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Abstract

Aims and objectives: To explore how couples with Parkinson's disease (PD) discuss their needs, concerns, and preferences at the advanced stages of illness.

Background: The majority of care for people with PD is provided at home by family members. PD is characterized by a slow progressive decline with care needs often exceeding a decade.

Design: A descriptive qualitative study with 14 couples.

Methods: Data were collected on two occasions over a one month period utilizing semi-structured interviews, with both individual and couple interviews. Data were analyzed thematically by the research team.

Results: All participants discussed the strong desire to remain in their homes for as long as possible. For the people with PD, placement to long-term facilities was not an option to be considered. For spouses, there was an acknowledgement there may come a time when they could no longer continue to provide care. Concerns regarding falls, choking, voice production, financial strain and need for prognostic information from providers were influences on what they believed the future would hold and the decisions they would need to make.

Conclusions: The need for improved communication between providers and PD couples is evident. Interventions to support the couple in their discussions and decision making regarding remaining in the home or not, and options to support advanced care needs are required.

Relevance to clinical practice: Nurses can help support decision making **by providing tangible information regarding the advanced stages of PD including adequate prognostic information.**

What does this article contribute to the wider global clinical community?

- Preferences for placement to long-term care facilities are different among people with PD and their spouses. Beliefs about the future and decision making are influenced by concerns about physical complications including falls and choking and the need for prognostic information from health care providers.
- The need for improved communication between health care providers and PD couples is reported.
- Nursing interventions to support the couple in their discussions and decision making regarding placement and options to support advanced care needs are required.

Introduction

Parkinson's disease (PD) is a chronic, neurodegenerative disease which affects at least one million people in the United States (U.S.). World-wide estimates suggest there are seven to 10 million people living with PD (Parkinson's Association of the Carolinas, retrieved 1/25/16). A slow progressive decline in functioning of people with PD requires ongoing care often exceeding a decade. In the advanced stages of PD, people with PD may require more supportive care due to increased discomfort from functional limitations and cognitive decline (Bunting-Perry, 2006). As the majority of care for people with PD in the U.S. is provided at home by family members, family caregivers play vital roles in the care of advanced PD (Aarsland, Larsen, Tandberg & Laake, 2000; Goetz & Stebbins, 1993). Caregivers of people with PD have reported their unmet need for detailed information about the prognosis of the disease to make necessary decisions for future care and assistance with physical tasks and emotional stress (Goy et al, 2008).

Background

As the disease progresses, people with PD experience more physical impairment and functional limitations. For instance, people with advanced PD may experience multiple non-motor symptoms, including pain, fatigue, nausea/vomiting, urinary tract disorders, dementia, agitation and restlessness (Bunting-Perry, 2006). People with PD and their family caregivers often face multiple changes and challenges, including loss and uncertainty, feeling of psychological and social isolation, financial hardship, challenges of managing physical changes, and finding help for advanced stages of PD (Hudson et al, 2006).

While family caregivers were vastly involved in the care of people with advanced PD, they often did not receive enough information regarding symptom management and the prognosis of PD (Giles et al.,

2009; Goy et al., 2008). Lack of information regarding the disabling symptoms and decision making about goals of care hinders quality end-of-life care for patients with PD (Goy, Carter & Ganzini, 2007). In contrast, some family caregivers reported the ambivalence of knowing about a prognosis of their loved ones in order to avoid tension between reality and hope, which causes a dilemma for health care providers (Giles et al., 2009). Careful assessment of the preparedness of caregiver roles is an important aspect of planning care of people with PD. In a retrospective survey of 47 family caregivers of dying people with PD, over one-third of caregivers were unprepared for the stress and physical strain encountered during the period of the end-of-life (Goy et al, 2008).

Although PD may not be a terminal disease, it is a life-limiting disease and thus, considerable benefits of palliative care for people with advanced PD have been suggested in previous studies (Bunting-Perry, 2006; Giles et al., 2009; Hudson et al., 2006). A few studies reported the placement of people with PD in the final months of their lives (Goy et al., 2007; Snell, Pennington, Lee, & Walker, 2009). In a study in the United Kingdom, most people with PD died in hospitals or care homes rather than their own homes (Snell et al., 2009). Along a similar line, sixty-six percent of dying PD patients spent their final month in a skilled nursing facility in the U.S. and thirty-six percent of PD patients received hospice care through a home care agency (Goy et al, 2008). Although these limited studies suggest people with PD may be **accessing some needed palliative care and advanced illness services**, they are occurring only at the very end stages of PD. Due to the complexity of care of PD and the burden of caregivers, the goals of the advanced PD care should be clearly set and communicated among people with PD, their family caregivers, and health care providers. This would include communication regarding location of care, care support required and advanced planning needed to ensure care preferences for the person with PD and their family member. While PD patients' desires for symptom management are respected, caregivers of cognitively impaired patients struggled to make decisions on behalf of their loved ones (Goy et al., 2008). Caregiver support, including education about the caregiver role and assistance with physical tasks

were recommended in order to meet caregivers' unmet needs. Therefore, advanced care planning, which is a longitudinal care plan of PD care could assist people with PD in achieving autonomy of their care (Bunting-Perry, 2006).

Little is known about how people with PD and their family caregivers plan the care at the advanced stages of PD. A recent systematic review of Parkinson's disease research in the past decade concluded the family caregiving has been the most addressed area but with few studies exploring advanced stages of the disease (Shin & Habermann, 2016). This study attempts to address this gap by studying advanced PD stages and by exploring the perspectives of couples rather than solely looking at either the person with PD or at the caregiver. This knowledge gap must be addressed in order to provide effective care and improve quality of life in people with advanced PD and their caregivers.

Aim

To describe the needs, concerns and preferences of couples with advanced PD as they plan the care needed for the future.

Method

Study design

This study utilized a qualitative descriptive approach (Sandelowski, 2000; Sandelowski, 2010). Individual and couple interviews were employed.

Participants

Prior to initiation of the study, Institutional Review Board approval was obtained from the primary investigator's university. Participants were recruited from a movement disorder practice and from Parkinson's support groups in the Midwest region of the U.S. In order to be eligible, participants with PD

had to be totally dependent on assistive devices for mobility, be able to participate in interviews and have a partner or spouse who was willing to participate in the study. Exclusion criteria for the couple include either member being on prescribed memory enhancing medications, a history of psychiatric illness, or an identified life limiting terminal illness such as cancer, end stage renal, respiratory disease, or heart failure. Potential participants on initial contact received an explanation of the study and upon expressing a willingness to participate, were scheduled for consent and data collection. All eligible participants consented, there were no study refusals. Interviews were scheduled in their home or place of their choice. At the prearranged date and time, the study was re-explained and time was provided for questions to be answered before written informed consent was obtained from each participant.

Data collection

Data collection occurred at two time periods. At the first time, demographic data were collected jointly from the couple. Then each person was interviewed separately but simultaneously by two interviewers. Data were collected by the primary investigator and a trained research assistant (RA). The same RA was utilized throughout the study duration. Interviews were conducted utilizing a semi-structured interview guide along with associated probes. Interviews were audio-recorded and transcribed verbatim and checked for accuracy by the research assistant. The transcripts were completed and reviewed for content prior to the second data collection. The second data collection was a couple interview. While an interview guide was utilized, the second data collection was also used to clarify any data or any areas that were unclear in the first interviews along with capturing the perspective of the couple jointly. The second data collection was done within a one month period of the first data collection in order capture data as close in time to the first interviews. A month interval permitted transcription of interviews, review of transcripts and scheduling to occur in a small window of time that was feasible. The majority of data collection occurred in participant's homes. At the second data collection, several interviews

were conducted at the long-term care facility where the person with PD was residing. Interviews on average lasted 45-60 minutes.

Fourteen couples comprised the sample ($N = 28$). Mean age of the PD participants was 73.31 years ($SD = 9.3$ years) and mean age of the spouse was 72.13 years ($SD = 8.8$ years). PD participants were diagnosed an average of 12.18 years ($SD = 4.2$ years). All couples were married and had been for a considerable number of years (Mean = 49.39 years, $SD = 11.7$ years). All PD participants were dependent on assistive devices of some type with four being chair bound and one being totally homebound. **Seven PD participants were male, with the remaining half being female.** All participants were Caucasian. **Half of the participants were residing in urban areas and with the other half being in rural areas.** At the time of study enrollment, all participants were residing in their homes. All home support services were being paid for out of pocket not by insurance coverage. At the second data collection, three persons with PD were residing in a long-term care facility. One had experienced an acute event (fall/hip fracture) which resulted in the placement. The other two were due to declines in caregiver health. In these cases, the spouse remained in the home but was involved in the care of their partner with daily interactions.

Data Analysis

Forty-two interviews comprised the data analysis set. Review of transcripts and initial data analysis began after the first few interviews. Simultaneous collection of data and concurrent data analysis proceeded throughout the study. Initial data analysis was guided by the original research aims with openness to additional themes that emerged from the data. Data analysis was conducted as a team of the primary investigator, the RA and two doctoral students who had experience with qualitative data. Interviews for the individuals and the **couple** (three interviews) were reviewed and coded for themes by each member of the team. The team then met bi-weekly to compare coding and reach consensus regarding the codes. This process continued over several months till all interviews were coded. At key

points in the process, codes were reviewed for overlap and redundancy and deletion of similar codes occurred. Themes along with data exemplars were presented to the second author who had not been involved in the data analysis for confirmatory purposes.

Results

Analysis revealed three major themes with associated sub-themes. Each of the following themes will be presented: troublesome symptoms and problems, unmet needs, and concerns for the future.

Troublesome Symptoms and Problems

The most common troublesome symptom or problem was more frequent falls. This was discussed by both people with PD and their spouses and in all interviews.

Participant with PD # 3: "...I began to fall much more than I did. When I first fell she could get me up, but now she can't pick me up so we have had to call the fire department."

Spouse #1: "She's been falling more. It seems like for no apparent reason. Well, like the night that she fell and busted her head open. I had to go into the grocery store, which as you can tell is probably about three blocks away. And when I came home there she lay on the bathroom floor with her head busted open. She was trying to get from a chair onto her scooter and fell and hit her head on the concrete floor. I knew she was hurting because she didn't argue when I said we're going to the emergency room".

For most spouses the frequent falling (sometimes as often as daily) resulted in either only leaving the person for brief periods of time as mentioned in the previous quote or only going out when someone else could stay with their loved one.

Two other problems were frequently discussed during interviews by both person with PD and spouses.

Problems with voice production and clarity of speech were common. During the interviews, it was common practice for the interviewer to repeat what the people with PD whose speech was affected in order for the data to be understandable for transcription. Speech issues ranged from low voice

production to being able to only speak a few words clearly. The underlying problem was not a cognitive issue but rather producing speech that was intelligible and audible.

Participant with PD #2: “I used to sing in the church choir for many years. I would even help the priest sometimes and singing and all. But I can’t do that anymore because my voice doesn’t work right as you can see”.

Spouse # 9: “The difficulties in not being able to speak or be understood. People cannot understand her”.

A third troublesome area related to swallowing and choking problems.

Spouse #6: “Mastication is a much more serious problem so the risk of choking is very serious. We’ve had one choking incident that almost killed her. ... She’s limited on what she can eat but we get her treats when we can. I know what she loves and what she can manage without choking”.

This couple between the first and second interview had made a decision to have a percutaneous endoscopic gastrostomy (PEG) tube placed due to increasing difficulty in being able to eat adequate nutrition along with the high risk for aspiration.

Spouse # 6: (describing interaction with physician) “I have to tell you that you have a choice as to whether or not you want to do the G-tube. And she told S that she thought she had much to live for, that she was getting excellent care.... And so I told S I did not want us to press, that I knew it was a decision she needed to make, and I frankly broke down. It hit me harder than I expected. Even though Dr. J was explaining that for S it would be supplementary, that she can still take what she can by mouth. It really would not do anything except benefit her. Well, we have discussed that. I think ad nauseam. And yes, I am relieved. It is a big adjustment but it is a huge benefit for S in her care.

While this example illustrates an exemplar case regarding tube placement, other participants were keenly aware of swallowing issues. These issues ranged from having difficulty swallowing pills that required taking medicines with applesauce, to being on a mechanically processed diet to being supervised by the spouse while eating.

Unmet Needs

The theme of unmet needs describes areas where either the person with PD or spouse felt they needed help or additional resources that they were not accessing or unable to access. There were two

categories of unmet needs. The first was inadequate financial resources and the resultant financial strain. Both spouses and person with PD discussed this need. A few examples:

Spouse #12: "I recorded for one year that \$36,000 was what we paid for in cash out of pocket. We have probably gone through over \$200,000 of our savings".

Spouse #7: "We have gone through our savings. We are in the process of applying for Medicaid. But that is a very long process." (Had been involved in the process for over six months)

The second area of unmet needs involved the need for respite care for the spouse. Primarily it was the spouses who identified it as a need. Much of the needs arose from not feeling that they could leave the person with PD due to concerns about safety and falling.

Spouse #1: "I would like to have some time to the grocery store or go to the library things like that. Because she can't transfer, I can't leave her. What if she has to go to the bathroom?"

Spouse # 14: "I cannot leave her for even 30 minutes. She falls out of her chair and I find her on the floor."

Other times the need for respite was expressed because the spouse either needed a break or needed to be able to sleep.

Spouse #4: "I have to do everything for him. I am here 24/7. I probably need to have someone come in so I can go to another bedroom and get a decent night's sleep".

In some cases, spouses had begun to use paid caregivers to help and provide them the opportunity to get out once a while. However, this was not always accepted well by the person with PD. An example from a person with PD who was only left at home when paid caregivers were in the home:

Participant with PD #5: "The only thing that upsets me is when J has to leave the house. She usually goes to the grocery every day. She may do that because she likes to get out. I don't know. But I don't like it and I get very upset if she is going out".

For the spouse of this person with PD, she was definitely aware of his feelings but was cognizant of in order for her to continue to care for her husband she needed these breaks. She spoke of having her doctor's support and her children and friends support.

Concerns for Now and Looking Forward

When looking towards the future both people with PD and spouses expressed a strong desire to remain in the home for as long as possible. This desire was expressed in all couples. A few couples had made decisions several years earlier to relocate to a one story home, a condominium, or a retirement community in the hopes that those physical environments would facilitate remaining in the home. These residential changes had occurred in four couples. A serendipitous finding in each of the four couples was the spouse was a retired healthcare provider (nurse or social worker) or there had been a parent that had PD. With the exception of the four couples, the remaining couples had not made any housing accommodations. Many resided in multilevel homes and/or homes associated with significant acreage and maintenance. Despite where couples were residing, the desire to remain in their homes was unequivocal.

Spouse #7: "And we both realize that as long as I am able, we want to keep him here at home, as long as we can, and just do the best we can."

Spouse #6: "I think we want her to stay out of nursing homes for as long as she can. I doubt that it is the same as being at home."

While the desire to remain at home was very strong, spouses often recognized there may come a time as reflected by the language "as long as I am able". Spouses in their individual interviews would discuss there may come a time when keeping the person with PD at home would not be feasible.

Spouse #5: "Well I have said to P I will keep you here as long as I can. I have not promised that I will never put him any place. I have not gone that far. I hope I don't have to, but I don't know that."

The person with PD of this spouse would not consider this as an option:

Participant with PD # 5: "I just as soon got to the penitentiary for a week. We got married for life, this is the life."

As mentioned earlier, during the study three people with PD were placed in a nursing home. Two were due to declines in caregiver health and one due to the health of the person with PD. In the case of the person with PD decline, it was the hope of the couple that eventually they both could return to the home. In the cases of the caregiver health decline, the spouses considered the placement a permanent decision. Both people with PD were angry at the time of the second data collection and at times pleading with their spouses to take them home.

Another area of concern was how little information people had to help them plan for the future and make informed decisions. This was expressed by both people with PD and spouses. In some cases, participants directly asked their physician what to expect next and how will the disease progress. But more often than not, these conversations did not yield any information. Participants reported being told disease progression is unique that they could not predict. Most people with PD accepted this type of response, but for spouses it was often frustrating since it did not help them with planning or making decisions. A couple of examples:

Spouse #6: "Let's talk doctor. I can take it. If my wife had cancer, you would have that kind of dialogue. Can you tell me so that I can plan? More importantly can't you tell me so I can get my kids prepared?"

Spouse #8: "I have sleepless nights wondering what will happen with him It isn't discussed. I wish the doctor would just tell me."

This lack of prognostic information resulted in many of the couples not making any plans or decision relative to the future. More than half of the couples had no plans in place relative to advance directives, wills or any other legal documents or power of attorney for healthcare. When asked about this, the

most frequent response related to not knowing when and how the disease would progress farther, therefore, they did not know how or what to plan.

Discussion

The symptoms experienced in advanced PD are not only troublesome but present a great risk for safety and potential life threatening complications. Increasing number and frequency of falls were experienced by all people with PD in this study. This factor was contributing to most spouses leaving the person with PD at home very infrequently and for short periods of time. However, despite implementing strategies to minimize the chance of a fall happening, falls did happen that resulted into hip fractures, fractured skull and other injuries that required emergency room visits and inpatient hospitalizations. In the U.S., respite care is not a covered entity by insurance, thus, for a spouse to obtain these services there is an out of pocket expense. Thereby, most families do not utilize these services as the financial costs of having PD are already high. However, these safety and potential life threatening symptoms and associated complications may cost our healthcare delivery system more in the end.

The swallowing difficulties are another symptom that is not only troublesome but an issue of safety and preventing serious complications such as aspiration pneumonia. Whether or not a person with PD decides to undergo a PEG placement is a personal decision, but the risks of aspiration pneumonia and the advantages and disadvantages of tube placement need to be presented in a timeframe which allows enough time to process and make an informed decision. Waiting to a person is already experiencing choking, inadequate nutrition and is at extreme risk for aspiration, suggests conversations between providers and people with PD and their family members are not occurring early enough in the disease progression.

The area of unmet needs included the financial costs of PD and the need for respite services for the family member. These two need areas tie directly to how the couple may be making choices about some of the troubling symptoms such as falls. As the participants pointed out, in the U.S. there is a significant out of pocket cost for medications. Many with PD take several medications for their disease with increasing frequency as the disease advances. The out of pocket costs of the disease over the duration of time can be astronomical (Johnson et al., 2013; Kowal, Dall, Chakrabarti, Storm & Jain, 2013) and can totally exhaust people's savings as was described by some participants. This unfortunate fact then can influence how and when people can afford services, and what services they choose to spend on. If it comes between paying for the medications versus purchasing respite services; for those with limited resources the medications will be the understandable priority. Thus, the financial out-of-pocket costs associated with PD in the U.S. health system influences the decisions people with PD and their spouses make in the advanced stages of PD.

The areas of future concerns were significant. The primary concern was the area of being able to stay in the home as long as possible (for the spouse) and being able to stay in the home always (for the people with PD). Spouses were clearly struggling with wanting to respect and live out the wishes of the people with PD versus what was humanely possible for them to do given their age and their health. While spouses had come to some level of acknowledging that they might not be able to care for the people with PD till the very end, they were unequipped to have discussions or make decisions about options and timing of options for the future due to the lack of discussions and prognostic information they were receiving from healthcare providers. The need for more information especially regarding what to expect related to disease progression was widely discussed among participants. For example, some participants had "researched on the internet" the stages of PD and how long people were in various stages as they tried to understand better where they were in the progression and what the future held. However, the serendipitous finding that those whose who has a healthcare background and/or a previous experience

with PD in the family were able to plan and make lifestyle and living decisions, suggest that knowledge about progression, timeframes and expected challenges can be extremely helpful to couples trying to plan and make the most informed decisions. This finding supports the need for educational and decisional support interventions for couples at the advanced stages of PD to be developed and tested so as to eliminate the tension and struggles couples are experiencing. Beyond the dyad level of research, further exploration of how to promote and facilitate prognostic discussions between providers and families is warranted.

Limitations

This study was conducted in one geographic area of the U.S. and is not necessarily generalizable to the broader U.S. or outside the U.S. However, it explicates the symptoms, needs and concerns from the perspective of couples.

Conclusions

This study adds to the literature by documenting the common symptoms, needs and concerns experienced by Parkinson's couples at the advanced stages of disease. The results suggest areas for healthcare delivery and interventions needed to improve quality of life and support decision making in advanced PD. The findings support further research examining how best to support discussion between couples and health care providers about planning for advanced and end of life preferences care is needed.

Relevance to clinical practice

This study sheds light on what couples with advanced PD are dealing with, and managing and trying to make the best decisions they can about how to live out their illness in the advanced stages. It is clear that challenges in advanced PD are significant for the PD couple. As clinical providers, it is imperative

that the needs of advanced PD couples be assessed and information be provided to meet these needs. A crucial part of the interaction between providers and PD couples is to have an informed dialogue about prognosis and progression so that the couple can make critical decisions in a timely manner and do the necessary planning together as a couple. The results suggest this is not the current practice standard and this practice needs to be modified to better support PD couples.

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