Parkinson's Disease: Barriers and Facilitators to Optimizing Function

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KEY WORDS

activities of daily living
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strategies

The purpose of this qualitative study was to explore with caregivers and people with Parkinson's disease (PD) the facilitators and barriers that they encounter in trying to optimize participation in functional activities and exercise. Face-to-face interviews were conducted with a purposeful sample of seven caregivers and three people diagnosed with PD. Data analysis was performed using content analysis and yielded 94 codes, which were reduced to five specific themes: personality components, physiological symptoms, communication difficulties, environmental factors, and tricks of the trade to optimize function. Findings from this study provide useful practical techniques for professionals and caregivers to promote optimal function and participation in physical activity among people with PD.

People with Parkinson's disease (PD) often experience a progressive decline in motor function typified by tremors, muscle rigidity, bradykinesia, and postural instability (Jankovic & Kapadia, 2001). These symptoms can have a significant effect on one's ability to perform activities of daily living (ADLs) and can affect one's ability to live independently (Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2006). Over time, people with PD may lose their ability to navigate through their environment, communicate, and perform self-care tasks such as eating, dressing, and toileting.

Medical and surgical treatments intended to mitigate the physical signs of PD are partially helpful, but even with reasonable control of symptoms, people with PD still experience progressive disability (Suchowersky et al., 2006). Further complicating self-care is the fluctuation of symptoms and freezing episodes that people often experience in later stages of their disease (Chapuis, Ouchchane, Metz, Gerbaud, & Durif, 2005; Schrag & Quinn, 2000). As it becomes more difficult for people with PD to perform theirADLs, they often lose the determination to participate in them, thus precipitating a decline of physical function and deconditioning beyond what can be explained by disease pathology alone (Bello-Haas, 2002; Inkster, Eng, MacIntyre, & Stoessl, 2003; Nallegowda et al., 2004; Scandalis, Bosak, Berliner, Helman, & Wells, 2001).

As the disease progresses and people with PD are less able to manage their own care, the responsibility inevitably falls on family members, friends, or other caregivers who must find ways to deal with the person's daily needs and functional decline (Bhatia & Gupta, 2003). Family caregivers often are untrained and unsure of what to do or how to respond to the ever-changing needs of people with PD and feel frustrated, burdened, and depressed (Bhatia & Gupta; Caap-Ahlgren, Lannerheim, & Dehlin, 2002; Edwards & Scheetz, 2002). Not surprisingly, caregivers of people with PD have identified lack of knowledge about PD symptom management, lack of independence in ADLs, and the potential for falls as stressful for them (Davey, Wiles, Ashburn, & Murphy, 2004; Edwards & Scheetz).

The functional decline of people with PD and the lack of preparedness of their caregivers necessitate a restorative care intervention that is specifically designed for this population. Restorative care is a philosophy that focuses on restoring physical function by compensating for functional impairments to maximize the level of function and time in physical activity (Resnick, 2004). Although several studies have assessed the psychosocial effects of caring for people with PD, few studies have addressed strategies caregivers can use to help people with PD maintain and optimize their function and independence.

The purpose of this study was to learn about the barriers, facilitators, and helpful techniques used by people with PD and their caregivers (informal and formal) to facilitate function and participation in physical activity and exercise. Specifically, the investigative team wanted to explore this question from the perspective of both caregivers and people with PD; therefore, both groups were interviewed. The findings from this study would then be used to help revise a restorative care intervention (Resnick et al., 2006) for people with PD and their caregivers in the home setting.

Method

Design

This study was approved by the University of Maryland Institutional Review Board. This was a qualitative study using a grounded theory approach in which face-to-face interviews were conducted with

10 purposefully selected participants who were recruited from the community. The requirements for participating in this study were having a diagnosis of PD established by a neurologist or being a formal (paid) or informal (family, friend, significant other) caregiver with experience caring for a person with PD.

All participants were interviewed separately in a quiet, private place and at a time of their choosing, with the exception of one dyad (a husband and wife) who chose to be interviewed together. Interviews lasted approximately 1.5–3 hours, with one interview conducted in two sessions. Interviews were conducted by an advanced practice nurse who used a structured interview guide. The interview guide was developed by the research team and built on prior work with older adults and their caregivers that focused on exploring the factors that facilitated or prevented them from engaging in functional activities and exercise (Galik & Resnick, 2007; Resnick, Cavo, Galik, & Pretzer-Aboff, in press). The interview guide for caregivers moved from general caregiving questions to those that focused on function and daily physical activity **(Figure 1)**. People with PD were similarly asked about barriers to participation in daily functional activities **(Figure 2)**. Participants were recruited into the study until the researchers thought that data saturation was reached.

Sample

Flyers seeking volunteers for the study were placed in two local continuing care retirement communities (CCRCs) and the associated clinics and outpatient practices. A total of eight women and two men consented to participate. Three participants had PD (two were male) and lived in a CCRC. Three participants were formal caregivers (nursing assistants) who worked in a CCRC and were accustomed to providing assistance to people with PD. The remaining four were informal caregivers (spouse or significant other) of a person with PD. The four informal caregivers each cared for a family member who needed assistance with at least four ADLs (dressing, toileting, bathing, and transferring). Two of the informal caregivers lived with their spouses in the community, and the other two lived in the CCRC with their spouses **(Table 1)**.

Figure 1. Sample Interview Questions for Caregivers

1. Tell me about your experiences in taking care of your loved one/patient with Parkinson's disease.
2. Describe some of your greatest challenges in working with your loved one/patient with Parkinson's disease related to personal care activities, such as bathing, eating, dressing, toileting, continence, walking, transferring, and communication.
3. What techniques have you discovered that are helpful when assisting with care?
4. Describe how you decide when to help your loved one/patient with personal care activities.

Figure 2. Sample Interview Questions for People with Parkinson's Disease

1. Tell me about your Parkinson's disease and how it affects the way you care for yourself.
2. Describe some of your greatest challenges related to personal care activities, such as bathing, eating, dressing, toileting, continence, walking, transferring, and communication.
3. What strategies and devices have you used that are helpful (also, not helpful) when performing self-care?
4. Describe how you decide when to ask for help with personal care activities.

Data Analysis

Data from caregivers and people with PD were analyzed together. A general inductive approach for analysis was used. Interviews were tape-recorded and transcribed verbatim. Content analysis was performed independently by two investigators who read and coded the transcripts using "in vivo" coding technique, in which categories were created from actual words or phrases used by the participants (Ryan & Bernard, 2003). After the two investigators completed coding, the codes were compared and discussed until consensus among the researchers was achieved for a final master code list. These codes were then categorized by the researchers into themes that identified factors influencing functional performance of the person with PD. Five factors emerged from this process.

Credibility and Confirmability of the Qualitative Data

Credibility is the trustworthiness and accuracy of the interpretations of data collected in the study (Lincoln & Guba, 1985; Sandelowski, 1986). Credibility of the findings was based on the use of the two reviewers and the consensus achieved with coding. Consensus was reached with the addition of two new codes to the original lists, whereas the thematic groupings remained intact. A third member of the research team who is familiar with the PD population and restorative care was asked to review all transcribed records and subsequent clustering of the data to confirm the findings (Morse & Field, 1995).

Confirmability of the data is the objectivity of factual aspects of the data (Sandelowski, 1986). The findings in this study were brought back to the participants to confirm what they said. In addition, the findings were presented to other PD healthcare experts, people with PD, and caregivers of people with

PD, who also confirmed these findings as true to their own experiences.

Results

Ninety-four codes were initially identified that reflected the experiences of the people with PD and their caregivers related to the barriers, facilitators, and helpful techniques for promoting participation in physical activity and exercise. These codes were then grouped into categories that supported five specific themes **(Table 2)**: personality components of the person with PD and the caregiver, physiological symptoms, communication difficulties, environmental factors, and tricks of the trade to optimize function **(Figure 3)**.

Theme 1. Personality Components

As participants told their stories, they noted characteristics in both the person with PD and the caregivers that influenced functional performance and willingness of the person with PD to engage in functional and physical activity.

Characteristics of the Person with PD. Participants spoke of personality traits that promoted independence in physical activities such as resilience, determination, need for independence, denial of need for assistance, and humor. One participant with PD clearly articulated his need and desire to stay self-sufficient. This man admitted to falling as many as 20 times daily. He clarified, "I don't ever call for help, really. I try to stay independent." Using humor, he responded in the following way when asked what he does after one of his many falls: "I dust myself off and fall again!"

Participants also identified characteristics including embarrassment, apathy, laziness, frustration, discouragement, and sadness that they thought may explain why the person with PD may not be willing to engage in physical activities. A participant described herself as able but lazy: "I need help with dressing, and I need help with getting in the shower. . . but in an emergency I can do it myself. I am lazy!"

Characteristics of the Caregiver. Characteristics of the caregivers that encouraged functional independence and physical activity included kindness, patience, caring, not dwelling on the negative, and taking a "so what?" attitude. A "so what?" attitude toward embarrassing symptoms of PD, such as excessive drooling, tremor, or incontinence, was particularly helpful. One caregiver stated, "Sometimes it is a function of not getting to the bathroom on time. I told him if it happens, it happens, no big deal."

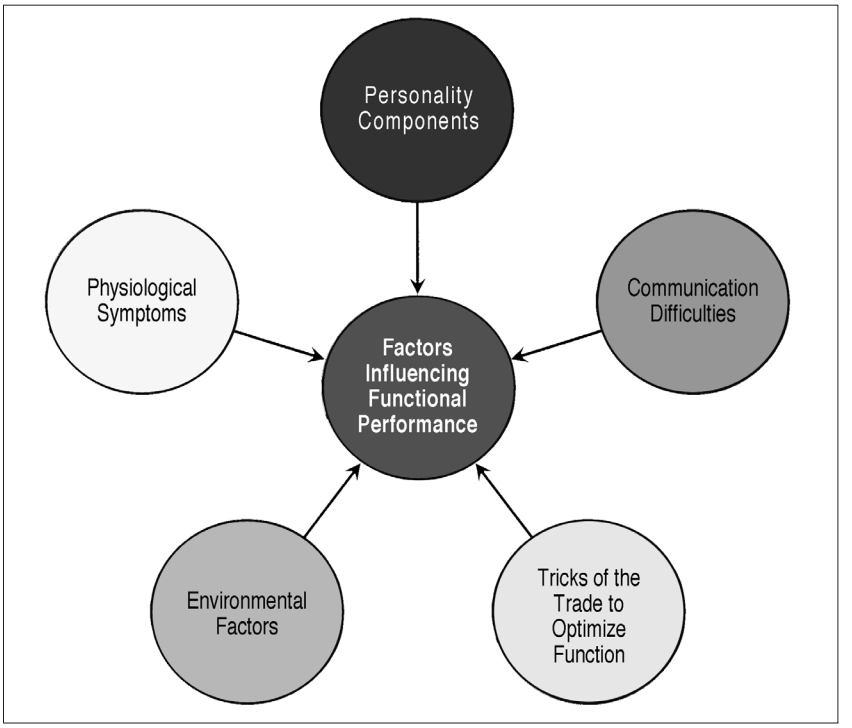
Behaviors that hindered functional and physical activity included impatience, doing tasks for the person, and displaying frustration. These behaviors surfaced when the caregivers felt the challenge of time constraints. One caregiver confessed her impatience: "Time is an issue. If we are running late for lunch I would do more for him to get out on time. He takes so long!"

Table 1. Description of Participants

	Informal Caregiver Mean *(SD)*, Range	Formal Caregiver Mean *(SD)*, Range	Person with PD Mean *(SD)*, Range
N	4	3	3
Age (years)	—	—	78.7 (± 3.5), 75–82
Number of years that participant knew person with PD	48 (± 27.0), 17–67	—	—
How many years ago family member was diagnosed with PD	15 (± 8.0), 3–20	—	—
Number of years working with patients with PD	—	20 (± 7.8), 15–29	—
Number of years with PD diagnosis	—	—	7.3 (± 7.0), 1–17

Note. PD = Parkinson's disease.

Figure 3. Factors Influencing Functional Performance of People with Parkinson's Disease



Theme 2. Physiological Symptoms

Physiological manifestations, both motor and nonmotor, of PD were noted by caregivers and people with PD to limit the ability to engage in physical and functional activities. People with PD readily

Table 2. Five Themes with Underlying Codes

1. Personality Components: Codes reflect participants' ideas of what they thought were positive and negative personality traits of people with PD and caregivers.		
	Positive	**Negative**
People with PD	Resilience, determination, need for independence, denial of need for assistance, humor, efforts to be useful, requests for help	Embarrassment, apathy, laziness, frustration, discouragement, hopelessness, sadness, self-consciousness
Caregivers	Kindness, patience, hope, caring, verbal persuasiveness, a "so what?" attitude; stimulating, not dwelling on the negative	Impatience, discouragement, frustration, avoidance; feeling rushed, doing for person (instead of waiting for person to do for self)
2. Physiological Symptoms: Codes reflect physical symptoms that participants thought impeded functional performance.		
	Motor	**Nonmotor**
	Tremors, loss of fine coordination, fluctuation, stuck or frozen episodes, falls, difficulty transferring, stooped posture, imbalance, slowness	Pain, fatigue, drooling, choking, visual deficits, apathy, incontinence, urgency, hypotensive episodes, difficulty multitasking, difficulty sequencing, behavior problems, fear of falling, fear of steps
3. Communication Difficulties: Codes address the physical and cognitive ability to receive and express information.		
	Expressive	**Receptive**
	Inability to write, read, type, or speak; halting voice	Not communicative; decreased conversation, communication difficulties, forgetfulness
4. Environmental Factors: Codes involving social support, use of healthcare professionals, and the physical environment fuel this theme.		
	Facilitators	**Challenges**
Social Support	Visits from family and friends, stimulation, emotional support, motivation to continue activities	Lack of social visits
Healthcare System	Neurologists; nurse practitioners; psychologists; physical, speech, and occupational therapists	Lack of access to adequate healthcare
Physical Environment	Safety devices, supportive devices, setting up of physical environment to facilitate functional performance	Physical space, clutter, stairs
5. Tricks of the Trade to Optimize Function: Codes reflect helpful ways of adapting to PD and facilitating functional independence and participation in activities.		
Helpful techniques and motivational strategies for dressing, bathing, toileting, transferring, eating, walking, freeze episodes, communication, laziness, apathy, lack of stimulation, and cognitive decline were identified.		

described their difficulties with fine coordination maneuvers such as replacing tops on bottles, buttoning buttons, and using cell phones. One person with tremors stated, "I have lost the technique for doing both of these things because of my hands. I can't thread a needle; I can't use a socket wrench."

Fear of falling and actual falls elicited much concern from the participants. One man described his experience: "I am afraid of falling. The shower is slippery. I also fell just the other day inside the bedroom. . . . My ribs hurt from the fall." Another participant described his experience with bradykinesia: "It is difficult. I muddle through. . . . It takes me forever . . . my speeds have gone from slow and stop." A caregiver described her experience with those who have bradykinesia: "I think the challenge [in caring for people with PD] is seeing that they get the [morning] care done because it takes longer." For some people with PD, their days can vary tremendously, as do their needs for assistance in ADLs. An observant caregiver noticed, "There are days she can't walk to her walker because of her rigidness; the PD makes her freeze. And there are some days where she is free and she can walk all around. Sometimes I help her with dressing, and some days I don't."

Nonmotor symptoms such as fatigue, cognitive decline, incontinence, and pain also influenced function and physical activity. One person with PD stated sadly, "You know, I got up at 7 o'clock and I could walk so well. I got across the room, made breakfast, and then had back pain and I had to stop, and then I didn't

want to eat anymore, so I sat down." One caregiver spoke with frustration about her spouse's unrelenting fatigue: "He takes a nap after breakfast and then goes down [back to bed] at 11:30 am. Then after lunch he wants to go to bed, and then he falls asleep."

Theme 3. Communication Difficulties

Difficulty writing and speaking because of tremor, hypophonia, and freeze episodes were described as hampering the ability to communicate with others. A man with PD relayed how tremors affected his writing, "I cannot write. There is a stack of condolence letters here, from when my wife died. I initially said I will answer each of them myself. I had all the intentions of doing so, but I couldn't write. So I decided that I could do it all with a machine, on the computer. But I couldn't do it on the computer because I couldn't type either. Now I can't hit the right key for nothing."

Theme 4. Environmental Factors

Environmental factors including the social support network, members of the healthcare team, and the physical environment were identified as either facilitating or challenging the person's day-to-day ability to function. Facilitators included family members and friends who offered emotional support, stimulation, and continued encouragement to keep participating in daily activities. One caregiver stated "I make sure we get out of this house once a day." Many members of the healthcare team, such as nurse practitioners, neurologists, and physical and occupational therapists, were cited by subjects as being integral to their feeling well and functioning better. A participant with PD stated, "My [nurse practitioner] is so supportive. She really helps me."

Alterations in the physical environment and environmental aids such as reacher-grabbers, canes, walkers, gait belts, safety bars, shower benches, lift chairs, and raised beds and seats were described as offering a sense of security and safety and improving mobility. One caregiver explained "He has the walker that I keep beside his bed every night. I back it up to the bed, and he uses that to assist him at night to get out of bed and to go to the bathroom."

Participants noticed that small spaces, clutter, and stairs decreased mobility. One caregiver commented, "You know, some spaces look really large to us, but it looks very small to them. For instance, he walks okay until he gets to the tables by the front door, and then he starts shuffling because the space there becomes narrow to him. When he gets to the table or other small areas, that is when he gets in trouble." Stairs can evoke freezing episodes in this population; many participants told stories about getting "stuck" on an attempt to climb down the stairs.

Theme 5. Tricks of the Trade to Optimize Function

ADLs. Caregivers identified numerous tricks to optimize participation in ADLs **(Table 3)**. Caregivers used cueing judiciously in many situations, particularly when a person with PD had procedural memory problems or a freeze event, shuffled, or had communication problems. One formal caregiver described her technique of step-by-step cueing to help one man participate in his grooming: "If I say, 'Put the lotion on your hands, chest, and arms,' he says, 'Wait a minute; you are telling me too many things at the same time.' I have to say, 'Put it on your chest [pause], put it on your arms [pause], and now put it on your legs and feet.' And he will say, 'Legs and feet?' You have to have a lot of patience when you [work with him], a lot of patience."

The use of assistive devices was encouraged, such as weighted utensils for tremor, walkers with brakes, and electric toothbrushes. Touch was also described as a useful tool, particularly when the person was experiencing a freeze episode: "Sometimes just touching their arm helps them to move." Several participants had this advice to share: "Above all, have patience!" and "Do not rush!"

Knowing When to Help. Formal caregivers all recognized the value of preserving patients' independence. They would offer assistance if they saw the person struggling or becoming frustrated with a task or if the resident asked them for help. It was important to all formal caregivers to first establish what the person with PD was able to do before they offered assistance. One caregiver noted that she allowed approximately 5 minutes of trying a task before she offered assistance. Formal caregivers who were interviewed felt confident that they knew when they should step in to assist and when they should step back and allow the person with PD to do things for themselves: "Just patience, allow them to do what they can do. Let them show you some of what they can do; don't take away their independence. When you take away their independence, even if it is no more than brushing their teeth or putting on a blouse, you are killing them. You are taking away their life. So be patient, and allow them to show you what they can do for themselves."

Family caregivers had slightly different motivations for stepping in and doing things for their loved ones. Not having enough time to wait for the person with PD to accomplish a task was commonly cited as a reason: "Time is an issue; if we are running late for lunch, I would do more for him to get out on time. He takes so long." Avoiding messes, running out of time, and keeping their loved ones safe by cutting their food for them were cited as reasons to do tasks. Some family caregivers were not really sure when to step in and help or when to insist that the person with PD

Table 3. Tricks of the Trade to Optimize Function in People with Parkinson's Disease

Task	Suggestions Offered by People with Parkinson's Disease and Caregivers
Dressing	Sit down when dressing.
	Use pullovers (sweaters, blouses, and dresses).
	Do not use buttons; instead, use zippers, hooks, or snaps.
	Use skirts or pants with elasticized waistbands for women.
	Use paper clips, zipper pulls, or safety pins for zippers.
	Use elastic shoelaces.
	Use grabber–reacher.
	Use sock helper.
Bathing	Install shower chair or bench with back.
	Install grab bars in shower and next to sink and toilet.
	Use electric toothbrush and electric shaver.
	Set up the shower and place everything within easy reach so that reaching up or down is eliminated.
	Use hand-held shower head.
Toileting	Toilet every 2 hours.
	Use pull-up protective undergarments; travel with extras in car or bag.
	Use waterproof cover on mattress.
	Use urinal or commode at bedside for nighttime.
Transferring	Use chair with arms.
	Instruct patient to move forward on seat to get out of chair.
	Raise bed, chairs, and toilet seats.
	Use small bed rail at top of bed to help get out of bed.
Eating	Adopt "so what?" attitude for spills and food messes.
	Eat foods with thicker consistency, such as cheese, soups, or pureed foods.
	Use spoon instead of straw.
	Use microwave instead of oven.
Walking and stairs	Use verbal cueing to take big steps.
	Train with walker early in the disease so that stance is straighter.
	Use walker with brakes, seat, and a basket.
	Use gait belt.
	Be familiar with stairs.
Freeze episodes	Avoid small spaces, clear clutter.
	Touch the limb that is frozen. Sometimes just touching the arm helps the person to move.
	Use humor to distract.
	Be patient; wait for the freeze to thaw.
	Use verbal cueing to get the person started moving: "Pick up your feet, left, right, left, right, pick it up and put it down now."
Communication	Program telephone with important phone numbers.
	Post phone numbers in an easy-to-find place.
	Use emergency alert necklace.
	Cue patient to speak slowly, sit straight, clear throat, take a deep breath, and project voice.
	Give extra time for patient to speak. Let the patient say what he or she wants to say. Don't answer for the patient.
Laziness	Keep busy so that the patient will help himself or herself.
	Have patience.

(continued)

Table 3. Tricks of the Trade to Optimize Function in People with Parkinson's Disease *(continued)*

Task	Suggestions Offered by People with Parkinson's Disease and Caregivers
Apathy	Treat with kindness and treat gently.
	Family and visitors seem to motivate patients to get ready and do things.
Lack of stimulation	Use books on tape.
	Read the newspaper to patient.
	Get out of the house at least once every day.
	Encourage conversation with others.
	Do not stop traveling and doing what you have done before.
	Be careful about appearance in public (do not wear shabby clothes).
	Go to exercise classes. Stay active.
	Do not rush. Allow extra time to get ready.
Cognitive decline	Keep surroundings familiar.
	Use verbal cueing.
	Use signs to remind patient to use assistive devices or do simple tasks.
	Give specific directions.
	Simplify directions to patient; use step-by-step directions.
	Above all, have patience.

should do more for himself or herself: "Sometimes he is on the bed and he asks me to hand him things, like a tissue. He can get it on his own. Sometimes I help him, sometimes I think, he can do this himself, and I tell him to reach over and get it himself." Other family caregivers look for cues in the behavior of their loved one: "If I see him struggle, if we are in a hurry, or he wants to get food, I will help him if he asks for it. If I see he has trouble getting up, I help him up."

Discussion

The five themes that emerged from the data—personality components, physiological symptoms, communication difficulties, environmental factors, and tricks of the trade—supported the known finding that the classic motor symptoms such as tremor, rigidity, bradykinesia, and postural imbalance often affect the ability of people with PD to perform ADLs and other activities (Backer, 2000; Brod, Mendelsohn, & Roberts, 1998; Davis, Ehrhart, Trzcinski, Kille, & Mount, 2003; Lee, Merriman, Owen, Chew, & Tan, 1994; Waite, 2000). What has not been discussed in previous literature is the effect of muscle rigidity and bradykinesia on caregivers' behavior. It became clear in this study that slowness of movement coupled with the caregiver's feeling of running out of time often motivated the caregiver to take over an activity such as dressing or feeding, or the caregiver would try to rush the family member through an activity. This "doing for" response of the caregiver can compound the deconditioning and deleterious effects of immobility on the person with PD. Rushing the person with PD often had the opposite effect of triggering a freeze or confusing the person as to what the next step was in completing a task.

This study also showed that nonmotor symptoms such as pain, fatigue, autonomic dysfunction, apathy, and decline in cognitive function could affect the person with PD, and, in many instances, these symptoms can be more distressing and debilitating for the person with PD and for caregivers than motor symptoms. These findings are supported by previous studies of how nonmotor symptoms affect functional performance (Allcock, Ullyart, Kenny, & Burn, 2004; Chaudhuri, Healy, & Schapira, 2006; Garber & Friedman, 2003; Holroyd, Currie, & Wooten, 2005; Pluck & Brown, 2002; Tinazzi et al., 2006; Weintraub, Moberg, Duda, Katz, & Stern, 2004). What is notable from this study is the level of despair and frustration conveyed by caregivers and people with PD, who spoke of these symptoms as being difficult to deal with on a daily basis. The emotional responses of the participants emphasize the importance of education in dealing with these symptoms.

It also became apparent that the personalities of the person with PD and the caregiver influenced the functional abilities of the person with PD. Although it has been documented that the quality of social support can affect one's ability and willingness to engage in functional activities (Koukouli, Vlachonikolis, & Philalithis, 2002), the specific personality traits of both caregivers and people with PD have not been documented. Identifying and fostering positive traits in those with the disease and their caregivers may go a long way in facilitating optimal function. Moreover,

Key Practice Points

1. People with Parkinson's disease (PD) often experience a progressive decline in motor function typified by tremors, muscle rigidity, bradykinesia, and postural instability.
2. The motor symptoms experienced by people with PD can have a significant effect on their ability to perform daily activities and live independently.
3. Techniques that help encourage independent living include allowing more time for tasks of daily living, not rushing the individual through a task, and refraining from "doing for" the person with PD.
4. Nonmotor symptoms of PD, such as fatigue, autonomic dysfunction, apathy, and decline in cognitive function, could be more distressing and debilitating for people with PD (as well as their caregivers) than motor symptoms.

identifying and offering remediation in the form of education on the effects of detrimental behaviors can also facilitate optimal function and should be incorporated in future interventions.

Three components of the environmental theme arose during data analysis: social support, the healthcare system, and the physical environment. Whereas the effects of both social and healthcare support on the function of people with PD are documented in other studies (Backer, 2000; Davis et al., 2003; Lee et al., 1994), the importance of the physical environment has been given less attention in this population.

The physical environment in the home can pose some unique challenges to the functional performance of the person with PD. In this study, the participants related stories of how small spaces and clutter in a room or hallway can trigger freeze episodes in those with PD. Stairs can also evoke fear of falling and freeze episodes in those with the disease, particularly when they are climbing down. Conversely, many adaptive devices were reported to be very helpful in promoting functional independence in this population, such as safety bars, raised seats, and buttonhooks. Consistent with a person-environment fit approach (Cress et al., 2005; Fange & Iwarsson, 2005), interventions that decrease environmental demands on the person with PD may be particularly helpful.

The fifth theme incorporated creative strategies that the participants in this study shared as helpful ways of adapting to PD and facilitating function. Although cueing has been supported as an effective intervention (Rochester et al., 2004; Suteerawattananon, Morris, Etnyre, Jankovic, & Protas, 2004; Thaut et al., 1996), a majority of the strategies described by participants are not commonly recommended to people with PD. Dissemination and testing of these interventions, such as allowing extra time for tasks, exercise, and the use of supportive devices such as sock helpers, would greatly facilitate efforts to improve function in people with PD.

Strengths and Limitations

Although this study included only three people with PD and seven caregivers in both the community setting and an extended care facility, the people with PD represent more than 29 years of cumulative experience living with the disease, and the caregivers collectively have 120 years of caregiving experience. Moreover, the credibility and confirmability of the results are strong and suggest that the study findings are reasonable for this study population. Given the small sample size and qualitative nature of the findings, however, it is impossible to generalize these results to all people with PD and their caregivers.

Implications

The results of this study suggest that there are helpful and practical techniques for professionals and family caregivers to use in encouraging optimal function and participation in physical activity among people with PD. Interventions including care-related interactions such as allowing more time for ADLs, not rushing the person through a task, and refraining from doing things for the person with PD encourage independent living. Environmental interventions such as clearing clutter from walking paths and using safety bars in bathrooms are simple alterations to the environment that can foster independence and safety. Decreasing or eliminating unpleasant sensations related to the nonmotor symptoms of PD such as fatigue, depression, orthostasis, and pain, in addition to limiting the effects of the motor symptoms, can go a long way toward helping people with PD optimize function. The interventions recommended by the participants could be shared with other dyads in PD support groups and taught in nursing programs and long-term care facilities. The findings of this study were useful in our development of a restorative care intervention that is specifically designed for people with PD and their caregivers (Pretzer-Aboff, 2007). Future work should be done to develop and test interventions that help people with PD optimize function.

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