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Third-Party Disability in Family Members of People With Communication Disorders Associated With Parkinson's Disease

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The purpose of this study was to explore the impact of communication disorders on family members of people with Parkinson's disease (PD) through the lens of third-party disability. Nine community-dwelling family members who live with people with PD participated in semi-structured interviews. Data were collected and analyzed using the qualitative research methods from the tradition of phenomenology. Two themes emerged from the analysis of data. The first theme, "What?" captures examples of how communication between participants and their family members has changed because of PD, and how participants attempt to manage frequent communication breakdowns. Two subthemes address communication challenges related to changes in speech and changes in cognitive–linguistic skills, respectively, in their family members. The second theme, "It brings up things that have changed," addresses the broader life impact that the communication changes have had on participants. The first subtheme describes how participants are changing their roles to take on more communication-related responsibilities in their households while still trying to maintain the dignity of their family members. The second subtheme reveals how participants experience grief and loss in that the decline in communication between themselves and their family members brings about a loss of connection with the person they may be closest to and, hence, changes their relationship with that person. Family members experience third-party disability related to communication disorders in their family members with PD. Some of these experiences are similar to third-party disability experienced by family members of people with other types of communication disorders. Better understanding of the extent and nature of third-party disability would help clinicians address the communication needs of both their clients with PD and their family members. **Key words:** *caregiver burden*, *cognitive–communication*, *communication disorders*, *dysarthria*, *family members*, *Parkinson's disease*, *third-party disability*

PARKINSON'S DISEASE (PD) is a complex, degenerative neurological condition associated with a wide range of changes that typically initially involve movement (tremor, rigidity), but progress to include changes in cognition, and other associated symptoms (Beitz, 2014; Rana, Ahmed, Chaudry, & Vasan, 2015; Wong, Gilmour, & Ramage-Morin, 2014). Of specific concern to speech–language pathologists (SLPs), PD is associated with progressive dysarthria, changes in cognitive communication and language function,

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and dysphagia. These changes have wide-ranging impacts on many aspects of people's lives including their abilities to remain employed, to remain engaged in social and community activities, and eventually to care for themselves (Dauwerse, Hendrikx, Schipper, Struiksma, & Abma, 2014; Miller, Noble, Jones, & Burn, 2006; Murphy, Tubridy, Keveighan, & O'Riordan, 2013).

When illnesses such as PD strike, the consequences are felt not only by the person with the health condition but also by family members and others who are close to that person. Existing research has explored broader issues of quality of life in family members of people with PD (Kudlicka, Clare, & Hindle, 2013; Leroi, McDonald, Pantula, & Harbishettar, 2012; Martínez-Martín et al., 2005). These studies have documented that caregivers' quality of life is influenced by a multitude of factors in the person with PD such as cognitive impairments, limited awareness of executive function deficits, health status or health-related quality of life, or functional abilities of the person with PD to engage in activities of daily living. Family members may need to provide direct care to assist the person who is ill if that person cannot care for himself/herself. Family members may need to take on more responsibilities related to household management, caring for children, providing for the family financially, or other duties that their injured family member is no longer able to perform (Martin, 2015; McLaughlin et al., 2011). While managing new or changing duties, family members may also be dealing with many possible emotions such as concern for the family member, anxiety for the future, or strain from the new pressures and responsibilities (Carter et al., 1998; McLaughlin et al., 2011).

One term that has been used to describe the impact of health conditions on family members is caregiver burden in quotations, which has been defined as, "The extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical, and spiritual functioning" (Zarit, Todd, & Zarit, 1986, p .261, as cited in Mosley, Moodie, & Dissanayaka, 2017). Caregiver burden in family members of people with PD has been described as a multifaceted experience encompassing social, emotional, and financial aspects as family members take on more roles that range from managing household responsibilities to supporting the person with PD as they deal with their own frustration and loss (Martin, 2015; McLaughlin et al., 2011). The range and complexity of the caregiver burden borne by family members of people with PD were highlighted in a systematic review by Mosley et al. (2017), which described symptoms such as depression, anxiety, apathy, cognitive impairment, and disrupted sleep in people with PD as contributing significantly to caregiver burden in family members. Because of the progressive nature of PD, caregiver burden is likely to increase as the disease advances (Carter et al., 1998).

Another term that has emerged to reflect the experiences of family members of people with various health conditions is "third-party disability." This term was introduced by the World Health Organization (WHO, 2001) and is defined as "the study of disability and functioning of family members ... due to the health condition of significant others" (p. 251). The WHO is often cited for promoting a biopsychosocial view of health through the International Classification of Functioning, Disability and Health (ICF). The ICF provides a structure for recognizing that an individual's experience with a health condition depends upon a range of factors including the physical injury or impairment, the physical and social environments, personal context, and how they shape performance of activities and participation in situations of daily life. In the conceptualization of third-party disability, the WHO extends that biopsychosocial perspective to family members. In essence, a health condition in one person becomes part of the environment for that person's family members. Because of the interactive nature of elements in biopsychosocial frameworks of health, having a loved one with a significant health condition may impact family members' physical health, personal context, daily activities, and life participation (Grawburg, Howe, Worrall, & Scarinci, 2013; Scarinci, Worrall, & Hickson, 2009).

Although it has not yet been studied empirically, there is likely considerable overlap between the constructs of caregiver burden and third-party disability. Despite this potential overlap, there may be important differences that might argue in favor of using the latter term. First, there may be situations in which an illness or injury is not so severe as to require family members to assume much if any care for the person or to change their responsibilities; yet family members might still be affected by fears or concerns related to their loved one's change in health, or may need to make changes in their daily lives that while not regarded as caregiving, still reflect an impact of the health condition. Furthermore, there may be family members who would not necessarily ever take on a significant caregiving role because of situation or relationship but who might still be affected in various ways by their family member's health condition. Thus, the impact of health conditions on family members may be broader than specific caregiving roles, and family members who would not necessarily identify themselves as caregivers may also be impacted. The term "third-party disability" supports the recognition of many possible ways that a family member might be impacted by a loved one's health condition that do not necessarily include caregiving roles. A third, although perhaps related issue pertains specifically to the use of the term "caregiver" to refer to family members. The term "caregiver" may not fully explain the nature and complexities of relationships between most family members and the person with the health condition. Fourth, caregiver burden may not separate the impact of individual symptoms from the neurologic condition as a whole in a way that third-party disability may permit. For example, caregiver burden might not capture the nuance of communication disorders and how that affects family members in a manner that is uniquely different from the impact of the physical disabilities that are associated with the condition overall (Grawburg et al., 2013). Thus, the concept of third-party disability may provide a mechanism for a broader and more inclusive view of how health conditions impact family members beyond a narrower focus on caregiving.

Emerging research has begun to explore the experiences of third-party disability related to communication disorders. For example, family members of people with hearing loss have reported difficulties initiating and maintaining conversations with the person with hearing loss. These problems have impacted not only their interactions with the person with hearing loss but also how they socialize and interact with others in group settings in the presence of the person with hearing loss (Scarinci et al., 2009). Family members of people with aphasia have reported impacts on their own life that begin with changes in how they interact with the person with aphasia but extend beyond that to impact other aspects of their lives including employment, education, and volunteer work (Grawburg et al., 2013; Grawburg, Howe, Worrall, & Scarinci, 2018). The need for family members to take on more responsibilities within the home leads to less time that they can spend with friends or engage in their own leisure activities. Manifestations of third-party disability can range from withdrawal from social situations, to changed relationships with family and friends, to difficulty maintaining their own health (Grawburg et al., 2013).

Third-party disability has also been associated with dysphagia, another condition frequently addressed by SLPs (Nund et al., 2016). Family members of people with head and neck cancer have reported less participation in social and community activities because of their loved one's dysphagia. For example, if the person with dysphagia is on a restricted diet, eating at restaurants or going to other people's homes for a meal becomes very difficult; hence, the opportunities for the family member to go out to eat are likely restricted as well (Nund et al., 2016). Even when eating at home, family members may alter their own diet and nutrition. They may often restrict what they eat to the foods that the person with dysphagia can eat as well so as to avoid having foods around the house or eating foods in front of the person with dysphagia that that person cannot have. Family members might eat a wider variety of foods only when the individual with dysphagia is not present (Nund et al., 2016). Consideration of third-party disability associated with dysphagia may be important for family members of people with PD as well, given that many people with PD also experience dysphagia.

Although prior studies (cited previously) provide insight into a wide range of experiences of family members of people with PD, they do not specifically focus on the impact on family members of the communication disorder in the person with PD. Prior research on communication disorders in PD has included family members (Miller, Noble, Jones, Allcock, & Burn, 2008; Miller, Noble, Jones, Deane, & Gibb, 2011). However, these studies were primarily focused on the family members' perspectives on the speech or swallow changes in the individual with PD and how they support the individual with PD. Experiences and viewpoints of family members specifically regarding the impact of the communication disorder on themselves, as well as their own needs as family members related to living with someone with a communication disorder have received limited attention. The lack of knowledge in this area is concerning because communication disorders, specifically dysarthria, are common in people with PD. Dysarthria has been estimated to occur in 70%–100% of people with PD (Hartelius & Svensson, 1994; Ho, Iansek, Marigliani, Bradshaw, & Gates 1998; Logemann, Fisher, Boshes, & Blonsky, 1978; Müller et al., 2001). Thus, there is the potential for many family members to also be affected by these communication changes. Better insight into family members' experiences specifically related to their loved ones' communication disorder may assist researchers and clinicians, particularly SLPs, to improve clinical practice to support the needs of family members as well as the person with PD. This is critical as prior researchers (Visser-Meily et al., 2006) have suggested that addressing family members' needs can lead to improved treatment outcomes. Furthermore, better understanding of third-party disability associated with communication disorders in people with PD may also support the broader ranges of stakeholders (care providers, family members, community advocates) in their efforts to understand and ameliorate the wide-ranging impact of PD not only on the person with the diagnosis but on their communities.

This study is part of a larger project designed to explore the experiences of family members of people with PD, specifically regarding living with their family members' communication disorder symptoms, as well as how any family member needs regarding third-party disability related to the communication disorder are addressed in speech–language intervention programs. This first article released from this project focuses on data gathered in qualitative interviews from family members specifically regarding their experiences of living with someone with a communication disorder associated with PD and how that might represent the construct of third-party disability. Later articles to be released from this project will address a broader range of issues including family members' views on speech–language pathology interventions for the person with PD, as well as their experiences and recommendations regarding how SLPs might address third-party disability in family members.

METHODS

This study utilized qualitative methodology from the phenomenological tradition (Creswell, 2007). Phenomenology was chosen for this project because exploration of the topic of third-party disability associated with communication disorders is relatively new both in the field of speech–language pathology and specifically for family members of people with PD. The objective for this study was to identify key issues of relevance for family members from their perspectives. The phenomenological tradition enables participants, in this case family members, to raise the issues and experiences most relevant to them so that clinicians and researchers may begin to understand the landscape of experiences of family members and what these experiences mean to them. These in-depth discussions provide foundational insights that then may be included in later research using other methodologies, such as survey methods to gain a broader understanding of the extent of these experiences across larger samples. Methods were approved by the Institutional Review Board at the University of Washington.

Participants

The inclusion criteria for this study were community-dwelling adults who live with a family member who has been diagnosed with PD, who has demonstrated changes in communication abilities related to PD, and who has received SLP services for the communication disorder at some point in the past. No restrictions were placed on nature or severity of communication disorder in the family member with PD, nor on the type or extent of past SLP services received. No restrictions were placed on the type of relationship between the participant and the "family member" (as the term will be used in this study; could be spouse, domestic partner, child, or sibling). However, participants who did not reside with the individual with PD at the time of the study, or who's family member with PD lived in assisted living communities or long-term care facilities were excluded as they would be expected to have less frequent interactions with the individual with PD. A history of participation of the family member with PD in speech–language therapy was selected as an inclusion criterion because exploring family members' involvement in and opinions about SLP services was a secondary purpose of the larger study. Participants were not screened for depression or any history of cognitive or neurological impairment, but recruitment materials noted participants with no known cognitive impairments qualified for this study. Using convenience sampling, the participants were recruited through the Washington Parkinson's Disease Registry, the University of Washington Speech and Hearing Clinic, and Parkinson's disease support groups within the Puget Sound region of western Washington State.

Data collection

Qualitative data were collected through individual, face-to-face, semi-structured interviews that lasted approximately 45–90 min. Interviews were conducted at the homes of participants in the absence of family members with PD or in meeting rooms in the Department of Rehabilitation Medicine at the University of Washington per participant preference. Information gathered from interviews focused on participants' experiences of living with an individual with communication changes associated with PD. The participants were asked about how any communication changes affect their daily lives as well as ways in which they manage the changes. Information on their opinions about and involvement with SLP services was also gathered and will be reported in a later article.

Consistent with phenomenological methods, an interview "schedule" or list of topics was generated to ensure that the key areas of interest in this study were raised with all participants, but the sequence and structure of questions varied somewhat in an effort to follow the participants' leads to the topics and experiences that were most relevant to them. Interviews began with a grand tour question of "Describe to me what your experiences are like as a family member now that your family member's communication has changed." The participants were encouraged to share experiences and examples from their own lives that they wanted to share, and hence there was a range of topics that were covered in different interviews. However, the participants were consistently asked follow-up questions that focused on eliciting further examples or details about the participants' experiences and included, "Tell me about how those communication changes have impacted you," and "What does communication look like in different situations?" All the participants were also asked about how they manage communication in different settings when family members with PD are present and how they cope with any emotional challenges associated with the communication changes if these challenges were mentioned. However, questions about the participants' involvement with or participation in support groups or other peer groups were not directly asked. All interviews were audio recorded and transcribed verbatim for analysis.

The participants were also asked to provide basic demographic information about themselves and their family member with PD and to complete a short set of questionnaires. For all but one participant who requested to complete questionnaires prior to the interview, the questionnaires were administered after the interviews were completed. Information collected about the participants included age, gender, employment status, relationship to the person with PD, and self-reported presence of hearing loss. The participants were also asked to report the age, gender, and time post-onset of PD in their family members. In addition, the participants rated the speech severity of their family members using an adapted version of the speech severity item from the Amyotrophic Lateral Sclerosis Functional Rating Scale, with the adaptation involving referring to the family member instead of one's own speech (Cedarbaum et al., 1999). However, other data on the severity of the PD were not collected. As an additional descriptive measure, the participants were asked to complete the Zarit Burden Interview (Zarit, Reever, & Back-Peterson, 1980) to assess the level of caregiver burden they experienced. This questionnaire was selected as a measure for this study because it has been tested for validity and reliability (Hagell, Alvariza, Westergren, & Årestedt, 2017; Hébert, Bravo, & Préville, 2000). Furthermore, reviews of prior research with caregivers of individuals with PD demonstrate that it has strong psychometric properties (Martinez-Martin, Rodriguez-Blazquez, & Forjaz, 2012; Mosley et al., 2017).

Analysis

To analyze the qualitative data, interview transcripts were uploaded to Dedoose, a web-based indexing program. In the initial stage of analysis, interviews were read multiple times to achieve deep understanding of the content. To sort and organize different content areas in the transcripts, the researchers developed a set of codes for coding segments of the transcripts according to topic. The codes were not predetermined but emerged from the content of the transcripts. Once the codebook was finalized, all transcripts were coded into excerpts for later analysis. Excerpts for each code across all participants were extracted and summarized. Then, themes were developed that provided an overview of salient experiences as described by the participants.

Trustworthiness

Several steps were taken to ensure trustworthiness and authenticity of the data (Lincoln & Guba, 1985; Merriam, 2009). During data collection, one author conducted all interviews (H.M.) with two other authors (C.B. and K.Y.) participating in different interviews. Two student volunteers assisted with transcription of interviews, and the lead author checked two interviews for reliability. During data analysis, peer examination was used in which three investigators collaborated in development of the codebook, analyzed the coded transcripts, and developed themes from the data. Finally, all participants were invited for member checks, but only six participants completed the member checks with the lead author, during which negligible changes were recommended to the summaries.

RESULTS

Demographic data

Nine participants completed this study including eight females and one male. Their ages ranged from 64 to 81 years. All were spouses or domestic partners of people with PD except for one adult child. The time since diagnosis of PD in their family members ranged from 5 to 16 years. On the Zarit Burden Interview, five participants were scored as having little or no caregiver burden, whereas the other four were rated as having mild-moderate caregiver burden. When rating their family members' speech quality, six participants endorsed the description that their family members sometimes have to repeat words to be understood. The other three participants rated their family members' speech quality as normal, although quotes included in the interview data below reveal that these three participants did have difficulty understanding their family members' speech. Further details about demographic data are reported in Table 1.

Interview data

Throughout the interviews, the participants shared many examples of ways in which their family members' communication changes had impacted interactions between the two of them, interactions with other people, and other aspects of broader life roles. As participants described these experiences, details about how they adapted, accommodated, and coped were a central aspect of the stories. These experiences are summarized in two themes. Theme 1, "What?" describes the nature of common interactions experienced and/or observed by participants and how participants managed those situations. Theme 2, "It reminds me that things have changed," addresses broader life implications in terms of changing life roles and relationships, as well as how participants cope and adjust to these changes (Table 2).

Theme 1: "What?"

When invited to describe what communication was like with their family members, the participants described many examples of situations in which communication was challenging. The participants attributed the communication breakdowns primarily to two PD symptoms—changes in speech and changes in cognitive–linguistic skills, both complicated by interactions with various environmental characteristics.

Subtheme 1: "She tends to mumble a little bit"

There emerged from the data a description of a prototypical communication exchange between participants and their family members that was highly similar across all participants. The key characteristics of this dynamic were an initial communication breakdown attributed to the family member's reduced speech loudness or clarity, followed by a cycle of rising tensions as efforts were made, often either unsatisfactorily or at the participants' inconvenience, to understand the family member. Invariably, the situation started with the family member saying something that the participant could not understand, to which the participant responded, "What?" (P7) or some other variant of, "I can't hear you" (P4). Most participants reported that they have to continuously ask family members to repeat or to speak up because the family members do not seem to be aware that their speech is difficult to understand. For example, P5 described how his wife, " . . . tends to mumble a little bit but doesn't think she does. So [I] have to ask her to speak louder." He continued, "I'm just getting used to the idea that I'll need to remind [her] to speak up pretty regularly." Participant P6 described typical interactions with her husband:

> And I find myself often either guessing at what he's trying to say or nodding or there's just an awful lot of "Would you say that again" or "How about looking at me as opposed to off into space?" And making more eye contact before you try to communicate . . . ?

Two issues raised by multiple participants further complicated this escalating spiral of miscommunications. First, these communication breakdowns seemed to happen most often when the participants and their family members were in different rooms of the house, thus not face-to-face for communication. "Don't try from two rooms away to expect I'll hear you" (P6). In another example, P7 reported on similar experiences with her partner, "She gets angry when I keep asking, 'What?' . . . I don't know why she doesn't

Table 1. Demographic data of family members and the individual with Parkinson's disease

	Family Members[a]							Individual With Parkinson's Disease[a]			
ID	**Gender**	**Age**	**Relationship Status**	**Employment Status**	**Hearing Status**	**Zarit Burden Interview Score[b]**	**Zarit Burden Level[b]**	**Gender**	**Age**	**Years Since Diagnosis[c]**	**Speech Severity[d]**
P1	F	78	Spouse	Retired	Wears hearing aids	4	Little or none	M	79	5	4
P2	F	67	Child	Retired; continues to work for pay	Hearing problems, no hearing aids	39	Mild to moderate	F	94	12	4
P3	F	64	Spouse	Retired	No problems hearing	16	Little or none	M	67	8	2
P4	F	61	Spouse	Working part-time for pay	No problems hearing	29	Mild to moderate	M	66	10	2
P5	M	81	Spouse	Retired	Wears hearing aids	12	Little or none	F	80	10	2
P6	F	77	Spouse	Retired	Wears hearing aids	35	Mild to moderate	M	77	16	4
P7	F	64	Long-term partner	Working full-time	No problems hearing	28	Mild to moderate	F	61	5	2
P8	F	68	Spouse	Retired	Hearing problems, no hearing aids	7	Little or none	M	66	15	2
P9	F	65	Spouse	Working full-time	No problems hearing	21	Mild to moderate	M	77	8	2

Note. $N = 9$.

[a] Racial status of all individuals = White.

[b] Zarit Burden Interview score and associated burden levels: 0–21 = little or none; 21–40 = mild to moderate; 41–60 = moderate to severe; and 61–88 = severe.

[c] Years since diagnosis are reported in approximation by family members.

[d] Speech severity is rated by family members: 4 = normal; 3 = sounds different but people understand the person with PD; 2 = sometimes have to repeat words to be understood; 1 = use gestures, writing, or drawing to help people understand the speech of the person with PD; 0 = not understandable or person with PD does not use speech for communication.

Table 2. Themes, subthemes, and examples

Theme	Subtheme	Examples
"What?"	"She tends to mumble a little bit"	Participants struggle to understand their family members, which leads to a cycle of communication breakdowns, efforts to repair, and increasing frustration for both people.
	"Trouble coming up with a word"	Decline in family members' cognitive and linguistic abilities creates further communication breakdowns.
"It brings up things that have changed"	"It's a question of respecting dignity"	Participants' roles change as they take on responsibility for more of the communication-related tasks in their homes, but they struggle to find the balance between providing enough support versus stripping their family members of their dignity.
	"You feel like you're losing the person"	As their family members' communication abilities decline, participants grieve the loss of connection with people they have been closest to for much of their lives and the subsequent changes in their relationships.

come to the room I'm in. I'm always going to where she is. So I'll say, 'I can't hear you.'"

The second issue that added complications was that of hearing loss—in the participant, the family member, or both. As P1 described, "... having to have hearing aids, it's hard because he's had to tell me to talk louder, and I've had to tell him to talk louder." In another example:

> ... half the time he heard something different because of his hearing. But other times he would say stuff to me and I couldn't understand what he was saying, so then I'd have to ask him to repeat it. And then he'd repeat it ..., and a lot of times I still couldn't understand what he's saying. (P9)

A sense of irritation and frustration seeped into the participants' accounts as they described the repetitive nature of difficulties understanding what their family members were saying. The participants were also frustrated by the constant need to ask their family members to speak up because family members seemed to be unaware that their speech was difficult to understand or unable or unwilling to change how they talked. The participants were aware that their family members were frustrated, too. Participant P4 described when her husband is, "... mumbling and not being very clear, [I] sometimes make an assumption of what he said, and then he gets frustrated because [I'm] way off. So [I see] his frustration, and [I'm] frustrated." She reiterated later, "[He] also gets frustrated when I've asked for the 14th time, you know, 'What did you say?' So, I do see some frustration there and sometimes we get a little bit irritable." Similarly, P8 described how she and her husband both likely felt with the communication challenges, "It's probably frustrating for both of [us] at some level." Participant P9 described similar experiences with the difficulty communicating with her husband: "It makes you feel just kind of annoyed, so that transfers onto him when I get annoyed."

Although most of the methods that the participants described using in an attempt to repair communication breakdowns involved those mentioned previously such as asking for repetition and reminding their family members to speak louder, one participant described more drastic accommodations that she had felt she had to make. This participant changed her sleeping arrangements for 6 months while her mother recovered from a fall to ensure that she would be able to hear her mother if her mother needed help during the night:

> I wound up sleeping on the floor next to her bed at her apartment. And I figured out if I put my head at the opposite end, and put my feet right where her feet would land, if she got up then that would wake me up and I could actually sleep. This was good because otherwise it was like having a newborn. You just had to be tuned in. (P2)

The situations described previously focus on the participants' reports of communication between themselves and their family members. The participants also described their experiences either observing or being involved in situations in which their family members were communicating with other people. One participant would hear from friends or other communication partners how it was becoming more difficult to understand their family members with PD: "Well, it's simply commenting to me on the side afterward, 'I enjoyed lunch with [your husband] but I really am having trouble understanding him.'" (P6).

Most participants reported responding to communication difficulties between their family members and other people in various ways. In some situations, the participants try to arrange the environment to be more conducive to communication, such as asking for a quiet table in a noisy restaurant or choosing a quieter restaurant. Some participants try to coach or cue their family members to speak more loudly but still encourage family members to do the talking. "If he's not talking loud enough when we're at a restaurant, we kind of have a little signal, so that I don't have to say, 'Nobody can hear you,' … and he knows he needs to speak up" (P4). This same participant described other interactions such as with cashiers in stores: "On occasion, I will have to say, 'They didn't hear you.' I try not to answer for him but make him answer" (P4). Some participants step in and act as a translator between their family members and other communication partners: "… the store clerks might ask him to repeat himself. Or if I'm with him, I may translate like, 'This coat doesn't fit'" (P8). Participant P8 continued on to further explain how her familiarity with her husband's speech allows her to translate for him:

> I think it's when we're around other people, it's hard for them to understand him … I might have understood it because it's like listening to a kid. You learn your own kid's way of talking. Nobody else could understand the kid, but you could. So if I feel like they didn't quite understand what he said, I may repeat it or ask him to repeat it.

Finally, one participant acknowledged simply speaking for the family member instead of giving the family member a chance to speak for himself: "A lot of times [I] will speak for him because people can't hear him well. Rather than wait for him to say what he's going to say, [I] will just say it for him" (P9). This participant acknowledged that her tendency to speak for her husband could be attributed to various influences including her husband's reduced speech clarity, her own personality to "go ahead and charge in," and her confidence that after being married to her husband so long she knows what he will want to say.

Subtheme 2: "Trouble coming up with a word"

Although the participants attributed many challenges communicating with their family members to reduced speech loudness and clarity, some participants also raised examples of how changes in their family members' cognitive and language skills impacted communication:

> Well, if he was trying to tell me how to do something, it would be hard to listen to because he would have trouble coming up with a word that I needed to continue the process. Or, I would be telling him something that I was asking him if he could do or wanted him to do, and he wouldn't follow it exactly. (P3)

Similarly, P6 reported that "There's some memory function also going on" in her husband and reflected on how it can affect communication with her as well as with other communication partners: "When he's trying to express something, often he's either slow or he's hesitant. He'll start one idea and then there'll be a pause .... I think people tend to tune him out." Finally, P7 described how speech changes combined with cognitive changes in her partner make it more difficult for her partner to use strategies to prevent or repair communication breakdowns such as recognizing that they need to be in the same room when speaking:

> No matter how loud she talks, we have to be in the same room. It's not loud enough. ... And the cognitive part is the harder part. So I go to the room cause I don't know if she gets—she must get it to some level that we have to be in the same room.

Just as with the speech changes described previously, the participants have worked out ways to manage communication breakdowns due to the changes in cognitive and/or language skills in their family members. Again, some participants have talked with their family member to agree on strategies to use. For example, P3 asked her husband about when he struggles with word finding:

> But I've asked him about it a long time ago, whether if he wanted me to supply a word or if he wanted to try and come up with it himself, and he wanted to come up with it himself. So I try to do that, but sometimes I have to [Participant covers mouth as if to signify that she has to remind herself to be quiet].

Likewise, P6 explained how she tries to support communication when memory changes affect her husband's train of thought as they converse:

> I don't know how you got to this point, but can you go back? You started talking about "X." Where were you going with that or what were you trying to say, 'cause I left the track of what you were saying.

In summary of theme 1, the participants provided many examples of communication struggles between themselves and their family members that they attributed to both changes in speech and changes in cognitive–linguistic abilities in their family members with PD. The participants had worked out strategies to try to manage some of these communication challenges. Some strategies represented collaborative efforts between the participants and family members such as when participants asked family members how they wanted to be helped or reminded about communication. Other strategies reflected that participants felt that they needed to step in and exert more control in the situation. The participants conveyed awareness and willingness to assist their family members with communication, but they acknowledged feeling frustrated with the need for constant reminders along with the seeming lack of awareness or effort to repair the problems on the part of their family members.

Theme 2: "It brings up things that have changed"

Theme 1 provided examples of how communication has changed between participants and their family members, as well as with their larger communities, due to changes in both speech and cognitive–linguistic abilities in the family members with PD. These changes, although important to recognize in and of themselves, had implications that extended beyond specific communication instances. These broader implications, as presented in the following subthemes, included changes in participants' life roles (subtheme 1) and changes in their relationships (subtheme 2), both with life consequences.

Subtheme 1: "It's a question of respecting dignity"

Several participants described many ways in which the speech and cognitive–linguistic changes detailed previously had led to broader changes in their own life roles. These changes included taking over household activities that required high cognitive or communication demands that family members had done in the past but were no longer able to do.

> . . . I've taken over more of the communications and paying the bills now . . . I'll make some phone calls for him. For email and stuff like that, I do most of that. He tends to get confused with paying bills and stuff, ... So I'm just gradually starting to take over some of that stuff. (P9)

Another participant, P7, was also taking on similar responsibilities for her partner, "...and to have to make more and more decisions. And I've always been the one to write the checks and do all that. But at some point, I'll probably have to do her account, too, and that'll be hard." Sometimes the extent to which participants had taken on extra roles or provided extra support to help their family members remain functional was so gradual that they did not recognize it until something out of the ordinary brought it to their attention. For example, P7 described how a sudden change during a backpacking trip that required some repacking by her partner made her realize how much she has been compensating for her partner's cognitive difficulties with various organization tasks:

> I was helping her pack, which was exhausting, and we would pack and unpack and she couldn't organize the pack.... And I didn't realize the extent of how much I was compensating for it . . . she really can't organize stuff that well . . . but just the energy of working with her—that was tiring.

As participants described these trends toward taking on more of the communication and cognitively demanding responsibilities in their households, they also struggled with finding the right balance between stepping in to do what needed to be done without stripping family members of their autonomy or dignity. For example, P4 was figuring out how, " . . . not to just jump in and try to fix it. Some of it he needs to do himself." Similarly, P6 reflected that, "Anything that encourages more dependence on me is not helpful. [My husband] needs to feel like he's an individual person." A third participant expressed similar views, "It's a balance of how much do I do . . . , it's still hard to stop yourself from wanting to help" (P7). Specifically regarding communication, P2 described figuring out how much to help her mother with communicating in social contexts noting that, "It's a question of respecting [her] dignity and not messing with that. Not being obvious about the ways I'm helping . . . and the question is, 'How can I avoid doing that publicly?'"

Subtheme 2: "You feel like you're losing the person"

People communicate for various reasons, but ultimately communication connects people to each other. When describing the larger implications of the communication and cognitive–linguistic changes in their family members, many participants spoke about their feelings of grief and loss both for what their family members were losing for themselves and for the loss of their own relationships with their family members.

About half of the participants acknowledged that it was difficult to bear witness to the changes and losses associated with the deterioration of communication skills in their family members. As one participant noted, she gets, " . . . very frustrated by the things that are being lost" (P6). Another participant acknowledged,

> . . . the grief that's involved in watching some of the memory . . . go away . . . it's sad to see some of these skills leave. Verbal skills . . . to see him not being able to come up with words when he never used to have problems with them. (P3)

Another participant described how observing her husband in social situations served as a poignant reminder of the ongoing progression of many PD symptoms:

> This last year, his symptoms have changed quite a bit. And so I think sometimes for me, it's anxiety and some sadness, you know, after we're together with friends and I know he's tired and he hasn't talked as loudly, it just makes me sad 'cause it brings up things have changed. (P4)

The participants reported that the increased challenges with communication had a direct impact on their relationships with their family members with PD. "With not hearing well and not speaking, I found that we didn't converse as much as we used to. And I thought our communication wasn't what it was. And I thought it affected our relationship" (P9). Another participant described the losses associated with her changing relationship with her husband as his communication abilities declined:

> . . . there's a part that's very isolating . . . from the person that he once was. We've been married 54 years. So it's a change in relationship. So you feel like you're losing the person who you have had the most intimate contact or life experience with . . . ." (P6)

The participants were also very aware that further changes with their subsequent impact on their relationships with their family members would continue in the future. "It'll be a loss not to have someone to talk to. I mean, we share a lot, like all couples do . . . it's just knowing that at some point, that'll change" (P7).

The two subthemes under this second theme of dealing with the impacts of the communication disorders have addressed how roles have changed as well as how relationships have changed. One participant described how these two issues intertwine in that the increased need to take on more roles around the home or to help family members more with various tasks leads to less time and energy for relationships:

> I come home and I barely have my coat off and we're problem solving something. [Partner]'s . . . working on her scheduling and trying to figure things out a lot more in her room, so we have less time together where she's not trying to figure things out, do emails . . . . It affects the quality of our time together . . . . (P7)

Although participants expressed a clear sense of grief over these losses, several also expressed attitudes and outlooks that suggested that they retained resilience in the face of the losses. Some participants reflected on adjusting priorities and not getting uptight about things that they could not control, " . . . look at things in a more relaxed manner and letting things go that aren't important" (P3). The same participant continued on to say that she used, " . . . jokes as a way to just kind of make light, and maybe focus more on the positives with this time [we] have together." Other participants conveyed an attitude of acceptance, "You just have to learn to live with it" (P6).

In summary, theme 2 describes how participants felt that changes in communication and cognitive-linguistic abilities in their family members represented the broader losses associated with PD. The participants identified increased communication responsibilities that they were taking on as their family members declined. Although the participants recognized the need to assume these roles and responsibilities, they acknowledged that these changes brought up feelings of grief and loss for what their family members were losing and for the increasing isolation in their relationships. The participants were exploring ways of coping and adjusting to the progression of symptoms, knowing that further changes were to come. One participant, P5, summarized this constellation of experiences in describing his acceptance of taking on more responsibilities and helping his wife in the context of their marriage: "Well it's a role that I accept because I love the girl. And she appreciates it, and that's nice" (P5).

DISCUSSION

The purpose of this study was to explore the experiences of family members living with people who have experienced changes in communication due to PD. The data here are part of a larger study designed to investigate how communication disorders impact family members, how family members view SLP services, and how SLPs might better meet the needs of family members of people with PD to minimize their experiences of third-party disability. This article presented data from the first stage of that project, which was to understand the impact of the communication disorder on family members in their daily lives.

The results of this study were organized into two themes, the first of which described common daily experiences of communication breakdowns and how those are managed. All participants shared some variant of the same communication pattern in which they have difficulty understanding their family members' speech due to reduced speech loudness or clarity. The participants ask for repetitions and clarifications that are not always successful because the family members have difficulty recognizing that their speech is hard to understand, or remembering that they need to speak louder, get in the same room as their family member, or make other adjustments. Thus, it largely falls to the participants to remind their family members to speak up, to go and find their family members so that they can be in the same room to communicate, or to otherwise implement communication repair strategies. Escalating annoyance and frustration were inherent to these encounters. Although this pattern of communication between participants and their family members was common to all participants, greater variability was observed in how the participants assisted (or not) with communication between their family members and other people. Some participants stood back and encouraged their family members to communicate for themselves as much as possible, some helped ease communication between their family members and other people by serving as translators, and one participant acknowledged just stepping in and communicating in place of the family member.

One salient finding from this study was the participants' descriptions of how much their family members' cognitive changes, in addition to speech changes, impacted their communication in their relationships and daily activities. The participants reported using various strategies to repair these breakdowns ranging from waiting patiently for family members to find the words they wanted to say to actively helping them retrace a conversation to fill in missing or confusing information.

The second theme captures participants' descriptions of how the changes in communication, whether due to speech or cognitive–linguistic problems, had contributed to broader changes in their life roles and relationships. The participants provided many examples of how they were taking on more communication-related roles in the home such as making phone calls, sending e-mails, or handling other correspondence as their family members' communication skills declined. Not only were the participants taking on more responsibilities and work but they were also experiencing increasing feelings of grief and loss as they watched the deterioration of their family members and coped with the changes in their relationships with their family members. The participants felt increasing loss and isolation as their family members gradually became less able to engage and communicate with them.

Themes that emerged from this study support findings from prior research exploring the experiences of family members of people with PD. For example, prior research has also documented the extent to which PD leads family members to assume a larger number and greater variety of roles and responsibilities (Martin, 2015; McLaughlin et al., 2011). This study highlighted how communication changes related to cognitive–linguistic impairments led the participants to assume more responsibility for household tasks that require communication. This was consistent with prior studies indicating that cognitive changes in the individual with PD can contribute to decreased quality of life in family members as well as increased levels of caregiver burden (Kudlicka et al., 2013; Leroi et al., 2012; Mosley et al., 2017). Closely related to the issue of assuming more responsibilities, the participants in this study were concerned about how to find the right balance between taking on roles that their family members could no longer do, or providing increased assistance to their family members as they completed tasks, without overstepping their bounds and threatening the dignity of their family members. This theme of balancing support with loss of dignity or autonomy has been found in other studies involving people with PD as well (Berger et al., 2017).

This study, along with prior studies conducted with family members of people with aphasia (Grawburg et al., 2013) and hearing loss (Scarinci et al., 2009), highlights the presence and characteristics of third-party disability specifically associated with communication disorders. Two particularly salient examples of how third-party disability can manifest in family members of people with communication disorders could be drawn from these comparisons. One example is the increased demands placed on the participants to take on more communication-related roles and responsibilities in the household. A second salient example of third-party disability is the increased isolation that people experience as they are increasingly unable to communicate with their family members. As participants in this study noted, the loss of communication significantly disrupts relationships with the person that they have been closest to for much of their life. A final issue to keep in mind, particularly relevant to communication, is that there may be more than one communication disorder involved—and in more than one person. This study highlighted how hearing loss, increasingly common as people age, might be a factor for both the person with PD and his or her family members, thus creating additional barriers to communication.

The clinical implications of this study invoke inquiry about the needs of family members and how adequately those needs are acknowledged and met when working with people with communication disorders associated with PD. In addition to possibly improving outcomes for the person with PD, family members warrant attention simply and specifically for their own well-being. This can be achieved through a family-centered approach to treatment such as by addressing the needs of family members (Visser-Meily et al., 2006). Speech–language pathologists likely routinely distribute information related to support groups, respite care, or other community resources to family members of clients. Many SLPs include family members in therapy sessions for the person with PD to provide education, instructions for home practice, or other information that would support the person with PD in his or her intervention program. Yet, recognizing that family members are experiencing their own path through third-party disability compels us to consider what is the nature and extent of our role as SLPs to specifically intervene to address family members' needs? Focusing the spotlight specifically on third-party disability associated with communication disorders may also help stakeholders in the broader PD community (e.g., health care providers from other disciplines; community support organizations) to appreciate the impact of this aspect of PD on family members and thus to include increased supports and advocacy for these needs.

When looking to the future and considering SLPs' scope of practice, preparation and training, and feasibility for addressing third-party disability in family members, future research could provide considerable guidance. One area in need of research is to obtain a more complete understanding of the range of experiences that characterize third-party disability. Recognizing that the construct of third-party disability is tied to the WHO ICF, prior authors have attempted to map reported experiences of family members onto the ICF framework (Grawburg et al., 2013; Grawburg, Howe, Worrall, & Scarinci, 2014; Scarinci et al., 2009; Threats, 2010). Recognizing that the components of the ICF are sometimes ambiguous, key findings from the current study might also be mapped onto the ICF. For example, the participants reported on many changes in activities and participation related to assuming more household tasks, taking on more household roles, and experiencing changes in their relationships with their family members. Environmental variables came into play in the examples of difficulties communicating room to room in their homes or in noisy public places such as restaurants. The personal context component of the ICF was particularly salient in this study as feelings of loss, adjustment, and resilience were a central theme of participants' experiences. Future research would be beneficial to both add support to this existing evidence of third-party disability and also explore other characteristics or examples of third-party disability and how they related to the ICF that were not evident in these findings.

Additional future research might further explore the overlap or distinctions between the constructs of caregiver burden and third-party disability. For example, the participants in this study generally reported low–moderate caregiver burden, yet all shared examples of how the communication disorders experienced by their family members had significantly impacted their own lives. Qualitatively, there appeared to be overlap in these two constructs such that the participants in this study had the burden of taking on more household organization and communication for their family members. However, other central experiences in this study, such as grieving the loss of the relationships, might not be sufficiently captured by the concept of the burden of caregiving.

Finally, future research, including that underway by this group, should explore the current practices and viewpoints of SLPs to achieve a better understanding as to what clinicians are currently doing well to meet the needs of family members in order to minimize third-party disability, and where we could do better.

This study has several limitations including the small sample size, which prevents saturation of findings at this stage in the research, and limits transferability to other family members of people with PD. A second limitation of this study is that information gathered about the person with PD was constrained to family member reports, and hence more objective or detailed information about the nature and severity of communication or other PD-related impairments in the person with PD was not gathered. Closely related to this, detailed information related to the history of health issues, including depression in the family member participants, was not gathered. Furthermore, lack of information about family member opportunities to participate in support groups limits greater insight into their backgrounds. It may also affect our understanding about the potential influence that support group discussions can have on family members' self-appraisal regarding the impact that the communication changes in people with PD can have on themselves. The combination of the small sample size, limited clinical information about the person with PD, and limited health history collected on family member participants prevents identifying clear connections between factors that may influence third-party disability in this population. A final limitation of the study, related to convenience sampling, was that all participants except one were female, and all but one were the spouse of the person with PD. Future research should pursue a more balanced representation of gender and family relationships in family members.

There is a need for future research to improve the transferability of these findings and to delve more deeply and broadly into the many variables that might influence third-party disability. Despite this, this study contributes to the growing appreciation for the strengths, resilience, and unmet needs of family members who are so often sitting in the corners of our treatment rooms quietly observing our sessions and perhaps not often enough being asked how they are doing themselves.

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