Research Article

Speech Versus Speaking: The Experiences of People With Parkinson's Disease and Implications for Intervention

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Purpose: In this project, we explore the experiences of people who report speech changes associated with Parkinson's disease as they describe taking part in everyday communication situations and report impressions related to speech treatment.

Method: Twenty-four community-dwelling adults with Parkinson's disease took part in face-to-face, semistructured interviews. Qualitative research methods were used to code and develop themes related to the interviews.

Results: Two major themes emerged. The first, called "speaking," included several subthemes: thinking about speaking, weighing value versus effort, feelings associated with speaking, the environmental context of speaking, and

the impact of Parkinson's disease on speaking. The second theme involved "treatment experiences" and included subthemes: choosing not to have treatment, the clinician, drills and exercise, and suggestions for change.

Conclusions: From the perspective of participants with Parkinson's disease, speaking is an activity requiring both physical and cognitive effort that takes place in a social context. Although many report positive experiences with speech treatment, some reported dissatisfaction with speech drills and exercises and a lack of focus on the social aspects of communication. Suggestions for improvement include increased focus on the cognitive demands of speaking and on the psychosocial aspects of communication.

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The classical definition of dysarthria suggests that it is a group of neurologic speech disorders associated with abnormalities in the movements required for control of the physiologic aspects of speech production (Duffy, 2005, p. 5). Depending on the neuropathology, one type of dysarthria sounds different from another. It is clear that this definition focuses on the physiologic impairment rather than on its psychosocial consequences. The physiologic characteristics are well described perceptually (Duffy, 2005) and acoustically (Kim, Kent, & Weismer, 2011); however, the psychosocial consequences are only beginning to receive research attention.

With the adoption of the International Classification of Functioning, Disability and Health (World Health Organization, 2001), attention has been drawn to the psychosocial consequences of the condition. These have been described as participation restrictions and are recognized as being influenced not only by the physiologic and perceptual characteristics described above but also by contextual factors, including environmental or personal features. The psychosocial aspects of dysarthria have been examined through personal accounts (Cant, 1997) and using qualitative methods in acquired dysarthria (Brady, Clark, Dickson, Paton, & Barbour, 2011b; Dickson, Barbour, Brady, Clark, & Paton, 2008; Miller, Noble, Jones, & Burn, 2006; Walshe & Miller, 2011). Consensus exists that acquired dysarthria changes the lives of the speakers experiencing it. Speakers with acquired dysarthria report social isolation (Brady et al., 2011b), feelings of perceived stigmatization (Dickson et al., 2008), and changes in self-identity and social relationships (Brady et al., 2011b). Everyday activities, such as conversation, are difficult even when voice or speech changes are mild and do not interfere with speech intelligibility (Miller et al., 2006). Recent literature also suggests that psychosocial variables, such as communicative participation, are a separate and distinct construct from other physiologic and perceptual

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measures, such as speech intensity, that reflect speech production (Dykstra, Adams, & Jog, 2015).

The psychosocial aspects of dysarthria have also been examined using a small number of patient-reported questionnaires. For example, results of a 50-item questionnaire given to speakers with various etiologies of acquired dysarthria suggest that the psychosocial difficulties were not related to age, gender, diagnosis, or employment status (Hartelius, Elmberg, Holm, Lovberg, & Nikolaidis, 2008). Regardless of demographic characteristics, speakers with dysarthria reported restrictions in taking part in communication situations, negative emotions, and change in number or familiarity with people present in communication encounters. At least one scale has been developed to encompass some of these dimensions—that is, the Dysarthria Impact Profile (Walshe, Peach, & Miller, 2009) is a scale containing items related to several dimensions: self-concept/self-esteem, acceptance of dysarthria, others' reactions, and communication with others. Thus, although the research literature is limited, the psychosocial consequences of dysarthria are viewed as encompassing many social, personal, and environmental dimensions.

Information gained from the growing number of studies examining the psychosocial aspects of dysarthria has important implications for speech treatment. These implications remain largely unexplored with the exception of one survey conducted in the United Kingdom for speakers with Parkinson's disease and their caregivers (Miller, Noble, Jones, Deane, & Gibb, 2011). Results of this survey suggest improvements could be made in the logistics of speech treatment, including timing, intensity, duration, and access to speech treatment. Respondents also listed a lack of attention to psychosocial dimensions as an important limitation to current clinical practices.

In previous studies, researchers have explored the broad topic of psychosocial consequences of dysarthria, particularly the personal and environmental dimensions and, to some extent, impressions of speech treatment. The purpose of the current study was to explore the experience of participating in a variety of communication situations from the perspective of people with communication difficulties associated with Parkinson's disease. Further, the in-depth interviews provide insights into experiences with speech treatment for these speakers.

Method

Participants

Twenty-four community-dwelling people with Parkinson's disease took part in semistructured interviews as part of a larger study examining the impact of communication disorders and associated intervention for adults with a variety of underlying medical diagnoses/communicative impairment. Participants with Parkinson's disease were recruited through several venues, including the Parkinson's disease registry associated with the University of Washington and speech-language pathology clinics

and Parkinson's disease support groups throughout the Puget Sound region. Inclusion criteria included participants who reported that Parkinson's disease interfered with everyday communication for at least 2 years. Participants had to pass the Blessed Cognitive Screening, a measure that could be administered via telephone (Kawas, Karagiozis, Resau, Corrada, & Brokmeyer, 1995). The sample included nine women and 15 men. Participants were not excluded on the basis of treatment history. Thus, they represented a variety of treatment experiences. Some had no speech treatment, some had treatment in the past (more than 6 months posttreatment), and some recently completed speech treatment. See Table 1 for demographic data and self-reported measures of speech severity and speech usage level. Data are also presented for the Communicative Participation Item Bank (Baylor et al., 2013), a patient-reported measure of the impact of the condition on communication in daily situations. Scores are reported as *t* scores with 50 = mean of the calibration sample (*SD* = 10), and high scores indicate more favorable communicative participation. A review of Table 1 suggests that scores on the Communicative Participation Item Bank ranged from 1.5 *SD* more favorable to more than 2 *SD* less favorable than the mean of the calibration sample. Thus, participants' self-reports ranged from little to extensive interference in everyday communication situations.

The Interviews

Data were collected during face-to-face semistructured interviews. Each participant attended two interviews 6 months apart to allow for reflections on experiences with communication disorders over a period of time. Although two interviews were conducted, there was a very strong trend for participants to raise the same issues and talk about the same experiences and concerns in the second interview that they had discussed in the first interview, so the second interview functioned largely to confirm our understanding of thoughts expressed in the first. Participants were asked about the variety of everyday communication situations and how their speech affected taking part in these situations. They were specifically asked about situations in different contexts such as at home, out in the community, and in paid or volunteer work (if relevant). They were also asked about communicating with different people, such as familiar versus unfamiliar people. They were also asked questions about their experiences with speech treatment and specifically asked to share what they had found helpful versus not helpful in treatment. General questions were followed by requests for more detail, for example, "Tell me about the exercises that the clinician recommended." If they had not taken part in therapy, they were asked about why they had not participated in therapy or what might make them want to do speech therapy in the future. The questions posed were broad, allowing participants to share information they felt was most critical. Beyond these broad questions, participants were encouraged to talk about any other experiences related to their speech, speech treatment, or Parkinson's disease.

Table 1. Characteristics of participants.

ID	Sex	Age (years)	Years post Dx	Speech treatment history	Self-rated speech severity ^a	Speech usage ^b	CPIB ^c
P1	F	73	6	None	2	Intermittent	47.8
P2	F	57	13	None	2	Routine	55.3
P3	M	60	14	None	2	Undemanding	42.2
P4	M	64	10	None	2	Routine	43.3
P5	F	58	4	None	4	Intermittent	54.0
P6	F	66	6	None	4	Routine	56.5
P7	M	72	11	Past	1	Undemanding	24.2
P8	M	75	6	Past	1	Intermittent	46.7
P9	F	79	11	Past	2	Routine	32.4
P10	M	65	6	Past	2	Routine	60.6
P11	M	84	21	Past	2	Not Available	40.1
P12	M	83	11	Past	2	Undemanding	54.0
P13	F	82	3	Past	2	Intermittent	49.0
P14	M	82	6	Past	2	Undemanding	45.5
P15	F	75	20	Past	2	Undemanding	35.4
P16	M	64	8	Past	2	Undemanding	45.5
P17	M	70	10	Past	3	Intermittent	57.8
P18	M	81	9	Past	4	Routine	64.2
P19	F	49	11	Tx plus DBS	2	Routine	42.2
P20	M	57	17	Tx plus DBS	2	Undemanding	37.8
P21	F	65	27	Tx plus DBS	1	Undemanding	30.6
P22	M	63	14	Recent	1	Extensive	44.4
P23	M	68	7	Recent	3	Intermittent	50.3
P24	M	62	7	Recent	3	Routine	47.8
<i>M</i>		68.7	11.0				
<i>SD</i>		9.9	5.9				

Note. P1–P24 = Participant 1–Participant 24; F = female; M = male; Dx = diagnosis; CPIB = Communicative Participation Item Bank; Tx = treatment; DBS = deep brain stimulation.

^aSelf-Rating Speech Severity: 4 = *sounds normal*; 3 = *sounds different, but people understand me*; 2 = *sometimes have to repeat words to be understood*; 1 = *uses writing/gestures to help people understand*. ^bLevels of Speech Usage (Baylor, Yorkston, Eadie, Miller, & Amtmann, 2008). ^cBaylor et al., 2013. Mean of calibration sample (adult with motor speech disorders) is 50 with *SD* = 10.

Analysis

Interviews were audio recorded, transcribed verbatim, and verified, and content was coded using Dedoose software (Dedoose.com). After reading and rereading the transcripts, an initial set of descriptive codes were developed and used to index and retrieve pertinent segments of the interviews. The codes were not chosen beforehand but rather emerged as different topics arose in the interviews. This coding was discussed by the authors and led to the themes that are described below. This approach to analysis was consistent with procedures used in phenomenological research (Benner, 1994) and utilized in research related to acquired neurologic communication disorders (Baylor, Yorkston, & Eadie, 2005; Yorkston, Klasner, & Swanson, 2001). All methods were approved by the Institutional Review Board at the University of Washington.

Results

Two major themes emerged: “speaking” and “treatment experiences.” Subthemes and examples of these subthemes are contained Table 2.

Speaking

Participants spoke extensively about what the process of speaking was like for them. Although they occasionally

mentioned the quality of their speech, for example, reduced loudness, they emphasized that the process and success of speaking involved much more than the physical characteristics of their speech. Rather, their comments involved several elements that contributed to the activity of speaking. Several interconnected subthemes reflected these elements, including thinking about speaking, weighing value versus effort, feelings associated with speaking, the environmental context of speaking, and the impact of Parkinson’s disease on speaking. Each of these subthemes is described below.

Thinking About Speaking

Unlike typical speakers, who are often not cognizant of the process of speaking, participants indicated that they are aware of the cognitive demands associated with the activity of speaking. One participant (P21) said, “I can articulate if I put my mind to it.” For many, speaking was described as a dual task involving both thinking about “how” to speak and also about other issues, such as word finding or following the content of rapid conversations. Another participant (P20) described the dual task of speaking as follows: “I can’t figure out how to speak so he can hear me ... just too hard for me to concentrate on how I say something rather than what I’m saying. And that was frustrating.” Rapidly moving conversations are particularly difficult for some. From P9, “Sometimes I’ll lose track in

Table 2. Themes, subthemes, and examples of issues discussed by participants.

Theme	Subtheme	Examples
Speaking	Thinking about speaking	"Hard for me to concentrate on how I say something rather than what I'm saying." (P20)
	Weighing value versus effort	"It's tiring. Making the unconscious conscious in everything you do." (P2)
	Feelings about speaking	"Frustration" (P21), "embarrassment" (P12), "loss" (P19)
	People and places	"My condition becomes distracting to the other person." (P22)
Treatment	Parkinson's disease and speaking	"Wait until the pills kick in to talk." (P9)
	Choosing not to have treatment	"The point where you couldn't hear me and then I'd seek speech therapy." (P6)
	The therapist	"She instilled me with the proper things, but it's hard to do... Voice gets very tired. You get bored." (P14)
	Drills and exercises	"I felt silly enough just doing it with [the therapist] there. By myself, it seems too ridiculous." (P20)
	Suggestions for change	"Ask people about the cognitive parts" (P23), "focus on community" (P2), "make everyone practice every day" (P11)

the middle of it. Forget what it was I was trying to say. And I also have a problem pulling up words. And so the more complex and extended ... the harder it is." Speaking requires so much attention that it might interfere with other activities. For example, one participant (P2) suggested, "But I can't multitask anymore. I'll fall down the stairs if I'm talking and I'm walking."

Weighing Value Versus Effort

Most participants described the great effort required for speaking. One participant (P13) summarized this effort as involving both cognitive and physical work: "I can't just off-handedly say something. I have to really prepare and force it out." The effort was described as draining. From P2, "It's tiring ... making the unconscious conscious in everything you do, including the writing, typing, and vocal expression." Others suggest that the effort leads to either withdrawal or extra effort that makes matters worse:

It takes so much effort to control them [extra movements] that when I'm home and nobody's watching me. I will socially isolate. They say the bad thing is that I isolate ... So I have to push through it. Pushing through it for me results in more fatigue, more dyskinesia. (P2)

The work involved in speaking leads many to question the value of the effort. For example, one participant (P22) indicated, "I would say in general I'm probably less aggressive in that area [of conversation] than I used to be. Like getting my voice in there because I think oh well, screw it." Other descriptions of the difficulty in conversational situations included the feeling of being a "spectator" (P15) or a reluctance to participate, for example, from P21, "I've dealt myself out of the game in a lot of situations." Another participant (P20) described the process of weighing the value of taking part in speech treatment in the following way: "I really work hard, have to ask myself ... how committed am I to working that hard to get that little improvement for that short a time? And it's pretty depressing."

Feelings Associated With Speaking

Speaking was associated with a number of emotions, with frustration being perhaps the most common. One

participant (P21) described it in the following way: "So I simplify my thoughts down to the bare bones, so it doesn't really reflect how I feel. And it's just so frustrating." Embarrassment was also a common emotion associated with speaking, especially when tremors were also present. The following quote from P12 is an example: "I'm reluctant to call attention to myself in a group of people that I don't know because I'm embarrassed. I might pull back. I don't participate. I'm not supposed to do that, but..." Another participant (P19) suggested, "It's embarrassing to the person who has Parkinson's disease to have their voice taken away." At times, the emotions were associated with loss. For example, one participant (P2) suggested, "I used to have a voice that I was proud of." Another participant (P19) described grieving her losses in the following way:

It's just like no one can know how it's like for me. I have to grieve over losing my job. I can't be a nurse anymore. I loved being a nurse ... It was like losing a family. ... then recreating myself in another role. I just have to suck it up basically.

The Environmental Context: People and Places

Participants indicated that the experience of speaking is influenced by the people they talk to and places in which communication occurs. Often, participants were concerned about what people think of them. One participant (P20) commented on the reactions of others, "Just about every time I talk to somebody, especially when I don't know who they are, they are kind of taken aback by my voice." Another (P21) indicated, "I just get so overwhelmed by the picture that I present to people that's not who I am. And I can't explain who I am to people anymore." At times, changes in speech might give a false impression; from P2, "I hear more flattening [in speech], which makes people think I'm depressed." At other times, it might interfere more directly with the adequacy of the communication exchanges. One participant suggested exchanges with others are disrupted in at least two ways:

I think my condition becomes distracting to the other person. They're trying to figure out what the hell's the matter with me ... and they're not paying as much attention to what I'm saying as they should

be. So it's two ways. They're not focused on my auditory output as much as they could be ... because they're trying to figure out what's the matter with this dude. (P22)

In addition to paying attention to what others think, participants also commented on what others do. At times, the action of others was clearly an obstacle. One participant told the story of someone asking her to not read aloud in her Bible study group. The participant (P19) described this, saying, "She tried to take my voice away from me." At other times, the actions of others were more subtle and felt to be more well-intentioned:

A lot of people don't want to hurt your feelings and say they can't understand, so they just keep nodding and acting like they understand you but they don't. ... Why didn't you tell me? Because I don't know I'm speaking unintelligibly. (P19)

Because speaking takes place in various settings, many examples of particularly difficult environments were given. As might be expected, these involved specific examples of public places, including a retail computer store, a department of driver licensing, a high school basketball game, and a noisy restaurant. Difficult environments also included home with radio or television noise, use of telephone, or riding in the car.

Participants described the accommodations they made to circumvent communication barriers. For some, this involved avoidance of tasks, for example, from P22, "I really resist calling people for information," or avoidance of people, from P19, "If they can't deal with my disease and with my speech and stuff, I don't need them." At other times, when communication was important, the accommodations involved complex management of the situation as described in the following quotation:

To be able to communicate is really hard. And that communication has to do with effort and making sure they understand what I'm saying, making sure I sit down with them. I can't talk to them while I'm doing something else, for example, which means that an important conversation has to be conducted seated face to face. (P2)

Parkinson's Disease and Speaking

The final issue affecting speaking is the Parkinson's disease itself. Participants viewed their symptoms within the context of the degenerative condition: From P20, "[Parkinson's disease is] progressive and chronic, so it's not going to get any better. It's just going upstream." Within the context of long-term decline, participants also indicated that the condition is difficult because function is difficult to predict: From P2, "The problem with this disease, it's so hard to predict ... Every hour and every day is different." Symptoms are often influenced by medication cycles. One participant (P19) indicated, "[My speech] wanes throughout the day as the medication wears off ... But I can only go three and a half hours before I start losing it

again. So it's just part of my day." Another participant (P9) tells her family to "wait until the pills kick in" before trying to talk with her. The adequacy of speech is also influenced by factors such as fatigue. One participant (P19) told friends, "I'm tired today, so just email me. I'll email you back, but I can't talk."

Nonspeech symptoms, such as resting tremor, also influence participation in communication situations. One participant (P22) indicated, "Tremor is a big one because it distracts your audience, and everyone's trying to figure out what the hell's going on with me." Another participant (P5) reported that she is reluctant to call attention to herself in a group: "When I get more nervous or anxious, my tremor gets worse, and then I'm more embarrassed. It's a cycle." Difficulty walking was also given as example of a troublesome symptom. One participant (P2) indicated that she wished to do volunteer reading to children at a local library but was prevented from doing this by her concerns about walking. She said, "I'm afraid if I sign up for something and I'm having an off day, it'll be spooky when I walk in. I'm walking off balance. I mean, kids pick up that stuff really quickly."

Treatment Experiences

The second major theme involved experiences with speech treatment. Because of the problems caused by changes in speaking, many of the participants interviewed sought speech treatment. Before discussing their experiences with speech therapy, comments of those who had not received speech treatment will be reviewed.

Choosing to Decline Treatment

One quarter of the participants ($N = 6$) had not participated in any speech therapy. Two others withdrew after a brief period of treatment. The reasons for these decisions varied. Logistical issues, such as transportation, schedule, and cost, were reported. For those who withdrew, treatment side effects, such as laryngitis, were mentioned. Several participants indicated that they would consider speech treatment if their speech worsened. For example, one participant (P6) said, "Even if it got 50% worse than it is now, I'd still be able to communicate ... Hopefully if I notice my voice getting worse and worse, to the point where you couldn't hear me, and then I'd seek speech therapy." Others indicated that they would rather do other things. For example, one participant (P2) indicated that she declined speech treatment because she preferred "to figure out a way to get involved with the community that was non-Parkinson's related that would improve my quality of life."

The Clinician

For those who had undergone speech treatment, impressions were often associated with the clinician. Most were positive, especially regarding clinicians who made the therapy "fun" (P19). Some participants who had also taken part in a local Parkinson's disease singing group spoke of the group leader when asked about speech treatment. One

participant (P23) suggested, “The woman who does it is quite a remarkable person. So I enjoy it. I enjoy singing. I learned to accept using my voice ... more strongly than I had before.” Clinicians were also praised for encouraging communication: from P18, “I thought she was great because I go through periods recently where I talk too low ... but I knew I had to talk about it, and if you’re asked a question you should answer it.”

Clinicians were also viewed as being directive, instructing participants about what was wrong with their speech and what to do to change it. One participant (P19) described the role of the clinician as encouraging “awareness of what you’re doing. [The clinician would say] ‘I see this in you ... Now try it this way.’” Despite the instruction, therapy was not always considered successful: from P14, “I know [clinician’s name] did a nice job. She instilled me with the proper things, but it’s hard to do. ... Hard to remember, hard to start out. Voice gets very tired. You get bored.” Another participant (P21) indicated that she was being asked to do difficult things: “[The clinician] said, ‘no, no, that’s not it, you have to learn how to ...’ and I felt like I was being asked to do things that at certain times, I couldn’t do as well.” Clinician roles also included measuring how well the client was doing: from P20, “[The clinician] did a lot of recording—or not recording but voice level measurement.” At times, participants did not agree with clinician judgments: from P20, “[Clinician name] would say that, ‘How does that sound?’ I say, ‘Well, it sounds like I’m shouting too loudly.’ [The clinician said], ‘No. you aren’t ...’ I wasn’t really sure if I believed that or not because to me it sounded fine or too loud in some situations.”

Drills and Exercise

Participants’ comments about their experience with treatment frequently included descriptions of the drills or exercises they were taught. As might be expected, some participants saw the exercises as repetitive; from P11, “I was encouraged by [speech treatment], the first time. And partially encouraged by the second. The third was repetitious.” Exercises were also described as tedious and lacking relevance: from P14, “[The clinician] had me write out 10 different phrases I never use. And we spoke those loudly. I’m trying as loud as I can to be loud now and it’s not working.” Impressions of irrelevance, at times, appear to reduce the likelihood of continued practice. One participant (P20) reported,

I felt sillier than all get out in there. These tones for as long as I could for at least half an hour of time almost every day of the week, so ... I felt silly enough just doing it with [the clinician] there. By myself, it seems too ridiculous.

Some (P23) who had recent therapy reported, “[My wife and I are] still practicing some of it at home.” But many did not continue to practice. Some participants who did not continue to practice felt like they ought to: from P13, “I thought [the drills] were good in just saying the phrases and making it come out clearly ... I should go

back and go through my notes. I should read the book again, because I think that those were valuable.”

Suggestions for Change

Participants were asked to provide suggestions for change. For example, when asked what was missing from speech treatment, P2 responded in one word, “community.” She went on to say that speech therapy was,

... only addressing one small segment of their communication system ... When in fact, they should be with a group of people they feel comfortable with, and they can be as loud or as quiet as they want. And they get feedback right away... [Speech treatment is] great if you’re in the middle of it, but it’s a time-consuming, boring therapy, and people when they get out they don’t keep doing it because it’s boring. So why not find something that could replace the phrasing, the breath support, the vowels ... Why not get involved in choir, or chorus?

For others, community meant family: from P19, “Really get the family involved ... have my husband come with me next session and teach him things he could do with me at home.”

Participants also suggested the strategies for helping them engage in regular practice were important. Simply continuing drills in isolation was not thought to be helpful. One participant (P11) suggested, “I think we need some way to make everybody practice every day. I don’t do it. If I had a reminder that shot me in the butt, I would probably do it. I need a shock.” One participant (P4) who was interviewed prior to taking part in speech treatment wished that speech treatment would be combined with physical exercise. He said, “I think it would help on the speech part more, just like exercise helps with other Parkinson’s problems. I think combining the two of those would really be a good thing to do.”

Participants listed a series of things that speech-language pathologists should know. Because speaking is both physically and cognitively demanding, P23 suggested that clinicians “ask people about the cognitive parts.” Because communication change affects relationships, P21 suggests asking “all about the social isolation that happens with speech problems.” Because communication is different for everyone, P19 suggested, “You have to be able to treat me as an individual person.” She went on to say that speech-language pathologists should know that people who “can’t speak correctly...feel a little bit self-conscious about it, that it’s not under their control most of the time. That’s the two big things. And three, work with them.”

Discussion

Speakers with Parkinson’s disease viewed communication difficulties within a broad psychosocial context. They viewed speaking with communication difficulties as

an active process that requires not only the physical effort of speaking but also cognitive and emotional resources. Speakers weighed the value of participating versus the effort required for successful communication. Speaking is viewed against the background of people and places in the environment and against other issues related to Parkinson's disease, including mobility limitations, tremor, fatigue, and medication cycles. The perspectives of speakers with dysarthria are consistent with many of the descriptions in the literature, including the cognitive/linguistic demands of speaking (Miller et al., 2006), the feelings of frustration or embarrassment (Hartelius et al., 2008; Walshe & Miller, 2011), attention paid to the reactions of others (Miller et al., 2006; Walshe & Miller, 2011), social isolation (Brady et al., 2011b), and impact on the speaker's identity (Miller & Walshe, 2011).

When describing their experiences with speech treatment, participants viewed the clinician as playing the role of teacher, instructing them how to produce speech and then measuring their success. This is in contrast to the roles described in the aphasia literature in which a clinician is viewed as a counselor (Holland, 2007) or life coach (Worrall et al., 2010). Drills and exercises were reported to be a major component of speech treatment. In general, these exercises were not viewed positively. Opinions ranged from the view that exercises were repetitive, boring, and irrelevant to the view that they were useful but failed to address some important social aspects of communication. Some felt that they were being asked to do things that they were not able to do. Practice was often abandoned after treatment ended. These perspectives are consistent with other research. For example, personal accounts suggest that speech treatment for dysarthria was the most stressful of all therapies (Cant, 1997). In another example, survey data indicate that people with Parkinson's disease reported a lack of attention to psychosocial issues, and interviews suggest that if treatment activities were not challenging and reflective of patients' interests, they were abandoned (Brady, Clark, Dickson, Paton, & Barbour, 2011a).

When discussing speech treatment, participants gave advice about how treatment could be improved. These suggestions might be incorporated into clinical practice. First, clinicians should appreciate how difficult speaking is, and they should increase the focus on the linguistic/cognitive demands of speaking. This could be done, for instance, by shifting the intervention focus to specific participation situations that are relevant or important to the individual client. Clinicians have grown accustomed to compartmentalizing disorders, focusing on dysarthria or word-finding difficulty or cognition. From the perspective of people experiencing Parkinson's disease, it is difficult and probably unhelpful to separate these disorders because they all contribute in complex ways to the process of communication. Second, exercises, although they were felt to be an important component, are abandoned if they are not tied to activities that are personally relevant to the client. Clinicians could make exercise more relevant if the exercises were placed in a larger context of the condition. For example, because

mobility may be limited with Parkinson's disease, speech treatment might be integrated with other physical activities, such as an exercise group. Because social isolation is an issue for many, engaging in therapeutic activities with a singing group or speech intervention in the context of conversation groups may be useful. Family education and support was also felt to be an important but under-used component of treatment. Last, participants appealed for clinicians to treat their clients as individuals and to place speech within the bigger context of aging with Parkinson's disease. This advice is similar to the advice given by people following stroke for whom the importance of self-selected activities is highlighted (Brady et al., 2011b; Woodman, Riaz, Pereira, & Jones, 2014).

The current study has a number of limitations that should be addressed in future research. First, the treatment experiences described here should be viewed as generic because no attempt was made to describe the type, extent, or timing of treatment. Future investigations should focus on specific treatment protocols. Further, the treatment experiences described by participants in this study may have happened years ago and may not reflect current trends, such as integrating speech treatment with physical therapy. Next, participants were recruited from a convenience sample and may not be representative of the general Parkinson's population in terms of geographic location, access to health care, and severity of dysarthria. This study is limited to speakers with Parkinson's disease. Experiences with other neurologic conditions may vary. For example, the lived experience of dysarthria may vary in those with a stable or recovering course, such as stroke (Walshe & Miller, 2011).

The perspective of speakers with Parkinson's disease is different in subtle but important ways from those who assess and treat dysarthria from an exclusively physiologic perspective and consider that the primary goal of treatment is to improve the physiologic dimensions of speech. Consider the difference between a focus on speech (the noun) in contrast to speaking (the verb). Speech is the final product of the production process that can be described physiologically, perceptually, or acoustically in terms of the distance from a typical production. In other words, speech can be examined without a social context. On the other hand, speaking is part of the active process of communication and cannot be separated from the social context. Therefore, the environment both in terms of people and places is critical. The adequacy of "speaking" needs to be measured from multiple perspectives, most notably the perspective of the speaker. The perspective of participants also suggests that boundaries between the various communication diagnoses are not always clear. Although dysarthria is the most common communication disorder cited in the literature related to Parkinson's disease, language and cognitive changes also affect communication. Appreciating the broad psychosocial perspective of our clients will help us to develop better intervention programs that are responsive to the needs of individuals living with acquired communication disorders.

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