD, how to handle emergent situations (e.g. falls and psychosis) and medications. Participants discussed the immediate impact of motor and non-motor symptoms as well as concerns about the future, including: finances, living situation, and caretaking challenges in advanced disease. Caregivers commented on the impact of PD on their social life and communication issues between themselves and patient. All participants expressed interest and openness to multidisciplinary approaches for addressing these needs.
***Conclusions:*** Caregivers of PD patients have considerable needs that may be met through a palliative care approach. Caregivers were receptive to the idea of multidisciplinary care in order to meet these needs. Future research efforts are needed to develop and test the clinical and cost effectiveness of palliative services for PD caregivers.

**Keywords:** caregiver needs; care preferences; Parkinson's disease; qualitative

## Introduction

THE MAJORITY OF PD PATIENTS live at home for many years following their diagnosis and become increasingly reliant on family members and other informal caregivers such as spouses, adult children, friends, or other nonpaid individuals.[1,2] The physical, social, and psychological support given by these caregivers occurs over years to decades[3] and having a caregiver versus no caregiver is associated with improved patient morbidity, mortality, and quality of life,[4,5] while caregiver distress and burn out are associated with increased risk for patient institutionalization.[4] Research from the Parkinson's UK suggests that the majority of PD caregivers spend over 50 hours a week on caregiving responsibilities.[1] Caregivers are impacted physically, emotionally, and financially by their role and are at risk for chronic illness,[6] depression,[7] cardiovascular disease,[8] and can have as much as a 60% increase in mortality.[9] One-third of caregivers

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felt unprepared for their role.[3] Dementia is common in PD and is an additional risk factor for caregiver distress and complicated bereavement.[10–12]

One of the most well-replicated findings within health research is that support from family and friends is important in facilitating coping with a long-term illness.[1] Palliative care addresses medical, psychosocial, and spiritual issues and transcends the patient–physician dyad by addressing caregiver strain and offering support services to family members.[13] Interest in palliative care for PD patients and their families has been increasing over recent years.[14–16] Previous studies specifically on the needs of PD caregivers report adverse effects of caregiving on not only their emotional and physical health but also with difficulty in accessing financial benefits and a lack of coordinated and continued care.[3,17,18] The objective of the present study was to validate and build on this work by eliciting PD caregiver needs, salient concerns, and care preferences using a palliative care framework to guide qualitative interviews.[19–21]

## Methods

### Participants

This research was part of a broader study investigating the palliative care needs of patients and caregivers living with PD.[22] English-speaking patients who were more than age 40, met UK Brain Bank Criteria for probable PD, and were Hoehn and Yahr Stage 2 or higher[23,24] and their informal caregivers were recruited for this study. We specifically included patients with dementia. Both patients and caregivers were recruited from the University of Colorado Hospital Movement Disorder Clinics, Denver Veterans Affairs Medical Center, and Parkinson's Association of the Rockies events between January 2014 and July 2014. The protocol was approved by the Veterans Affairs Research & Design Committee and the Colorado Multiple Institutional Review Board. All participants provided written informed consent. The data in this study include only the caregiver perspectives.

### Data collection

Of the 50 caregivers who completed the parent study questionnaires, 11 were selected for semistructured, in-depth interviews. We used maximum variance sampling of patients to ensure variety in terms of gender, age, home environment (e.g., urban, rural), PD severity, and cognitive status.[25] We also conducted one focus group ($n=4$) that comprised an independent group of caregivers to enable interactive discussions and elicit perspectives across a small group sample.

An open-ended interview guide (Table 1) consistent with study goals was initially used and was revised during the study to better probe emerging themes and with the input from our multidisciplinary scientific advisory board (J.J., J.C., D.B., J.M., J.K.). The development of our interview guide and domains assessed was informed by the National Consensus Projects' model of palliative care,[19] by studies of palliative care in heart failure,[20] and proposed models of PD palliative care.[20,21] Caregiver burden was assessed using the 12-item short form of the Zarit Burden Inventory (ZBI), which produces results comparable to those of the full version.[26] Each question is scored on a five-point Likert scale ranging from ''never'' (0) to ''nearly always'' (4) with higher scores indicating worse levels of burden. A score of 17 or higher on the 12-item ZBI indicates high levels of burden.[26]

A research assistant (I.B.), who was not part of participants' medical care team, conducted both the interviews and the focus group. Interviews allowed for in-depth personal exploration of needs, salient concerns, and preferences for care of PD caregivers. Interviews and the focus group were digitally recorded, transcribed, and entered into ATLAS.ti[27] for coding and analysis.

### Analysis

We used inductive qualitative data analysis techniques to interpret responses.[25,28] A code list was initially developed by the core research team and was revised with continued data collection and with input from the multidisciplinary team. Text within and between codes was compared to develop themes. Investigator and methodological triangulation (using our multidisciplinary research team and data coding by more than one person), member checking (eliciting feedback on themes from subsamples of participants to confirm their accuracy), and the use of multiple qualitative methods (interviews and focus group) were used to increase the rigor of our approach.

## Results

### Participant characteristics and overview

Interviews were conducted with 11 informal caregivers (9 females, mean age $=65\pm8.2$) and one nonoverlapping focus group ($n=4$). Participant and associated patient characteristics are presented in Table 2. The average reported length in the caregiver role was 63.5 months (range = 36–182 months). Scores on the ZBI were high (mean = 24.1, standard deviation = 9.6, range = 14–40), indicating that caregivers perceived caregiving as burdensome, which was consistent with caregivers' descriptions of their predominant emotions regarding caregiving as ''frustrated'' and ''sad.'' The following core themes emerged from the data: (1) the need for individual attention and support; (2) educational needs and helpful resources; (3) the consequences of motor and nonmotor symptoms; (4) concerns about the future; and (5) responses to palliative care. The results presented reflect these core themes with additional descriptive examples in Table 3.

### The need for individual attention and support

This theme described the need for caregivers to be treated by their partner's healthcare team and society at large as unique individuals with separate needs. Caregivers desired more individual attention and emotional support, including having their questions as caregivers addressed. One caregiver stated specifically that she needed support ''at the beginning'' (i.e., around the time of diagnosis) and another stated receiving a therapeutic effect simply by participating in the interviews associated with the current. Caregivers emphasized a need to be treated as individuals distinct from the patient. This included being properly greeted at office visits and for more questions to be directed at the patient. Some expressed frustration when physicians mainly aimed questions at them during appointments as they felt this put them in a role of simply being the spokesperson of the patient. They stressed it was important for physicians to recognize that they ''are not the ones with the disease'' and that it should not be assumed that caregivers would know everything that the

Table 1. Interview Domains and Sample Questions for Caregivers

| *Interview domains* | *Sample questions/probes* |
|---|---|
| Communication | How has your healthcare team communicated with you as a caregiver? |
| | ☐ *Probe:* mode and quality of communication |
| | Think back to the time a healthcare professional first told [name] he/she had PD. |
| | ☐ What did they do well? |
| | ☐ What should they have done differently? |
| | ☐ What would you recommend to a healthcare professional about how and what to tell people about the diagnosis? |
| | From where have you received the most useful information about being a caregiver of someone with PD? |
| | What kind of information do you think is most helpful? (Including information they have not found) |
| | Is there information that you think would have made you feel better prepared? |
| | How do you think communication with [patient name] could be improved? |
| Patient symptoms | What symptoms of [name] PD are most difficult for you to deal with? |
| | ☐ *Probe:* motor (i.e., tremor, slowness, balance, and fine motor impairment) |
| | ☐ *Probe:* nonmotor (i.e., mood, fatigue, sleep, cognitive, hallucinations, swallowing, and speech) |
| | What is it about [mentioned symptom] that is difficult to manage? |
| Psychological | Where do you find strength? |
| | What makes you feel hopeful? |
| | When you think about [name] PD, what are the strongest emotions that come to mind? |
| | When you think about being a caregiver to [name], what are the strongest emotions that come to mind? |
| | Which aspects of caring for someone with PD worry you the most? |
| Social | How would you describe your social life since [name] was diagnosed with PD? Has it changed? |
| | What might help you be more social and active? |
| Advance planning | What is the future to you? |
| | As a caregiver, what aspects of planning for the future are most important to you? |
| | Have you talked with [name] about what he/she would want done if he/she could no longer speak for himself/herself? |
| | ☐ If yes, could you tell me more about that discussion? |
| | ☐ Who would you want to help you with planning for the future? |
| | ☐ When do you think it would be appropriate to talk about planning for the future? |
| | ☐ What would be most helpful for starting this conversation? |
| Caregiver safety | Are you concerned about your personal safety around [name]? |
| | ☐ *Probe:* physical, sexual, and verbal abuse |
| Preferences | Is there anything you could use some more help with right now? |
| | What do you anticipate needing help with in the future? |
| | Were there any events that changed your role as a caregiver? (e.g., need for walker, wheelchair, dementia…) |
| | What kind of support would be most helpful to you as a caregiver? |
| | If you could design your perfect clinic, what would it look like? |
| | (Can give probes, e.g., team-members, availability, group visits, continuity…) |
| Palliative care | Have you ever heard of the term ''palliative care''? |
| | ☐ If yes, what does that mean to you? |
| | *Show palliative care brochure* and ask for feedback. |
| | ☐ *Probe:* Do you think this might be helpful for you? When do you think something like this might be helpful? |
| Other | Is there anything else you would like to talk about that I haven't mentioned? |

PD, Parkinson's disease.

patient experiences. Despite these concerns, caregivers felt attending neurology appointments with their partner was beneficial to them (i.e., note taking, asking questions, validating information).

This theme also became apparent in the context of social life—some participants discussed the necessity of boundaries in their role as an informal caregiver and reiterated the importance of maintaining their own social lives and involvement in hobbies despite PD. Caregivers also stated that their participation in social activities and spending time with friends and family was a major source of strength.

### *Education needs and helpful resources*

This theme referred to caregiver-identified gaps in education and includes resources caregivers have found to be helpful in terms of understanding PD. Despite most caregivers understanding the individual variation in disease progression in PD, participants generally wanted more information about disease progression and what to expect in the future as well as medications and their side effects. Participants also felt unprepared to respond to emergency situations (i.e., falls, cardiopulmonary resuscitation [CPR], psychosis). In general, the

Table 2. Caregiver Demographics and Burden

| *Caregiver demographics* | *Informal caregivers* | *PD patients* |
|---|---|---|
| Sample size (*n*) | 11 | 11 |
| Gender (*n*, %) | | |
| Female | 9 (81.8) | 2 (18.2) |
| Male | 2 (18.2) | 9 (81.8) |
| Age (mean, SD) | 65 (8.2) | 65 (5.9) |
| Range | 51–80 | 56–72 |
| Years of education (mean, SD) | 16.8 (1.8) | 17 (2.2) |
| Range | 14–21 | 12–20 |
| Marital status (%) | | |
| Married | 90.9 | 90.9 |
| Divorced | 9.1 | 9.1 |
| Length of caregiving in months (mean, SD) | 63.5 (55.2) | — |
| Range | 0–182 | |
| Income (%) | | |
| <$10,000 | 18.2 | 18.2 |
| $10,000–$19,999 | 9.1 | 9.1 |
| $20,000–$34,999 | 27.3 | 18.2 |
| $35,000–$49,999 | 18.2 | 27.3 |
| $50,000–$99,999 | 27.3 | 9.1 |
| >$100,000 | — | 18.2 |
| Hoehn and Yahr (*n*, %) | | |
| Stage I | — | — |
| Stage I.5 | — | — |
| Stage II | — | 6 (54.5) |
| Stage II.5 | — | 3 (27.3) |
| Stage III | — | 1 (9.1) |
| Stage IV | — | 1 (9.1) |
| MoCA (mean, SD), range | — | 25.5 (4.0), 14–28 |
| Deep brain stimulation (n,%) | — | 3 (27.3) |
| ZBI (mean, SD), range | 24.1 (9.6), 14–40 | — |

ZBI (scores range from 0 to 48 with higher scores indicating worse levels of burden; >17 = high burden).

MoCA, Montreal Cognitive Assessment; SD, standard deviation; ZBI, Zarit Burden Inventory.

uncertainty of how their partner's PD might progress was a significant source of stress and anxiety for caregivers.

During interviews caregivers were asked, ''From where have you received the most useful information about being a caregiver of someone with Parkinson's disease?'' The most commonly cited ''most useful'' resource was caregiver support groups. Other commonly cited useful resources included the Parkinson's Association of the Rockies (local PD organization) and Internet websites and associated webinars (e.g., the Parkinson's Disease Foundation and Michael J. Fox Foundation sites). Some caregivers felt they had an instinctual understanding of what it took to be a caregiver, taking a more or less ''learn as you go'' approach. One caregiver stated receiving the ''most useful'' information about being a caregiver from her medical team. Caregivers often found strength in prayer and through spending time with friends and family.

### *The consequences of motor and nonmotor symptoms*

This theme described the impact of symptoms on the caregiver's life. Cognitive dysfunction was challenging for many caregivers and negatively impacted their lives. For some participants, their partner's cognitive dysfunction had pushed them into taking on new roles and responsibilities (e.g., becoming the primary decision maker). In addition to cognitive dysfunction, relationship changes had an impact on caregiver's lives, including assuming a greater responsibility for household tasks, acting as a chaperone, and less time spent doing and planning recreational activities. Communication issues, including both voice and content, were also discussed and the majority of caregivers felt that communication could be improved between themselves and the patient. Caregivers also discussed the impact of sleep behavior disorders, bradykinesia, and tremor on their lives in terms of impact on their sleep, physical caregiving, and social embarrassment, respectively.

The majority of caregivers in this sample did not voice any concerns about their personal safety (e.g., emotional, physical, and sexual abuse). However, one caregiver did discuss concerns for her physical safety during a time period in which her partner was experiencing psychosis.

### *Concerns about the future*

This theme described the concerns about the future from the caregiver's perspective in relation to PD. The most commonly cited concerns related to the following: (1) finances; (2) housing/living situation; and (3) taking care of their spouses in advanced disease. The majority of caregivers we interviewed had advanced directives in place but commented that they would have liked more involvement and guidance from their healthcare teams. Notably, the majority of concerns about the future brought up by caregivers were related to topics not covered in an advanced directive.

### *Responses to palliative care*

At the end of interviews, participants were asked about their understanding of the term ''palliative care.'' Few had an accurate knowledge of palliative care, although the majority of participants stated being familiar with the term. When provided education on palliative care as a broad model of care that addressed suffering from multiple perspectives was not restricted to end-of-life care and that was inclusive of patients and families, all caregivers responded positively. Five participants expressed an immediate interest in outpatient palliative care services mentioning particular interest in the option for getting counseling and other resources for themselves and getting more guidance around behavioral issues and dementia. Five reported that while interested in the concept, they were not ready for it yet, reporting that they were satisfied with their current level of care and would be more interested if their partner was at a more advanced stage of the illness or requiring a higher level of care. Caregivers were especially supportive of models that provided individualized care in a team-based interdisciplinary or multidisciplinary clinic. Some concerns about this model of care included not wanting to add more clinicians to their healthcare team and more time with medical personnel.

## Discussion

The present study highlights the unmet needs, salient concerns, and care preferences of caregivers of PD patients. The emotional burden on caregivers was high and many caregivers desired individual attention and support. Caregivers had

TABLE 3. CORE THEMES WITH DESCRIPTIVE EXAMPLES

| *Theme* | *Descriptive examples* |
|---|---|
| Core theme #1 | The need for individual attention and support<br>“In the caregiver’s group that I go to, one of the things I wasn’t liking that they are doing a little better with is they always talk about their husband, or son or whoever it is that has Parkinson’s. We just…as women, we are taught anyway not to talk about ourselves and to be the focus of attention. And it’s like if somebody asks me: How are you? They just work their way into my heart. That’s what I need.”—Female, 63<br>“Just that it would be nice if once in a while they would allow us to vent to you guys. Like that. And it’s awesome. And I mean I don’t know what is going to happen with all this…but it’s still nice for me to be able to vent.”—Female, 62<br>“Parkinson’s is a very flamboyant disease. People notice it. People notice tremors. They notice dyskinesia. They notice this person looks a little strange. Whatever. And I think it happens a lot…Only two people have asked how are you? To me. How am I? It just doesn’t happen. It is always how is Steve? How is he doing? There are two of us…if all 4 of us get together—how are you doing Steve? Blah, blah, blah. They never, ever ask, how am I? And I think that would be helpful if someone gave a damn how I am. Because right now, and a matter of fact, I am more disabled than he is. No one knows it.”—Female, 63<br>“I think at the beginning I needed to talk to somebody.”—Focus group<br>“I think, ‘I am not the patient’, but the bedside manner would expand a little bit to the family. Because you almost want to tell the doctor, ‘Look. You don’t live with that person. You have no idea.’ I feel like that sometimes, depending on the doctor. You have no idea what is going on.”—Female, 60<br>“I just need someone to talk to. Cause my children don’t want to hear about this. You know? I’ve had enough and I don’t want to burden them. They’ve been very kind. But they don’t quite see from my perspective”—Focus group<br>“This is great! Talking to you is like therapy! Talking to you is like the best time I’ve had in 10 years!”—Female, 62<br>“So I’ve got several different groups, which are really important to me to keep that up. I mean it just keeps my interest into other things. It gives me something else to do…I think you have to have something, or you kind of go crazy.”—Female, 70 |
| Core theme #2 | Education needs and helpful resources<br>“There is communication that we need. Somebody to prepare us, because the time is going to come when we can no longer keep our husbands and wives at home.”—Focus group<br>“Like I’d want to know, what are the possibilities? What are the problems? Because they have been in the health profession for a long time. They have seen hundreds of patients. I have only seen one.”—Female, 60<br>“Yeah. And I’m quite worried about side effects…and I have to study that. I have to figure out what is the medicine going to do in the long run.”—Female, 60<br>“More information as to what to expect medically, you know, from the professional…what can you impart to me that can help me a little bit, should something come up? I get afraid that I may not know what to do. And quick, right now, something is going on. What do you do?”—Female, 60<br>“Maybe something on teaching caregivers how to deal with that [referring to falls]. How to help them fall. I mean you can’t catch them, cause you’ll hurt yourself. But helping them fall so they don’t hurt themselves or you. Or anything else. Right. Or…any of the first aid…I mean I have to be First Aid, CPR trained… but they don’t teach you some of that stuff for specific issues. And if he does get hurt or have a bad reaction to the medication, worse than some of the one’s he’s had…what do we do?”—Female, 51 |
| Core theme #3 | The consequences of motor and non-motor symptoms<br>“His memory. Forgetting the pills. Not being able to figure out—I’ve shown him 1,000 times—how to use his phone and how to make appointments. Those kinds of things. It’s just like…you know, at this point, I’m just like, it’s ok honey. I’ll show you. It’s ok. But Oh…it’d be nice if he just got it. But he doesn’t.”—Female, 62<br>“He doesn’t remember things. That’s an issue for us…I’m a little more alert day or night. And when I first heard that was what was going on, he’d had an accident with the car and finally the Neurologist just said, give me your keys. And that was devastating to him. And later he feels like he’s a burden. And that just breaks my heart.”—Focus group<br>“But he is forgetting. And then there was a period of time where we used to live, he would get out and walk by himself. But he didn’t always pay attention to the traffic. And scared me half to death, so I got to locking the door. But he could unlock it. But now where we are, it is very secure. So I can sleep, knowing he is up, which I couldn’t before. So I was losing sleep. And I had a heart attack about 3 years ahead of all that, so I was still recuperating from that. And so…it just got overwhelming.”—Focus group |

(*continued*)

Table 3. (Continued)

| *Theme* | *Descriptive examples* |
|---|---|
| | "The tremor. When I'm trying to sleep. Otherwise it doesn't bother me that much, otherwise. Just when I'm trying to sleep or something."—Female, 80<br>"When he has dreams. No, he actually has dreams and he is kicking a football or whatever…So you know, I don't sleep"—Female, 70<br>"Parkinson's is a very flamboyant disease. People notice it. People notice tremors. They notice dyskinesia. They notice this person looks a little strange. Whatever. And I think it happens a lot…Only two people have asked how are you? To me. How am I? It just doesn't happen."—Female, 63<br>"The cognitive and the diminished intelligence. It frustrates me! Even though I know it is part of the disease, it's just frustrating to have to deal with it. Because he used to be an extremely intelligent man, that could figure everything out. Now he can't figure anything out. And we've had role reversal."—Female, 61<br>"His sleeping at night when he is screaming and yelling at night and jumping and like that in the middle of the night…but I really don't sleep well in the same bed with him."—Female, 62<br>"It hurts me when I have to dress him. He talked about dressing. I have to put his clothes on. It hurts. Putting a man's clothes on…take him to the bathroom. You got to go to the bathroom? Don't drink so much water at night. And you get to the point where they can't walk and they will wet their clothes."—Focus group<br>"But during that year, I was very afraid…Like at night, he would get up in the middle of the night and peak out the window and maybe think there was somebody out there. At that time we did have some guns in the house and I finally gave them to his brother. I started thinking what about knives in the kitchen…He was not acting like I'd ever seen him act before. So I didn't know what he was capable of. I was afraid because he was actually accusing…well— and I understand it can be part of the Parkinson's—but he was accusing me of infidelity and all kinds of things…I didn't know what he was capable of and I was scared. It was very scary for me."—Female, 62 |
| Core theme #4 | Concerns about the future<br>"You don't know what to do. You run into this problem now with insurance. With the insurance don't want to pay for his medication. The medication is too high. If the Parkinson's person does not get the medication, it hurts. My husband was very sick. He could not get his medication because the insurance refused to pay for it. So then, that is when you come in as a family and you have to think about that. How are we going to pay for that medication? I forgot which one it was, but it was $500.00. We had to decide how are we going to pay for that medicine."—Focus group<br>"To make sure we are safe—as far as financially safe. So if something catastrophic were to happen, because of the illness, do the medical insurance and all that protect us? And I can't say…if he falls down and gets hit by a car, or if he is driving…and that kind of stuff. Being protected so I have security to make sure he is taken care of, if he gets to the point where he is incapacitated."—Female, 51<br>"I could use someone to help us with looking at—Ok, here is how much money you have. Here is …there are certain things around—Care Centers—you'd say Assisted Living or whatever around town. Basically I know this is not the way they'd put it, but you can afford these. You probably can't afford these. That kind of thing would be helpful. And most people already know their own resources on stuff like that. But I think that is going to be an issue for us. And particularly if say he gets dementia and now I'm alone. Now I've got some memory issues myself. Cause by the time I'm getting that old, you know? You need help with that stuff."—Female, 63<br>"I worry that if I die first—which could happen because I am not in the greatest of health either. It could well happen, because people get Parkinson's and live for years and years. I worry about him not being able to take care of himself."—Female, 63<br>"Well, I'd say…we probably should figure this out about where to move. You know, and that he is getting good care…And should we move before? I mean when should we move? That kind of thing. I mean we've been thinking about it, but we haven't come up with it."—Female, 70<br>"Well, I guess just the unknown. Cause we don't know what will be next."—Female, 70<br>"That it gets so worse that I would have to commit him to a place to be cared for because I would not be able to do it. Yeah, the ultimate is me not being able to be trained enough because I am not medical you know? I don't have any medical training to care for him. That is my worst fears. Is not being able to have to be, in a way, separated from him, because I cannot take care of him. That and the fact that, you know, you have your insurances and everything, but would that cover all? You know? How much would it cost to keep him and keep giving him the best care in the world? When we are no longer working and have to just depend on whatever insurance we are able to get or are given?"—Female, 60<br>"As he progresses, how am I going to work and care for him at the same time? Cause there is going to be a point where he can't go up and down the stairs very well. Or feed himself very well. And make it to the restroom. And I do know all this stuff, but as long as he can find medications, that is a lot further out. But you look into the future like…cause I have to work now. I mean I can't retire until forever. So I need to make sure that I keep working to help pay for all the bills and cause the insurance is through my work."—Female, 51 |

(*continued*)

Table 3. (Continued)

| *Theme* | *Descriptive examples* |
|---|---|
| | "I worry about that (the future). What would be the next step? Like a nursing home? Or what would that be?"—Female, 80<br>"And I am really concerned. Will we outlive our money? I think financial education about how you go about knowing, you know…nobody can predict, per se, but a year ago the doctor told us—one of the doctors—said my husband would be in need of nursing care. Well, he isn't just yet. Thankful. But it scared me."—Focus group |
| Core theme #5 | Responses to palliative care<br>"So all of that stuff, where there could be a team of people—or like I was calling earlier. Who do I call? If I have a question? I suppose the neurologist is an option, but I don't think it is a problem that the neurologist needs to spend time on. It is a lower level problem that we should be able to deal with. So I like the sound of that. That's a great idea!"—Male, age unknown<br>"But I think I would be interested in finding out. I would totally give my attention to it…Oh that is a very fantastic approach. And he got the different people to assist. That's fantastic. Cause a lot of the health care is your mental well being, you know? Your psychological part."—Female, 60<br>"I think this is a very, very important service. I'm glad to see you all are putting this in."—Female, 63<br>"Instead of early, maybe more mid-stage or advanced. But I do think this addresses some definite areas that …and what I like about it is, um…I doubt there are a lot—I hate to say this—I doubt there are a hell of a lot of other neurologist's practices that are going to be addressing all of these things for their PD patients. Or you know, for their patients. Which is a shame, but to have this addressed, offered, I think is really wonderful."—Male, 68<br>"I think that having a whole team is perfect. And even though something might be…like hospice care might not be until down the line, it helps to have all that information before you have to make that decision. And so…I think pretty much anytime you've gotten a diagnosis of something that is going to be life changing, whether it is the short term or the long term, that's what I think."—Female, 61<br>"I think it sounds wonderful…so to be able to do all of this from not only dealing with the symptoms of the Parkinson's physical and psychological aspects of it, but as a caregiver, giving me help and support and knowing where to go to find the different resources. Counseling. Yeah. Um…I think this is wonderful. I would personally like to get involved."—Female, 61<br>"Well, at some point. I don't think he needs anything else right now. He is just in a real good place right now I think."—Female, 80<br>"That would be nice. A one-stop shop! It would be a nice thing to be able to just go and take care of a lot of stuff at one stop. And …you wouldn't have to do it all, but that sounds like a very nice idea for care."—Female, 51 |

several unmet educational needs, including wanting more information about disease progression, what to expect in the future, and questions about PD medications and their side effects. Caregivers were impacted by both motor and nonmotor symptoms and were particularly affected by cognitive dysfunction, communication issues, sleep behavior disorders, bradykinesia, and tremor. For some caregivers, these symptoms led to a significant and disruptive role and relationship changes. Concern about the future was a prevalent topic and related to finances, housing/living situations, and taking care of their partner in advanced disease. After being educated on palliative care concepts for patients and families, all caregivers responded positively and five caregivers wanted to be enrolled immediately in outpatient palliative care. Caregivers who did not want to be enrolled at the current time brought up relevant concerns, particularly the potential burden of adding clinicians to their team and time with medical personnel.

This study complements and builds on previous studies of palliative care in PD caregivers.[3,13,17,18,29] Our findings regarding emotional burden is consistent with McLaughlin et al.[17] and Goy et al.[3,18] Our data include caregivers with partners with varying disease severities and suggest that a palliative care approach may be applicable to caregivers early on in the disease. Despite this clear need for improved emotional support for PD caregivers, there is currently very limited evidence regarding which interventions are clinically and cost effective for PD caregivers.[30] The educational needs described by caregivers are similar to those found by McLaughlin et al.[17] and suggest that neurologists may be able to improve care by having discussions with caregivers regarding disease progression, possibilities for the future, and spending more time answering caregivers' questions about medications and their side effects. Notably, many of our caregivers' concerns about the future were associated with issues not addressed in advanced directives, including concerns regarding their future living situation and ability to afford a nursing home or other additional care. In a multidisciplinary setting, a social worker may be beneficial in addressing some of these needs as well as assist in connecting caregivers to support groups, which often have an educational component.

Palliative care, which aims to improve quality of life for both the patient and the family, appears to be an ideal approach to supporting caregivers of PD patients. While more research needs to be done on the effectiveness of cognitive behavioral therapy (CBT) and other psychosocial interventions aimed at PD caregivers, we encourage the appropriate assessment of caregivers by physicians or other team members who can then refer for appropriate support. Because of the uniqueness of each caregiver and his or her situation, it is important to assess each individual caregiver's needs, level of known information, and what information is desired.[30] Table 4 presents the recommended domains and constructs of caregiver assessment created by the Family

Table 4. Caregiver Assessment: Recommended Domains and Constructs

| *Domains* | *Constructs* |
|---|---|
| Context | Caregiver relationship to care recipient<br>Physical environment (home, facility)<br>Household status (number in home, etc.)<br>Financial status<br>Quality of family relationships<br>Duration of caregiving<br>Employment status (work/home/volunteer) |
| Caregiver's perception of health and functional status of care recipient | Activities of daily living (ADLs; bathing, dressing) and need for supervision<br>Instrumental Activities of Daily Living (IADLs; managing finances, using the telephone)<br>Psychosocial needs<br>Cognitive impairment<br>Behavioral problems<br>Medical tests and procedures |
| Caregiver values and preferences | Caregiver/care recipient willingness to assume/accept care<br>Perceived filial obligation to provide care<br>Culturally based norms<br>Preferences for scheduling and delivery of care and services |
| Well-being of the caregiver | Self-rated health<br>Health conditions and symptoms<br>Depression or other emotional distress (e.g., anxiety)<br>Life satisfaction/quality of life |
| Consequences of caregiving | Perceived challenges<br>Social isolation<br>Work strain<br>Emotional and physical health strain<br>Financial strain<br>Family relationship strain<br>Perceived benefits<br>Satisfaction of helping family member<br>Developing new skills and competencies<br>Improved family relationships |
| Skills/abilities/knowledge to provide care recipient with needed care | Caregiving confidence and competencies<br>Appropriate knowledge of medical care tasks (wound care, etc.) |
| Potential resources that caregiver could choose to use | Formal and informal helping network and perceived quality of social support<br>Existing or potential strengths (e.g., what is presently going well)<br>Coping strategies<br>Financial resources (healthcare and service benefits, entitlements such as Veteran's Affairs, Medicare)<br>Community resources and services (caregiver support programs, religious organizations, volunteer agencies) |

Caregiver Alliance and provided by the National Guideline Clearinghouse, which may be useful for physicians, nurses, or social workers in triaging caregiver issues.[31]

There are several limitations to this study. We had a small sample size and thus may have missed issues important to many caregivers. Participants were highly educated and largely recruited from an academic clinical setting and support groups and thus may not be representative of general community practice. Participation was also voluntary and respondents may differ in important ways from nonparticipants. Themes from qualitative research may reflect the biases of investigators. To minimize bias, we used several methods, including using a multidisciplinary analytic team.

This study is the first to assess PD caregiver interest in outpatient palliative care services. All caregivers responded positively to palliative care and half of the participants who discussed palliative care wanted to enroll immediately. Importantly, these data suggest ways in which care might be improved in the clinic both through primary palliative care approaches and specialty palliative care clinics. From a primary palliative care perspective, healthcare teams may consider placing more emphasis on the assessment and appropriate referral of caregivers to support services and focus on education regarding disease progression, how to handle emergent situations, and medication and side effects. This will be particularly relevant for patients with early to midstage illness where the addition of an interdisciplinary team may be impractical from a resource perspective and an unwanted increase in time spent with medical personnel for patients and caregivers. In addition, clinicians may want to pay particular attention to caregivers of PD patients with dementia as this and previous research highlight the negative impacts of dementia on caregivers.[11,12] This approach should begin at the time of diagnosis, which can be a stressful time for both patients and caregivers. Overall, caregivers were open and enthusiastic about the addition of outpatient palliative care services to their partner's usual neurologic care. Further research on the development and implementation of palliative care services for caregivers of PD patients is merited.

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