Beyond the patient: Understanding and addressing third-party disability in family members of people with Parkinson's disease

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Abstract

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Purpose: Family members of people with communication disorders associated with Parkinson's disease (PD) experience third-party disability. It is unknown whether these experiences are addressed in the rehabilitation process for communication disorders. The purpose of this study was to explore family member involvement in treatment from the perspectives of family members and speech-language pathologists (SLPs) to understand how third-party disability is addressed.

Methods: A mixed-methods design was used to capture the perspectives from two stakeholder groups, family members of people with PD and SLPs who provided services to people with PD. The first phase of this study used qualitative interviews with nine family members. After a preliminary analysis of the family member data, a survey was developed and administered to SLPs in the United States as the second phase. A total of 110 completed surveys were used for analysis. Qualitative data were analyzed for emergent patterns, and quantitative data were analyzed using descriptive measures. Data were then integrated and analyzed together.

Results: Three topic areas emerged from the data. First, family member involvement in treatment was typically for the purpose of supporting communication for the person with PD. However, family members and SLPs held divergent views such that family members reported little to no involvement, whereas many SLPs reported involving most family members in treatment. Second, there was a range in perspectives of family members and SLPs with regard to meeting family member needs in treatment. Several family members reported that their need to understand the person with PD was met, as improvements were seen in his/her communication abilities. However, other needs such as managing the challenging communication interactions between them and the person with PD were not met. Many SLPs reported supporting family members by counseling them and referring them to additional supportive services, but few had goals specifically addressing family member needs. Although family members did not differentiate between the type of communication disorder in the person with PD, fewer SLPs reported involving family members of people with PD who had cognitive-communication disorders than those with dysarthria. Third, there were multiple factors influencing SLPs' ability to involve family members in treatment. SLPs' views about including family members and their perceptions about family members' and clients' beliefs and preferences suggested that these factors may not have a negative influence on their practice. However, SLPs held mixed opinions about the work environment to support their practice. Many SLPs reported that their work setting supported their time to involve family members, but insurance reimbursement also limited their

ability to do. The final key finding from this study suggested that SLPs perceived many resources to be helpful in preparing them to involve family members in treatment. Almost all (if not all) SLPs reported that the clinical experiences they gained over time and learning from colleagues were helpful resources. Attendance at continuing education events and reading publications that were both peer-reviewed and non-peer reviewed were also helpful. However, SLPs' had ambivalent ideas about the strength and usefulness of the evidence base. Most SLPs felt that there was strong evidence demonstrating the role of family members in treatment, but only about half believed that the evidence guided their practice specifically on meeting family members' needs. Finally, with regard to the clinical training and education that they received from their graduate education, fewer SLPs felt that these resources were helpful in preparing them to include family members in treatment.

Conclusions: Prior literature demonstrates that family members experience third-party disability associated with communication disorders that are present in people with PD. Family members in this study discussed needing various supports from treatment, but not all of their needs were met. SLPs appeared to express positive opinions about involving family members in treatment, but there may be barriers related to the work environment and the current evidence base to support them in their practice. The challenging experiences that family members face as a result of communication disorders in the person with PD and the barriers affecting SLPs' practice suggest that there should be a shift of the healthcare system to adopt family-centered care so that outcomes from the rehabilitation process can be enhanced.

Plain Language Summary

Family members are affected by the communication disorders related to Parkinson's disease (PD) in a loved one. When the person with PD receives treatment for the communication disorders, researchers do not know if family members are also supported through the treatment process. The purpose of this study is to learn specifically about how family members are currently involved in treatment from the viewpoints of family members and speech-language pathologists (SLPs).

This study uses interviews with family members and a survey with SLPs to learn about how family members are currently involved in treatment. We also wanted to learn about issues that help or make it difficult for SLPs to support family members in treatment. The major findings are reported below:

1. Family members noted that they had little to no involvement to treatment, but many SLPs reported that they involved many family members in treatment.
2. Family members had several needs for treatment but SLPs may not be meeting family members' most important need to manage their difficult communication interactions with the person with PD.
3. SLPs appear willing to involve family members in treatment and to meet their needs, but they felt that their work environments and the limited research available influenced their practice to fully embrace this as part of their clinical practice.

These findings suggest that although family members are affected by the communication changes in the person with PD, these challenges are not sufficiently addressed in treatment for various reasons related to the environment where SLPs work and the existing evidence base.

Therefore, family-centered care is critical for addressing family member needs and third-party disability, and for improving outcomes from treatment.

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With utmost respect and appreciation, I would like to conclude with a very big thank you to all who have supported me to any degree during this incredible roller coaster ride that has been my life for the past four years. Amitabha!

DEDICATION

To all participants in this study, the people with PD and their loved ones, and the SLPs working at the front lines to make a change.

Chapter 1. INTRODUCTION

While a neurologic condition such as Parkinson’s disease (PD) has an impact on the person living with the condition, it also affects family members. That impact is even more significant when family members take on caregiving duties for the person with PD (Martin, 2015; McLaughlin et al., 2011; Mosley, Moodie, & Dissanayaka, 2017). Family members may undertake greater responsibilities such as being the sole financial provider, managing finances, and doing a majority of household tasks (Martin, 2015). Spouses caring for a person with PD might also experience psychosocial burden associated with disorganized household routines, challenges with traveling for holidays, restrictions on social life, and sleep disturbances (Thommessen et al., 2002). The progressive nature of PD may lead caregiving family members to experience burden from providing care particularly as the symptoms (e.g., depression, anxiety, cognitive impairment, etc.) associated with the disease arises, and as the disease continues to advance (Carter et al., 1998; Mosley et al., 2017).

A term recently introduced by the World Health Organization (2001) is third-party disability, which refers to the “study of disability and functioning of family members (e.g. a study of third-party disability due to the health condition of significant others)” (p.251). Within the field of communication sciences and disorders, various authors have argued that attention should be paid to understanding third-party disability in family members of people with communication disorders so that appropriate interventions and supports can be provided (Grawburg, Howe, Worrall, & Scarinci, 2013b; Nund et al., 2016; Scarinci, Worrall, & Hickson, 2012; Threats, 2010). The researchers suggested that third-party disability in family members can be studied by applying the International Classification of Functioning Disability and Health (ICF) framework to understand how domains of family members’ body structure and function, activities, and participation are impacted by an individual's health condition. Using this perspective, emerging research is documenting the nature and extent of third-party disability among families of people with dysarthria and cognitive-communication disorders associated with PD (Mach, Baylor, Hunting Pompon, & Yorkston, under review), hearing loss (Scarinci, Worrall, & Hickson, 2009; Scarinci, Worrall, & Hickson, 2012), aphasia due to stroke (Grawburg, Howe, Worrall, & Scarinci, 2013a; Grawburg et al., 2013b), and dysphagia due to head and neck cancer (Nund et al., 2016). A common finding across these studies is that family members experienced participation restrictions and activity limitations as a result of the communication and swallowing disorders. For instance, spouses had difficulty initiating and maintaining conversation with the person with hearing loss (Scarinci et al., 2009). Taking time to maintain health and self-care was also a challenge for family members as they cared for the person with aphasia (Grawburg et al., 2013b). As a last example, caregiving partners participated less in community, social, and civic life due to diet modifications in the person with dysphagia (Nund et al., 2016).

Family members of people with PD experienced third-party disability related to managing communication breakdowns because of the speech and cognitive changes in the person with PD and as a result of role and relationship changes (Mach et al., under review). Family members described common interactions during which they were unable to understand the person with PD. In these situations, family members attempted multiple strategies such as asking the person with PD for repetitions or moving into the same room to communicate with him or her. However, these strategies were not always successful and led to feelings of frustration or irritation in both the person with PD and the family member. Family members also faced role changes such that they took on more communication-related responsibilities including making phone calls on behalf of the person with PD. They took on other roles such as helping with tasks that required an ability to organize when cognition was affected in the person with the neurologic condition. Family members also experienced relationship changes as a result of the communication changes. They felt grief and loss over witnessing the changes in speech and cognition, and engaged in less conversation because of the decline in communication skills in the person with PD. Altogether, the communication changes in the person with PD influenced activity limitations and participation restrictions in the daily lives of family members.

Although the emerging literature just described documents the presence of third-party disability in family members of people with communication disorders, there is limited evidence regarding how family members' third-party disability is addressed in intervention programs delivered by speech-language pathologists (SLPs). One way to understand this phenomenon is by examining how family members are involved in the treatment process. Unfortunately, there is limited research in this area. A small set of studies have indirectly explored family involvement by attempting to understand what family members of people with communication disorders want from the rehabilitation process (Howe et al., 2012; Miller, Noble, Jones, Deane, & Gibb, 2011). Howe et al. (2012) interviewed family members of people with aphasia to learn of goals that they had for themselves. They found that family members wanted a greater and more inclusive role in the rehabilitation process rather than passively receiving updates on progress or being dismissed from the process. Family members also wanted to be able to communicate more effectively with the person with aphasia in order to maintain their relationship. They reported wanting more information from SLPs about aphasia, stroke, and other services throughout the rehabilitation process. Some family members needed formal psychosocial support from social workers or counselors, while others wanted informal support such as through a support group. In a similar vein, Miller et al. (2011) surveyed individuals with PD and their caregiving family members to understand their views about the support they received from communication and swallow therapy. They found that individuals with PD and caregiving family members valued education from SLPs and had a preference to receive education at the time of diagnosis, before further communication changes arose. Family members also wanted informal educational support such as from a support group. It may be worth noting that Howe et al. (2012) and Miller et al. (2011) conducted their studies internationally. Thus, it is unknown if the preferences and experiences of family members involved in the treatment process in the United States (U.S.) may be different.

Other studies have explored the inclusion of families in the rehabilitation process from the perspectives and practices of SLPs when working with people with communication disorders. One study explored adaptation of a communication training program, originally intended for the conversational partners of people with aphasia, to the spouses of people with PD (Forsgren, Antonsson, & Saldert, 2013). The purpose of the program was to train spouses on supporting communication with the person with PD. Spouses in the study reported that the training met some of their needs with regard to frequency and duration of the training sessions. They also expressed mixed opinions about the amount of information provided as two spouses were satisfied, whereas one felt that there was slightly too much information. While this training program was intended for family members of people with the specific diagnosis of PD, family members' third-party disability was not addressed as part of this program. There are also few existing studies conducted internationally that have explored SLPs' practice to involve family members of people with aphasia in treatment (Johansson, Carlsson, & Sonnander, 2011; Sherratt et al., 2011). Through a survey method, SLPs in Sweden reported the perception that it was important to involve family members in treatment, but limited time and resources restricted them from doing so (Johansson et al., 2011). Lack of national guidelines also influenced their practice of include family members in treatment. However, Johansson et al. (2011) found that SLPs with more years of experience provided more support to family members such as counseling than those with only a few years of experience. Sherratt et al. (2011) completed interviews with SLPs in Australia and found that they had several goals for family members which focused on communication or training in communication strategies. SLPs also had other goals for family members such as providing education and support for coping and participation in daily life. To address these areas, SLPs counseled family members, helped them to deal with changes, or connected family members with additional counseling resources or support groups. However, many SLPs acknowledged that there was a lack of goals for family members overall because of factors such as their limited contact with this population. SLPs gave reasons for the limited contact such as family members' lack of time, exhaustion, preference not to participate in treatment, or distance as a barrier to their attendance.

Although not specifically using the term 'third-party disability,' several researchers have urged for rehabilitation professionals to implement family-centered care to address family member needs. Creasy, Lutz, Young, & Stacciarini (2015) noted that there is currently no agreement on a single framework for this model of care. However, the Institute for Patient and Family-Centered Care (IPFCC, 2017) has attempted to describe its core concepts, and these include: dignity and respect for patient and family perspectives and choices; communication with patients and families to share information; encouragement and support for patients and families to participate in care and decision-making to the degree that they prefer; and collaboration between healthcare providers, patients, and families in areas such as research, policy and program development, and delivery of care. To further investigate family-centered care, Bamm

& Rosenbaum (2008) conducted a literature review to explore the theory behind it and its implementation in the field of rehabilitation medicine. They reported that it originated from the field of child health and is slowly being transferred into adult care. The researchers ultimately urged for more research to be conducted in this area so that "…it can be universally adopted as best practice" (p.1623). Creasy et al. (2015) also conducted a review of the literature on family-centered care for nurses working in stroke rehabilitation. They concluded that there are positive implications to providing this model of care and urged for rehabilitation nurses to adopt this when working with stroke patients and their families. Within speech-language pathology, family-centered approaches have been encouraged. Researchers (Howe et al., 2012; Johansson et al., 2011) have argued for family intervention by balancing services for both the person with the communication disorder and the family members, and by finding new methods for including family members in the rehabilitation process.

Although literature is emerging to demonstrate the presence of third-party disability in family members of people with communication disorders related to PD, the extent to which family members are involved in the rehabilitation process in order to address third-party disability remains largely unknown.. Furthermore, there is limited literature to enable understanding of the perspectives and practices of SLPs regarding inclusion of family members of people with PD in rehabilitation. It is vital to gain the perspectives of both populations to gain insight into how family members are currently involved in treatment and to examine factors that affect this practice. Such knowledge will be critical for improving the quality of care provided to family members through a more holistic, family-centered approach to the rehabilitation process. Thus, there are three research questions for this study, and they are listed below:

1. How are family members of people with communication disorders associated with PD currently involved in treatment from SLPs?
2. How are the needs of family members currently being met in treatment?
3. What are factors that affect SLPs' involvement of family members in treatment?

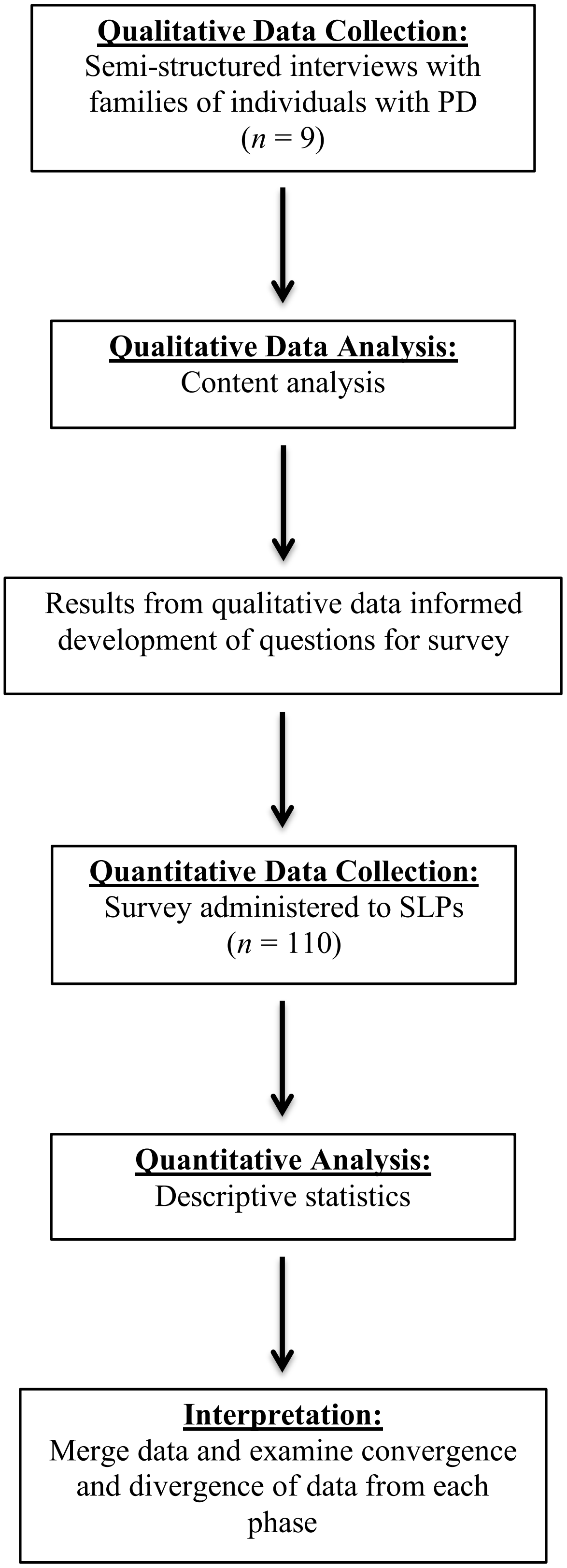
Chapter 2. METHODS

The following section explains the methods used for this mixed methods study. The research design will first be described. Then, details about participant groups including eligibility criteria and recruitment procedures will be defined. Finally, a description of the procedures for data collection and analysis will be included. This study received ethics approval (Study #00002743) from the Institutional Review Board at the University of Washington.

2.1 DESIGN

An exploratory, sequential mixed-methods design was used. The study was conducted in the sequence of a qualitative phase followed by a quantitative phase to gather perspectives from two stakeholder groups. Figure 1 is a flowchart that details each phase of this study.

Figure 1. Flowchart of the two phases of the mixed-methods design



This study used a mixed methods design so that data from two different methods (i.e., qualitative and quantitative) and two different participant groups (i.e., family members of people with PD and SLPs) could be integrated and analyzed (Creswell & Plano Clark, 2010; Tashakkori & Teddlie, 2003). Further, this design was chosen for the purpose of complementarity to "seek elaboration, enhancement, illustration, and clarification, of the results from one method with the results from the other method" (Greene, Caracelli, & Graham, 1989, p.259). That is, through a mixed methods design, integration of both sets of data allows for a deeper elaboration on our understanding of family member experiences in the rehabilitation process as each method informs the other. It can also be argued that the viewpoints of two key stakeholder groups at a knowledge-producing stage provides a bigger picture that is crucial for building a solid foundation of knowledge.

Qualitative methods were used as a first phase in this study to gain an in-depth understanding of family member experiences in the rehabilitation process for communication disorders associated with PD. Qualitative data also informed development of a survey for the second, quantitative phase of this study. The survey was used for gathering data from a larger sample of SLPs to observe practice patterns related to their involvement of family members in treatment.

2.2 PARTICIPANTS

There were two participant groups in this study. The first group was family members living with individuals with communication disorders associated with PD. The second group was SLPs working with individuals with PD. Procedures for recruitment will be described below as well as details on eligibility criteria.

2.2.1 *Family Member Participants*

Inclusion criteria for family members were any community-dwelling individual aged 18 or older and residing with a person who experienced communication changes related to PD. The relationship status of the family member to the person with PD was not restricted to spouses but could also include long-term domestic partners, children, siblings, or any other relative as long as they lived in the same household. However, paid caregivers were excluded. Additionally, the person with PD had to have experienced speech changes as reported by the family member and to have had treatment to address those changes. Family members of people with PD who did not meet this criterion were excluded as the purpose of this study was to gain information about family member involvement in rehabilitation for communication disorders. Family members were excluded if they and/or their loved one with PD resided in long-term care facilities or assisted living communities because the lack of independent living associated with living in these settings may alter understanding about the impact of communication disorders on family members' daily lives in community and home environments. Family members were recruited via convenience sampling through the Washington State Parkinson Disease Registry, the University of Washington's Speech and Hearing Clinic, outpatient speech-language pathology clinics including voice clinics, and support groups for family members of people with PD in Western Washington.

2.2.2 *SLP Participants*

Inclusion criteria for SLP participants were those who have worked with at least three clients with PD every year for the past three years (including the clinical fellowship year if applicable). This criterion was selected because SLPs who met this would have had an opportunity to establish some pattern of clinical practice with this client population and their family members. SLPs working with people with PD at university clinics, outpatient clinics including voice clinics, and home health agencies throughout the U.S. were also included. However, SLPs who were employed in acute care settings and skilled nursing facilities were excluded because the research team was interested in SLPs' practice patterns related to working with people with PD and their family members in community and home environments.

Using convenience sampling, SLPs were recruited to complete the survey by posting announcements that included basic information about the study purpose, the survey, and a link to access the survey on various American Speech-Language-Hearing Association (ASHA) message boards (i.e., Special Interest Groups on Neurological Disorders, Voice Disorders, and Swallowing Disorders). The announcements were also posted on various state association Facebook pages. Several state associations across various regions of the U.S. were contacted to share the survey with SLPs members belonging to those state associations. An instructor from the Lee Silverman Voice Training Program (LSVT) also shared the survey with all SLPs who have been certified to provide this therapy program.

2.3 DATA COLLECTION AND ANALYSIS

Data were collected from the two participant groups in two separate phases. In the first phase, qualitative data were collected from family member participants via semi-structured interviews. A discussion of data collection procedures will be reported, followed by a description of the procedures for analysis. In the second phase of this study, quantitative data were collected from SLP participants using a survey that was developed from family member qualitative data. Methods for data collection and procedures for analysis of the SLP participant data will also be described in the following sections.

2.3.1 *Family Member Qualitative Data Collection*

Qualitative data were collected from family members via semi-structured interviews. Family members met with researchers for interviews at their preferred location either in a meeting room within the Department of Rehabilitation Medicine at the University of Washington, or at family members' homes. Interviews lasted between 45 to 90 minutes and were audio recorded for later verbatim transcription. An interview guide (see Appendix A) was used to guide data collection on several topics. The first topic focused on family member experiences of living with a person with communication changes related to PD and its impact on their daily lives. The second topic explored their experiences or involvement in the rehabilitation process to address the communication disorders in the person with PD. The third topic was related to family member opinions about what SLPs can do to meet their specific needs as well as any suggestions they had for SLPs on how to include and support family members. The grand tour question was, "Describe to me what your experiences are like as a family member now that your family member's communication has changed." To gather data on family member experiences in treatment, family members were asked questions including, “As your family member [the person with PD] went through speech therapy, what was your level of involvement in that process?” or “Tell me about your experiences as the family member in treatment.” Regarding family members’ suggestions for supporting them in the rehabilitation process, an example interview question was, “What ideas do you have about what you would like speech therapy to address for you as the family member?” A portion of the collected data on family member experiences of living with a person with PD were reported in a prior study that described their experiences of third-party disability (Mach et al., under review). Qualitative data collected on family member experiences with the rehabilitation process were used for this current study.

Family members also reported on demographic data about themselves and about the person with PD (see Appendix B). Demographic data about themselves included age, gender, race, relationship to the person with PD, and employment status. Demographic data about the person with PD included age, gender, race, and approximate time since diagnosis with PD. Family members also rated the speech severity of the person with PD by responding to an adapted version of the speech severity item from the ALS Functional Rating Scale (ALS-FRS) (Cedarbaum et al., 1999). The item on this scale was originally designed so that a person with Amyotrophic Lateral Sclerosis (ALS) rated his or her own speech by responding to the following question: “Which statement best describes your speech”. This item used a 5-point response scale that ranged from ‘normal’ to ‘not understandable; does not use speech for communication.’ This item was adapted for this study such that family members were asked to rate speech severity of the person with PD using the same 5-point scale rather than having the person with PD rate himself or herself. The question item was modified to: “What statement best describes the speech of your family member with PD?” The same 5-point response scale was used. Other demographic data that family members reported about the person with PD included the approximate year when he or she pursued speech therapy, approximate duration of speech therapy, and the communication disorder that was treated.

2.3.2 *Family Member Qualitative Data Analysis*

Prior to analysis, two post-baccalaureate student volunteers from the Department of Speech and Hearing Sciences at the University of Washington transcribed all interviews verbatim. The lead investigator (HM) checked two interviews for reliability. All interview transcripts were uploaded to Dedoose™, a web-based indexing program. Qualitative analysis for family members was completed in two stages. In the first stage, a preliminary analysis was conducted for the purpose of developing the survey to be administered for the second phase of this mixed method study. In the second stage, a more complete qualitative analysis was performed to explore patterns of family member experiences and perspectives about the rehabilitation process for communication disorders in the person with PD. The two stages of qualitative analysis are described below. Methods to ensure trustworthiness of data are also reported.

2.3.2.1 Preliminary Analysis for Survey Development

A preliminary analysis of the qualitative data was completed to develop the survey instrument used for the second phase of this study. The lead investigator read all interviews and took detailed notes on family member discussions about their involvement in treatment and any suggestions they had for improving treatment to meet their needs. The notes were then converted into potential questions for the survey. In general, many topics raised by multiple family members were made into a single survey item. However, there were some instances in which a single point was mentioned by only one family member, and those points were also used to develop some survey items. Further details about the process of developing items on the survey are described in section 2.2.3.2.

2.3.2.2 In-depth Analysis for Major Patterns

For the in-depth analysis, family member data were examined using content analysis to describe the phenomenon of family member experiences in treatment (Hsieh & Shannon, 2005). Content analysis was used for the purpose of concept development (Lindkvist, 1981, as cited in Hsieh & Shannon, 2005) and because limited literature exists about a particular phenomenon (Hsieh & Shannon, 2005) such as family member experiences in treatment. The first step of conducing a content analysis includes developing codes for a codebook. To develop the codebook (see Appendix C), three investigators (HM, CB, and KY) reviewed two interviews and allowed codes to emerge from the content of the transcripts, rather than pre-determining the codes ahead of time. After a draft of the codebook was created, the two transcripts were coded into excerpts. The three investigators convened again to compare the codes and coded excerpts to reach an agreement on final codes and definitions. After finalizing the codebook, the primary investigator coded the remaining interview transcripts into excerpts. Each code and the accompanying coded excerpts were extracted from Dedoose into a word document for further analysis (e.g., the "family member involvement in treatment" code along with all the excerpts that were coded under this code was extracted). For each code, excerpts were then sorted by shared topics that formed three to five sub-categories. Each sub-category for each code was summarized into a paragraph. The summary paragraphs for each sub-category were then distilled into a single summary for each code. The single summaries were compared against each other to develop patterns that formed into themes. Two investigators (HM and CB) participated in the process of analyzing excerpts from each sub-category and comparing them against each other to develop the themes. Themes about family member third-party disability were reported in (Mach et al., under review).

For this current study, the lead investigator (HM) independently analyzed excerpts from sub-categories for three major codes a second time and compared them to observe for patterns that were relevant to this study's research questions. Primary codes from the codebook used for this current study included, "Family involvement in speech treatment," "Family member opinions about speech treatment," and "Family suggestions for improvement."

2.3.2.3 Trustworthiness of Qualitative Data

To ensure trustworthiness of the data (Lincoln & Guba, 1985; Merriam, 2009), the lead author conducted all interviews and two authors (CB and KY) served as a second interviewer for two interviews. Furthermore, all participants were contacted to participate in member checks, and a total of seven family members completed the member checks. Several family members provided updates since the interviews, but two family members requested minor edits. Finally, peer examination was used in which three authors (HM, CB, and KY) participated in development of the codebook.

2.3.3 *SLP Quantitative Data Collection*

In the sections that follow, information about the survey content are reported. Next, descriptions are provided about development of the survey. Finally, details about survey administration will be described.

2.3.3.1 Survey Content

There were questions that were used to collect information on demographic data and clinical practice data. To collect demographic data, there were questions that asked about SLPs' age, gender, race, highest degree earned, years of experience as an SLP, and region of the U.S. where they were employed. There were also several questions that collected data about the characteristics of SLPs' clinical practice with people with PD. These included setting where they see most clients with PD, number of clients with PD seen per year for the past three years, any special certifications that SLPs had, percentage of clients with whom they used special programs with people with PD, and breakdowns of their caseload into percentage of clients that have written goals for addressing dysarthria or cognitive-communication.

Four major topic areas were covered in the survey. The first topic inquired about ways that SLPs actively involved family members in treatment to support the person PD. These items asked about SLPs' participation in activities such as having discussions with family members about what communication is like between the person with PD and other people or working with family members on ways they can avoid or repair communication breakdowns in their daily routines.

The second topic focused on how SLPs include family members in treatment to meet their specific needs and preferences. These items inquired about activities that SLPs engaged in such as getting in direct contact with family members to find out how they might be impacted by the communication disorder in the person with PD, providing supports such as counseling or referring family members to additional resources, or writing goals specifically for family members.

The third topic inquired about SLPs' perceptions regarding various facilitating and impeding factors that influenced their inclusion of family members in treatment. Questions focused on five sets of issues. One issue was SLPs' opinions and attitudes about involving family members in treatment and meeting their needs. Other issues that SLPs were asked to report on included their perceptions about the environmental characteristics related to their work environments, the beliefs and accessibility of family members, and the beliefs of their clients with PD. One final set of issues focused on SLPs' beliefs about the current evidence base to regarding family involvement in treatment.

The fourth topic area explored SLPs' views about the helpfulness of various resources in preparing them support family members in the rehabilitation process. Resources included the clinical experiences that SLPs gained over time and learning from colleagues about ways to support family members. SLPs were also asked to report on their perspectives about resources including attendance at continuing education events, reading peer-reviewed literature, and reading publications that were not peer-reviewed. Finally, they reported on their views about the clinical experiences and coursework from their prior graduate school training in preparing them to include family members as people with specific needs in treatment.

2.3.3.2 Survey Development

After converting notes from the preliminary analysis of family member data into potential questions for the survey, three investigators (HM, CB, and KY) convened to develop the survey. The content of each item was revised, and decisions were made regarding the general format of the items (e.g., yes/no questions, open-ended questions, skip logic, etc.) and the response categories that were used (e.g., 'strongly' agree to 'strongly' disagree'). Skip logic was used such that some questions were skipped if SLPs responded in a way that indicated those questions did not apply. There were also some slight modifications in the wording of items, or the addition or omission of some items in several sections on the survey such that items would be relevant to a particular diagnosis. For example, if there was a section of questions about SLPs' practice with clients with dysarthria, items were worded appropriately so that they inquired about dysarthria (i.e., changes in the physical movements of the vocal mechanism that affects physical production of sounds for communication) and not cognitive-communication disorders (i.e., changes in cognition that affect communication). There was one optional open-ended question that gave SLPs an opportunity to comment on any of the closed-ended questions or express any other opinions that were not addressed in the survey.

Different response categories were used for the four different topics that were covered in the survey. For the first topic inquiring about how SLPs involved family members in treatment to support the person with PD, a response category with a 4-point scale was used. The categories indicated the proportion and percentage of their clients with PD with whom they participated in various activities to include family members. ‘None’ referred to none of their clients, ‘few’ referred to 25% or less of their clients, ‘many’ referred to approximately 50% of their clients, ‘most’ referred to 75% or more of their clients, and ‘all’ referred to all clients. The second topic asking about how SLPs included family members in treatment to support their specific needs and preferences used the same response options as the first topic. The third topic exploring SLPs’ perceptions regarding factors that influenced their involvement of family members in treatment used a different response category. The format for these categories was a 5-point scale ranging from ‘strongly agree to ‘strongly disagree’ and included an ‘unsure’ response option. For the fourth topic inquiring about SLPs’ perspectives regarding the helpfulness of different resources in preparing them to include family members in treatment, a response category with a 4-point scale was used. Categories ranged from ‘very helpful’ to ‘not helpful,’ and a ‘have not had/used” category was also included.

Prior to finalizing the survey, the lead investigator conducted four cognitive interviews with SLPs. The SLPs worked with people with PD in outpatient hospital settings and university-clinic settings affiliated with the University of Washington. Feedback was gained on content, format, and length of the survey. The lead investigator also inquired about rewording of questions reduce any ambiguous interpretation. After considering the feedback gained from the cognitive interviews, the lead investigator made minor revisions and then piloted the survey with three more SLPs to determine length of completion time.

2.3.3.3 Survey Administration

The final version of the survey (see Appendix D) was administered to SLPs nationally using a web-based tool through the University of Washington and could be completed in less than 15 minutes. SLPs were first provided with informed consent, and completion of the survey indicated their agreement to participate. All data were collected anonymously. The survey was open for completion for approximately two months.

2.3.4 *SLP Quantitative Data Analysis*

Descriptive statistics were used to analyze the data. These included collecting information on mean, standard deviation, and/or range of SLPs' demographic and clinical practice data. The remaining survey items were analyzed using frequency counts and percentages of SLPs endorsing each response category.

Chapter 3. RESULTS

Demographic data as well as major findings will be reported in the sections that follow. Demographic data will be presented for the family member participants followed by SLP participants. Then, results from analysis of the family qualitative and SLP survey data will be reported. There were three major topic areas that emerged from the qualitative and quantitative data. The first topic illustrates family member experiences regarding how they are currently involved in rehabilitation for communication disorders, as well as SLPs' perspectives on how they involve family members in rehabilitation. The second topic provides a discussion of what family members desired from treatment to meet their own, individual needs, again followed by SLPs perspectives on this topic. The third topic explains factors that, according to SLPs, influence their ability to involve family members in treatment. For topics one and two, qualitative data from family members will be presented first, followed by quantitative data from SLPs.

3.1 DEMOGRAPHIC DATA

Demographic data for each of the participant groups are described below. The data will be reported for family member participants followed by SLP participants.

3.1.1 *Family Member Demographic Data*

There was a total of nine family members who participated in the first, qualitative phase of this study. All family members identified as being white, and all but one were female. Family members also reported on the demographic data of the person with PD. They identified that all persons with PD were white. Characteristics of family members and persons with PD are reported in Table 1.

Table 1. Demographic Data of Family Member Participants and the Person with PD

Family Members					**Person with Parkinson's Disease**						
ID	Age	Gender	Relationship Status	Employment Status	Age	Gender	Years since PD diagnosis[a]	Speech severity[b]	Year when Speech Treatment Was Pursued[c]	Duration of Speech Treatment	Disorder Targeted in Speech Treatment
FM1	78	F	Spouse	Retired	79	M	5	4	2014	3 months	Dysarthria
FM2	67	F	Child	Retired; continues to work for pay	94	F	12	4	2016	Several months	Dysarthria
FM3	64	F	Spouse	Retired	67	M	8	2	2010	Approx. 6 months	Dysarthria; cognition
FM4	61	F	Spouse	Working part-time for pay	66	M	10	2	2013	8 weeks	Dysarthria
FM6	81	M	Spouse	Retired	80	F	10	2	2015	Ongoing	Dysarthria
FM7	77	F	Spouse	Retired	77	M	16	4	2013	Approx. 1 month	Dysarthria
FM8	64	F	Long-term partner	Working full-time	61	F	5	2	2014	2 months for dysarthria; 2 months for cognition	Dysarthria; cognition (through research study)
FM9	68	F	Spouse	Retired	66	M	15	2	2012	Approx. 3 months	Dysarthria
FM10	65	F	Spouse	Working full-time	77	M	8	2	2017	Ongoing	Dysarthria

Note. *N* = 9. [a]Years since PD diagnosis are reported in approximation by family members. [b]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. [c]Year when the person with PD pursued speech therapy are reported in approximation by family members.

3.1.2 *SLP Demographic and Clinical Practice Descriptive Data*

One hundred and twelve SLPs completed this survey. However, two SLPs did not meet inclusion criteria, and their responses were removed. One SLP from Australia responded to the survey but reported that she practiced in the U.S. for three years. Thus, her responses were kept in the data set. The final sample size was 110 SLPs. A majority of SLPs were female and white. About half of the SLPs in this sample (49.1%) practiced for more than 20 years. SLPs from the four regions of the U.S. (i.e., Northeast, Midwest, South, and West) were represented in this sample. Table 2 provides demographic information describing the SLPs in this sample.

A majority of SLPs in this sample (60.9%) were employed in outpatient hospital settings where most of their clients with PD were seen. Almost half of the SLPs (45.5%) worked with more than 10 clients with PD every year for the past three years, and a majority of SLPs (90%) held the LSVT certification. Most SLPs (76.3%) targeted dysarthria with ‘most’ or ‘all’ of their clients, but only 17.2% targeted cognitive-communication with ‘most’ or ‘all’ of their clients. These data are presented in greater detail in Table 3.

Table 2. Demographic Data of SLPs Working with People with Parkinson's Disease

Characteristic (*N* = 110)	**Frequency (Percentage)**
Age	
Mean, SD in years	47.06 (11.51)
Age range	26 – 67
Gender	
Female	101 (91.8%)
Male	8 (7.3%)
Prefer not to answer	1 (0.9%)
Race	
Asian	1 (0.9%)
Black	1 (0.9%)
Hispanic	1 (0.9%)
White	100 (90.9%)
More than 1	2 (1.8%)
Preferred not to answer	8 (7.3%)
Highest degree earned	
Master's	104 (94.6%)
Doctorate of Philosophy	6 (5.6%)
Experience as SLP in years	
Less than 5 years	8 (7.3%)
5-10 years	24 (21.8%)
11-20 years	24 (21.8%)
More than 20 years	54 (49.1%)
Region of the U.S. where SLP is employed	
Northeast	23 (20.9%)
Midwest	21 (19.1%)
South	32 (29.1%)
West	34 (30.91%)

Table 3. Descriptive Data on Characteristics of SLPs' Clinical Practice with Individuals with Parkinson's Disease

Characteristic (*N* = 110)	Frequency (Percentage)
Setting where most clients with PD are seen	
Outpatient hospital	67 (60.9%)
Private community-based clinic	16 (14.6%)
University clinic	9 (8.2%)
Home health	7 (6.4%)
Roughly equivalent PD clients in more than 1 setting	6 (5.5%)
Other	5 (4.6%)
Number of clients with PD seen per year for the past 3 years	
Less than 5 per year	20 (18.2%)
5-10 per year	40 (36.4%)
More than 10 per year	50 (45.5%)
Special Certifications	
LSVT	99 (90%)
SPEAK OUT!	18 (16.4%)
None	9 (8.2%)
Other	8 (7.3%)
Percentage of clients with whom SLPs use LSVT	
None	13 (11.8%)
Few (less than 25% of clients)	9 (8.2%)
Many (approximately 50% of clients)	17 (15.6%)
Most (75% or more of clients)	45 (40.9%)
All	26 (23.6%)
Percentage of clients with whom SLPs use SPEAK OUT!	
None	91 (82.7%)
Few (less than 25% of clients)	7 (6.4%)
Many (approximately 50% of clients)	7 (6.4%)
Most (75% or more of clients)	4 (3.6%)
All	1 (0.9%)
Percentage of clients that SLPs have written goals for addressing dysarthria	
None	0 (0.0%)
Few (less than 25% of clients)	7 (6.4%)
Many (approximately 50% of clients)	19 (17.3%)
Most (75% or more of clients)	48 (43.6%)
All	36 (32.7%)
Percentage of clients that SLPs have written goals for addressing cognitive-communication	
None	9 (8.2%)
Few (less than 25% of clients)	41 (37.3%)
Many (approximately 50% of clients)	41 (37.3%)
Most (75% or more of clients)	15 (13.6%)
All	4 (3.6%)

3.2 FAMILY MEMBER INVOLVEMENT IN TREATMENT TO SUPPORT THE PERSON WITH PD

The first topic that arose indicated that when family members are involved in treatment, it is largely to support the intervention program for the person with PD. However, there appeared to be some discrepancies between the family member and SLP data. Family members indicated they had limited engagement in the treatment process; whereas a majority of SLPs reported that they included most or all family members in treatment in various ways to support the person with PD. Results are described in greater detail below.

3.2.1 *Family Member Interviews*

Family members reported that they had little to no involvement in treatment, and they discussed several reasons for this. Four family members reported that they did not attend any treatment sessions and did not engage in any kind of activity outside of the sessions such as with home practice programs. One reason they gave for their lack of participation was the high level of independence of the person with PD. To illustrate this, FM1, noted that her husband was independent enough to attend the sessions alone: “I didn’t think that was something I had to go to. So I never did…I knew it was something he [husband] could go to by himself.” Similarly, FM9 provided her opinion about not going to therapy with her husband: “It was fine. He’s very independent.” She also expressed that she did not practice any home exercises him because, “He is very independent. ‘I’ll do it myself.’” FM7 spoke of her husband’s ability to drive as having an influence on her lack of involvement: "He was driving at that point so he was totally on his own. Independent.” For FM4, the cognitive status of her husband appeared to play a role in her decision to not be involved with treatment. She explained, “I didn’t feel like I needed to be at that point. He was certainly able to go through the therapy on his own…cognitively, he's totally with it."

A second reason that family members gave for not attending therapy was that they were simply not aware that it was an option for them to attend treatment sessions. FM4 commented that the thought never crossed her mind: "I never actually thought about it. I never thought about being involved." FM1 also had the same thought process, stating, "I didn't think about it at all." For FM9, she was not aware if the SLP extended an invitation for her to attend her husband's treatment sessions, "Not that I know of. They might have told him to tell me, but he didn't tell me." Family members' personal obligations were a final reason that they were not involved with treatment. FM9 recalled that when her husband was receiving treatment for dysarthria, "At the time I was still working…60 hours a week. I didn't feel like it was realistic for me to go…up until I was retired, my time was not flexible at all."

Among family members who were involved with treatment sessions, their engagement was often limited. Two family members were present for a handful of sessions. For instance, FM2 reported: "I got to be there the first two days, and then I was booted out." She further explained, "I assumed that if I was uninvited that there was something about the program that they figured was going to work better for mom if I wasn't there." Two family members were present for a majority of the treatment sessions, but participation was typically passive in that they mainly observed the sessions. As FM3 reported, "Well, not participated. I guess that's a strong word. I went along and watched because I wanted to make sure it was going to be okay." Similarly, FM6 indicated, "I attended most of [the therapy sessions]…mostly observing… just listening in." He added: "Occasionally, the speech therapist will ask me my opinion as to what's happening. So I feel that I speak out whenever I think I should…but being asked to provide certain clues or that sort of thing, not that much."

When family members were involved with treatment, it was for the purpose of supporting the person with PD to carry out home exercises that were prescribed by SLPs. This was often at the request of the person with PD. For instance, he or she would initiate family member involvement by reporting on what was learned during treatment sessions to the family member. FM4 summed this up by describing a scenario of how she supported her husband in this endeavor:

> My involvement was mostly [husband] would come home and say, 'Oh, this is what we did. These are the things I have to practice and if I'm not doing this would you remind me?'…Sharing what he was learning in the class…and so in the car he'd say, 'Okay, I need to practice for the next ten minutes,' while we were driving somewhere…And so I think that was really helpful, him just sharing that so that I could be supportive in that and giving him that time.

FM10 also assisted her husband in completing home exercises when he would "read off his things to me, and I would help him sometimes with the timing of when he's doing his volume controls and things like that." However, she felt that, "My involvement probably was more nagging to practice… to keep reminding him to do it. Usually he was pretty good about it…when he gets busy, he forgets and gets side-tracked." Family members reported that written information sent home by SLPs helped them to practice with the person with PD. For example, FM4 felt that, "For the most part, I'm okay with just the written material he's bringing home." She elaborated:

> It was helpful having the written information. So it wasn't like he just came home and said, 'I have to practice saying these funny words.' I was like, 'What are the funny words?' And everything was written there. So that was extremely helpful. And then practicing with him…

Likewise, FM9 was able to review information that her husband received from treatment: "Reading the information that he got and seeing the exercises that he was asked to do, it was pretty easy to figure out what they're trying to do."

3.2.2 *SLP Survey Responses*

Seven items from the survey administered to SLPs asked how they actively involve family members in the rehabilitation process to support their clients with PD, and these responses were supplemented by optional open-ended comments from participants. Table 4 presents the raw data regarding how SLPs responded to these items. The items are organized according to the dysarthria diagnosis from the highest to the lowest percentage of SLPs who endorsed the 'all' response category. Across these items, generally 70% or more of the SLPs reported that they involve family members of "most" (more than 75%) or "all" of their clients. Key highlights of these results are presented in the next paragraphs.

Table 4. Frequencies and percentages of SLPs endorsing inclusion of family members in treatment to support the person with PD when addressing dysarthria and cognitive-communication goals. The percentages for each of the dysarthria and cognitive-communication columns are based on the sample size of SLPs responding to the dysarthria or cognitive-communication items respectively.

Question Item: When working with clients on goals related to **[dysarthria/cognitive-communication]**, with **what percentage of your clients** do you do the following?	**Dysarthria** Frequency (Percentage) *n* = 110 (100%)	**Cognitive-Communication** Frequency (Percentage) *n* = 101 (92%)
4a. I ask family members about how their communication is going with my clients with PD.		
None	0 (0.0%)	1 (1.0%)
Few (less than 25% of clients)	6 (5.5%)	7 (6.9%)
Many (approximately 50% of clients)	5 (4.5%)	6 (5.9%)
Most (75% or more of clients)	31 (28.2%)	38 (37.6%)
All	68 (61.8%)	49 (48.5%)
4b. I ask family members how communication is going between my clients with PD and other people.		
None	1 (0.9%)	2 (2.0%)
Few (less than 25% of clients)	7 (6.4%)	11 (10.9%)
Many (approximately 50% of clients)	7 (6.4%)	10 (9.9%)
Most (75% or more of clients)	35 (31.8%)	32 (31.7%)
All	60 (54.5%)	46 (45.5%)
4c. I specifically reach out to family members to invite them to attend at least a few therapy sessions.		
None	3 (2.7%)	
Few (less than 25% of clients)	10 (9.1%)	Question was not asked for this diagnosis
Many (approximately 50% of clients)	14 (12.7%)	
Most (75% or more of clients)	32 (29.1%)	
All	51 (46.4%)	
4d. I provide educational materials to family members [regarding communication changes/cognitive-communication change] and/or therapy for my clients with PD.*		
None	2 (1.8%)	5 (5.0%)
Few (less than 25% of clients)	11 (10.0%)	9 (8.9%)
Many (approximately 50% of clients)	15 (13.6%)	19 (18.8%)
Most (75% or more of clients)	33 (30.0%)	33 (32.7%)
All	49 (44.5%)	35 (34.7%)

4e. I work together with family members and my clients with PD on [how to avoid or fix communication breakdowns in everyday life/everyday cognitive-communication challenges].*		
None	1 (0.9%)	1 (1.0%)
Few (less than 25% of clients)	9 (8.2%)	13 (12.9%)
Many (approximately 50% of clients)	16 (14.5%)	17 (16.8%)
Most (75% or more of clients)	39 (35.5%)	31 (30.7%)
All	45 (40.9%)	39 (38.6%)
4f. I include family members in the conversation when choosing goals for my clients with PD in treatment.		
None	1 (0.9%)	2 (2.0%)
Few (less than 25% of clients)	10 (9.1%)	13 (12.9%)
Many (approximately 50% of clients)	20 (18.2%)	17 (16.8%)
Most (75% or more of clients)	41 (37.3%)	32 (31.7%)
All	38 (34.5%)	37 (36.6%)
4g. I train family members to help with home practice for treatment carryover.		
None	0 (0.0%)	2 (2.0%)
Few (less than 25% of clients)	16 (14.5%)	11 (10.9%)
Many (approximately 50% of clients)	17 (15.5%)	12 (11.9%)
Most (75% or more of clients)	40 (36.4%)	39 (38.6%)
All	37 (33.6%)	37 (36.6%)

*These questions were asked separately based on the communication disorder diagnosis but have been combined into this table to summarize the data. Phrases in brackets denote portions of the question item that were modified as appropriate for the respective communication disorder diagnoses.

All participants (100%) reported that they address goals related to dysarthria with at least a ‘few’ of their clients (see Table 3). When treating dysarthria, the most common way that SLPs included family members in treatment was to consult with them about their clients’ abilities to communicate (items 4a and 4b), with over 90% of SLPs reporting that they do this with ‘most’ or ‘all’ of their clients. A majority of SLPs (75.5%) endorsed reaching out specifically to ‘most’ or ‘all’ family members to invite them to attend at least a few therapy sessions (item 4c). Regarding this issue, one SLP commented, “I always encourage them [the client with PD] to have a family member attend at least 1 session, and it is at their discretion to follow up.” Another remarked the following: “I would say I bring in the family member an average of once a week, with a schedule of twice a week (or 4 times a week for LSVT).” Roughly the same percentage of SLPs also provided ‘most’ or ‘all’ family members with educational materials about the dysarthria changes or about the treatment program for their clients (74.5%; item 4d); or worked together with family members and their clients on how to avoid or fix communication breakdowns in their everyday lives (76.4%; item 4e). Slightly fewer SLPs included family members in other aspects of treatment. For example, 71.8% of SLPs included ‘most’ or ‘all’ family members in conversations when choosing goals for their clients (item 4f). Seventy percent of SLPs endorsed training ‘most’ or ‘all’ family members to help with home practice for treatment carryover (item 4g).

A lower percentage of SLPs in the sample (92%) reported addressing goals related to cognitive-communication function in ‘few’ up to ‘all’ of their clients (see Table 3). Table 4 provides the data regarding the percentage of these 101 SLPs who reported involving family members in various ways to support their clients. In general, a lower proportion of SLPs involved family members when working with clients on cognitive-communication goals than on dysarthria goals, although there were similar patterns in terms of which activities were reported to be more common than others. Similar to the pattern observed with dysarthria goals, the most common way that SLPs included family members of clients with cognitive-communication goals was to consult with them about their clients' abilities to communicate. Over 70% of SLPs endorsed consulting with family members of 'most' or 'all' clients on these items (items 4a and 4b). Somewhat lower levels of family member involvement (between 60-70% for 'most' or 'all' clients) were reported for other types of activities such as sending home educational materials about cognitive-communication changes or about the treatment plan (item 4d), working with family members and their clients on fixing communication breakdowns in their daily lives (item 4e), and including family members in goal setting for their clients (item 4f) when working on cognitive-communication goals, whereas over 70% of SLPs reported involving 'most' or 'all' family members in these areas for dysarthria goals. The only item that a higher proportion of SLPs endorsed when treating cognitive-communication goals was training family members to help with home practice for treatment carryover (item 4g); 75.2% of SLPs endorsed engaging in this activity with 'most' or 'all' family members of their clients with cognitive-communication goals, whereas 70.0% of SLPs endorsed this item when working with family members of clients with dysarthria goals.

Regardless of whether treatment goals target dysarthria or cognitive-communication, one SLP summed up her opinions about including family members in treatment to improve treatment outcomes for her clients. While her "general operating principle…is that each patient will take 'ownership' of their therapy…" she felt that:

> In all cases family and friend supports are vital to some degree or another. This ranges from family education, family input re: the patient's communication and goals (since often [patients] initially may not think they have a deficit in soft speech), and can include

using family to help with HEP [home exercise program] reminders or cueing in more severe cases.

3.3 MEETING FAMILY MEMBERS' NEEDS IN TREATMENT

The second topic that emerged from the data focused on family members' goals for treatment to meet their own needs that would enable them to better support the person with PD as well as needs that they had for themselves related to living with someone with a communication disorder. Family members also discussed that there were some needs that were not met. Thus, they provided suggestions on how to address this. SLPs also reported on their efforts to involve family members in treatment in order to meet their needs. Findings from both participant groups are reported below.

3.3.1 *Family Member Interviews*

One goal for treatment that aligned with family members' needs was for the person with PD to speak more clearly. For some family members that meant increased volume or improved articulation in the person with PD so that communication could be more effective between both parties. For some family members, this was met. FM3 stated, "It all seemed helpful because I could hear him [husband] so much better." FM2 described that after her mother participated in treatment to target dysarthria, "Now she can make enough noise to wake me up in the middle of the night that I don't have to sleep so lightly." In contrast, FM6 was one participant who reported this need for increased loudness was not met and affected conversations with his wife: "I have had this feeling that it [speech therapy] has not been that effective. That it's a lot of time spent with not a whole lot of results." FM6 elaborated that he wanted to see, "…maybe an automatic increase in volume with conversation with me or with one person." There were other goals for treatment that were not met, and family members provided suggestions for meeting these needs, which are summarized in the following paragraph:

Related to the topic of their hopes for improved speech in the person with PD, family members requested receiving more direct and specific information from the SLPs about the therapy program and home exercises so that they could better support the home exercises. Although they reported being able to access written information that was sent home with the person with PD, FM10 suggested, “Just do a little bit more direct communication maybe with the family members than going through the client or patient.” FM9 also felt that direct communication about the content from treatment sessions was important so that it can be reinforced for the person with PD:

> If I would have had some orientation, it might have been easier to reinforce that at home…I think anybody that learns a new technique—you hear it in the classroom, but going home, you don’t always remember exactly what you’re supposed to do. So to have two people understand what needs to be accomplished might be helpful.

Family members also wanted additional information about the course of treatment. For instance, FM3 wanted “Just a general sketch. It doesn’t have to be in detail or anything, so you don’t feel like you’re sitting there going, ‘What’s happening? When does this program end? Or does it end’…more information about the program.” Moreover, family members requested to be actively engaged during treatment sessions. FM6 pondered, “It might be helpful if the speech therapist asked me to do certain things, yeah. Basically she’s [SLP] just dealing with [wife].” When family members are actively participating in treatment sessions, “it’s more of a team effort” such that they are not always reminding or dictating the person with PD when they return home and sit down to practice home exercises:

> Working together with a family member on things in some meetings to do exercises together with and get that input as a team…and sometimes with the outside person facilitating and coming up with exercises for us to do together is helpful for her. Then it's not me telling her what to do. We've got homework to do together. (FM8)

A third need that family members expressed was to have help with successfully managing the challenging communication interactions that existed between them and the person with PD. This need was not met in treatment. As mentioned in prior literature regarding third-party disability (Mach et al., under review), at the outset of a communication breakdown, family members experienced tension from not being able to understand the person with PD – even when he or she makes attempts to be clearer such as repeating oneself. These unsuccessful attempts to be understood, along with reminders from the family members to be loud, gave rise to – and were often intertwined with – mutual feelings of frustration and irritation in the family member and the person with PD. In this study, five family members discussed needing to learn how to manage these difficult interactions. They felt the first step was for SLPs to acknowledge these experiences. FM4 recommended that "recognizing the changes in speech impact every part of life and the emotional part. It's not just my emotion, [husband]'s emotions as well." Moreover, "Let the family member know, 'This is hard for you. You're going to be doing more.' Ways you can be involved, cue the person, what to expect, and how to get support for you" (FM8). Family members also suggested for SLPs to meet with them separately during the evaluation phase of treatment to gain a deeper understanding of how the communication changes directly impacted them. FM9 explained, "Sometimes I think the family members have to be met separately because it's a whole different relationship…I think that the family members need to have their own emotional support." FM2 also agreed that they should be given the opportunity to more freely express their thoughts: “If you want to know what the caregivers need or how they’re impacted, you could ask them…not in front of the person they’re trying to protect. They will think of things they wouldn’t think of otherwise to tell you.” After providing a safe space for open dialogue, family members suggested for SLPs to provide strategies that enable them to communicate in a way that minimizes giving off an impression of irritation or coming across as a nag:

> So if there were a way to tend to talk to people without sounding like a nag. I know there’s choice of words and things like that that you can do, but I think a lot of it, too, is a sense of irritation, I guess, when you’re constantly having to tell them something or can’t hear something. And so then it comes out in the way you’re speaking. So any way you can figure out how to express things without coming across as a nag is good. (FM10)

They also recommended that SLPs coach them to cope with the feelings of frustration and minimize the tension during communication exchanges by helping family members with “being patient…I think family members need more support in how to deal with their frustrations and the fact that you have to slow yourself down” (FM9).

A fourth goal that family members had for treatment was for SLPs to recognize when to connect them with additional resources such as mental health counseling or support groups when the counseling that SLPs provide is not sufficient. FM9 summarized the importance of this:

> Maybe it’s not always the speech therapist that’s their emotional support. But if you’re encouraging the families to be a part of a training or therapy session or whatever, it’s a point of contact that the family members—you might be able to recognize this family member’s really getting frustrated…I [the SLP] need to take that person aside, I need to get them into other kinds of—maybe a support group or their own psychological counseling…recognize when family members are growing into a period of crisis.

Additionally, FM3 noted, “I think it would be nice if spouses could talk about the problems they have…there are a lot of support groups out there…”

3.3.2 *SLP Survey Responses*

Six items on the survey asked SLPs about how they support the needs that are specific to family members, and some comments were provided on the supplemental open-ended question to elaborate on their responses. Table 5 presents the raw data regarding how SLPs responded to these items. Items are organized according to the dysarthria diagnosis from the highest to the lowest percentage of SLPs who endorsed the ‘all’ response category. Regardless of whether SLPs targeted dysarthria or cognitive-communication goals, there was a wide range (30-80%) in the proportion of SLPs who endorsed various activities to involve family members of “most” or “all” of their clients in an effort to meet their needs. Key findings of these results are presented in the following paragraphs.

Table 5. Frequencies and percentages of SLPs endorsing provision of the following services directly for family members to target their needs when addressing dysarthria and cognitive-communication goals. The percentages for each of the dysarthria and cognitive-communication columns are based on the sample size of SLPs responding to the dysarthria or cognitive-communication items respectively.

Question Item: When working with clients on goals related to **[dysarthria/cognitive-communication]**, with **what percentage of your clients** do you do the following?	**Dysarthria** Frequency (Percentage) *n* = 110 (100%)	**Cognitive-Communication** Frequency (Percentage) *n* = 101 (92%)
5a. I ask family members how their everyday lives have changed because of the [dysarthria/cognitive difficulties] in my clients with PD.*		
None	1 (0.9%)	2 (2.0%)
Few (less than 25% of clients)	12 (10.9%)	12 (11.9%)
Many (approximately 50% of clients)	9 (8.2%)	10 (9.9%)
Most (75% or more of clients)	36 (32.7%)	35 (34.7%)
All	52 (47.3%)	42 (41.6%)
5b. I direct families to additional supports/resources (e.g., mental health counseling, support groups, respite care, community resources, etc.).		
None	0 (0.0%)	1 (1.0%)
Few (less than 25% of clients)	19 (17.3%)	20 (19.8%)
Many (approximately 50% of clients)	14 (12.7%)	14 (13.9%)
Most (75% or more of clients)	29 (26.4%)	26 (25.7%)
All	48 (43.6%)	40 (39.6%)
5c. I counsel family members regarding coping with [the communication changes/cognitive-communication changes] in my clients with PD in their everyday lives.*		
None	3 (2.7%)	2 (2.0%)
Few (less than 25% of clients)	13 (11.8%)	12 (11.9%)
Many (approximately 50% of clients)	26 (23.6%)	25 (24.8%)
Most (75% or more of clients)	27 (24.5%)	31 (30.7%)
All	41 (37.3%)	31 (30.7%)
5d. I reach out specifically to family members to provide them with opportunities to talk with me separately about their concerns.		
None	12 (10.9%)	10 (9.9%)
Few (less than 25% of clients)	26 (23.6%)	25 (24.8%)
Many (approximately 50% of clients)	25 (22.7%)	16 (15.8%)

Most (75% or more of clients)	25 (22.7%)	24 (23.8%)
All	22 (20.0%)	26 (25.7%)
5e. I recommend to older family members to have their hearing checked.		
None	13 (11.8%)	Question was not asked for this diagnosis
Few (less than 25% of clients)	36 (32.7%)	
Many (approximately 50% of clients)	25 (22.7%)	
Most (75% or more of clients)	19 (17.3%)	
All	17 (15.5%)	
5f. I write goals specifically targeting the needs of family members.		
None	13 (11.8%)	11 (10.9%)
Few (less than 25% of clients)	29 (26.4%)	23 (22.8%)
Many (approximately 50% of clients)	34 (30.9%)	24 (23.8%)
Most (75% or more of clients)	23 (20.9%)	25 (24.8%)
All	11 (10.0%)	18 (17.8%)

*These questions were asked separately based on the communication disorder diagnosis but have been combined into this table to summarize the data. Phrases in brackets denote portions of the question item that were modified as appropriate for the respective communication disorder diagnoses.

When treating dysarthria, the most common way that SLPs involved ‘most’ or ‘all’ family members in this section of questions was by asking about how their daily lives have changed because of the dysarthria in their clients (item 5a). Eighty percent of SLPs reported engaging in this activity. A second common activity that SLPs participated in was directing families to additional supports such as mental health counseling, support groups, or community resources (item 5b), with 70% of SLPs endorsing this. A slightly lower percentage of SLPs (61.8%) counseled family members regarding how to cope with the communication changes in their clients’ everyday lives (item 5c). There were also a few activities that were less common for SLPs when involving family members. Less than half engaged in activities such as reaching out specifically to family members to provide them with opportunities to speak separately about their concerns (42.7%; item 5d), recommending to older family members to have their hearing checked (32.8%; item 5e), or writing goals to specifically target their needs (30.9%; item 5f).

Some SLPs provided comments about addressing the psychosocial needs of family members. One way to reduce some of family members’ difficult emotions was to counsel them as well as the client by providing them with information:

> It is also helpful to counsel both as the person with Parkinson's often feels the family member isn't listening to them or has hearing difficulties. Family members need counseling as well to recognize that the person with Parkinson's isn't simply just not trying but there are physical changes to vocal folds and that the brain isn't calibrating loudness correctly…

Another way SLPs reported assisting family members was connecting them with support groups, and as one SLP noted, “I do, almost always, refer patients and caregivers to a local community Parkinson's Support Group which does wonderful work.” On the other hand, these psychosocial needs may not always be addressed: “I realize I don't actively seek out family members to educate or refer to counseling.”

Although there was an overall lower proportion of SLPs involving ‘most’ or ‘all’ family members of clients with cognitive-communication goals, there were also patterns similar to their practices when working with family members of clients with dysarthria goals. The activity that most SLPs (76.3%) endorsed was asking family members about how their daily lives changed because of the cognitive difficulties in their clients with PD (item 5a). Slightly less common activities that SLPs reported engaging in were directing families to additional supports (65.3%, item 5b) and counseling family members regarding coping with the cognitive-communication changes in their everyday lives (61.4%; item 5c). There were two activities that half or less than half of SLPs endorsed when working with ‘most’ or ‘all family members. The first was reaching out to family members and providing them with opportunities to speak separately about their concerns (49.5%; item 5d). The second was writing goals to specifically meet their needs (42.6%; item 5f). Although the proportion of SLPs involving ‘most’ or ‘all’ family members was lower when treating cognitive-communication goals as opposed to dysarthria for most items, a noteworthy finding was that the proportion of SLPs who endorsed these last two activities was higher than the proportion of SLPs who did so when targeting dysarthria goals. The 49.5% of SLPs who reached out specifically to family members of clients with cognitive-communication goals to provide them with opportunities to separately discuss their concerns was higher than the 42.7% of SLPs who did so when targeting dysarthria goals (item 5d). Similarly, the 42.6% of SLPs who reported writing goals to specifically target the needs of family members of clients with cognitive-communication goals was higher than the 30.9% of SLP who did so when targeted dysarthria-related goals (item 5f). One SLP provided an explanation for this practice pattern: “Patients with needs in cognitive-communication…always attend with a family member/caregiver and that person is always allowed into the sessions by the patient (in part, because I ask the patient to invite them).” Another SLP also elaborated on this:

> Most of my sessions are with the client alone, but I bring in the spouse or other family member for the evaluation and periodically during treatment, depending on the patient's cognitive-linguistic abilities to follow through and accurately self-assess his/her progress in therapy.

3.4 FACTORS AFFECTING SLPS’ INVOLVEMENT OF FAMILY MEMBERS IN TREATMENT

The third topic of this study explored SLPs’ perspectives regarding multiple factors that affected their involvement of family members in the rehabilitation process. SLPs reported on perceived facilitators and barriers influencing their practice. They also reported on the helpfulness of resources to prepare them to include family members in treatment. Results regarding these findings are described in greater detail below.

Fifteen questions on the survey asked SLPs about facilitators and barriers that were divided into five topic areas. These included SLPs’ views about involving and meeting the needs of family members, their opinions about how their work setting supports involvement of family members, their perceptions about the beliefs and accessibility of family members and their clients with PD, and SLPs’ opinions about the current evidence to guide their practices. Table 6 provides a summary of the SLPs’ responses to survey items inquiring about facilitators and barriers. Per each topic area, items are organized from highest percentage to lowest percentage for SLPs endorsing the “Strongly Agree” response category.

Table 6. Frequencies and percentages of SLPs endorsing facilitators and barriers to support their involvement of family members in treatment.

Question Item: Please rate the extent to which you **agree or disagree** with each of the following statements about working with families of clients with PD:	**Frequency (Percentage)**
SLP Opinions and Attitudes	
6a. I feel confident supporting the needs of family members as part of the treatment process.	
Unsure	0 (0.0%)
Strongly Disagree	0 (0.0%)
Somewhat Disagree	3 (2.7%)
Somewhat Agree	37 (33.6%)
Strongly Agree	70 (63.6%)
6b. I believe it is appropriate to have goals specifically for family members to support their needs in living with the communication changes in my clients with PD.	
Unsure	11 (10.0%)
Strongly Disagree	0 (0.0%)
Somewhat Disagree	12 (10.9%)
Somewhat Agree	37 (33.6%)
Strongly Agree	50 (45.5%)
Environmental Characteristics of Practice Setting	
6c. My setting supports my time to work with family members (e.g., productivity adjustments, scheduling, etc.)	
Unsure	0 (0.0%)
Strongly Disagree	15 (13.6%)
Somewhat Disagree	16 (14.6%)
Somewhat Agree	36 (32.7%)
Strongly Agree	43 (39.1%)
6d. My setting provides supports specifically for family members (e.g., offering support groups, educational classes, educational materials).	
Unsure	0 (0.0%)
Strongly Disagree	31 (28.2%)
Somewhat Disagree	19 (17.3%)
Somewhat Agree	28 (25.5%)
Strongly Agree	32 (29.1%)

6e. Limitations in insurance reimbursement or other funding makes it difficult for me to directly address the needs of family members in treatment.	
Unsure	2 (1.8%)
Strongly Disagree	20 (18.2%)
Somewhat Disagree	11 (10.0%)
Somewhat Agree	47 (42.7%)
Strongly Agree	30 (27.3%)
Beliefs and accessibility of family members	
6f. It is difficult for family members to attend therapy sessions due to their own personal obligations or schedules.	
Unsure	4 (3.6%)
Strongly Disagree	4 (3.6%)
Somewhat Disagree	13 (11.8%)
Somewhat Agree	78 (70.9%)
Strongly Agree	11 (10.0%)
6g. Having family members in therapy sessions interferes with the autonomy of my clients with PD.	
Unsure	6 (5.5%)
Strongly Disagree	40 (36.4%)
Somewhat Disagree	38 (34.5%)
Somewhat Agree	23 (20.9%)
Strongly Agree	3 (2.7%)
6h. Family members do not express the desire to participate in speech therapy.	
Unsure	7 (6.4%)
Strongly Disagree	27 (24.5%)
Somewhat Disagree	44 (40.0%)
Somewhat Agree	31 (28.2%)
Strongly Agree	1 (0.9%)
Beliefs of Clients with PD	
6i. I can easily get permission from my clients with PD to reach out to their family members and involve them in treatment.	
Unsure	2 (1.8%)
Strongly Disagree	1 (0.9%)
Somewhat Disagree	7 (6.4%)
Somewhat Agree	37 (33.6%)
Strongly Agree	63 (57.3%)

6j. My clients with PD do not want the family members in the therapy sessions.	
Unsure	11 (10.0%)
Strongly Disagree	25 (22.7%)
Somewhat Disagree	35 (31.8%)
Somewhat Agree	35 (31.8%)
Strongly Agree	4 (3.6%)
SLP beliefs about the current evidence base	
6k. There is a strong evidence base to support the role of family members in treatment.	
Unsure	20 (18.2%)
Strongly Disagree	1 (0.9%)
Somewhat Disagree	4 (3.6%)
Somewhat Agree	47 (42.7%)
Strongly Agree	38 (34.5%)
6l. There is an evidence base to guide me in addressing the needs of family members.	
Unsure	26 (23.6%)
Strongly Disagree	4 (3.6%)
Somewhat Disagree	20 (18.2%)
Somewhat Agree	39 (35.5%)
Strongly Agree	21 (19.1%)
6m. Addressing family member goals are specifically part of the protocols of the therapy programs I have been trained to provide.	
Unsure	3 (2.7%)
Strongly Disagree	14 (12.7%)
Somewhat Disagree	28 (25.5%)
Somewhat Agree	45 (40.9%)
Strongly Agree	20 (18.2%)

SLPs’ perspectives about their clinical practices is one factor that influenced their involvement of family members in treatment. Almost all SLPs (97.7%) ‘somewhat’ or ‘strongly’ agreed that they felt confident to support the needs of family members in treatment (item 6a). Most SLPs (79.1%) also agreed to some extent that it is appropriate to have goals specifically for family members to support their needs in living with the person with PD (item 6b). These findings indicate that most SLPs feel that they are capable of supporting family members’ needs in treatment and that it is appropriate to directly target those needs through formal treatment goals.

The environmental characteristics of SLPs’ practice settings are another factor that can impact their inclusion of family members in treatment. A majority of SLPs (71.8%) ‘somewhat’ or ‘strongly’ agreed that their setting supports their time to work with family members such as by making productivity adjustments (item 6c). Slightly more than half of SLPs (54.6%) agreed that their setting provides supports specifically for family members such as offering support groups or educational classes (item 6d). SLPs also reported on whether or not their practice setting specifically offered support groups on communication or swallowing issues in particular for family members of people with these concerns. To report on this, they answered a ‘yes/no’ question (not listed in any table) that asked, “Does your setting offer support groups specifically focusing on communication and/or swallowing issues?” Only about one-third of SLPs (36.4%) responded ‘yes,’ reporting that their facilities did offer such groups for family members. One SLP also explained, “There is a PD support group in my city but it is not specifically sponsored by the hospital.” A majority of SLPs (70.0%) ‘somewhat’ or ‘strongly’ agreed that limitations in insurance reimbursement or other funding makes it difficult for them to directly address the needs of family members in treatment (item 6e.) One SLP summarized the challenges with reimbursement:

> Regarding reimbursement/coding/billing/productivity -- most of our codes are defined as direct treatment with the patient, therefore we are encouraged to have the patient at least present and participating in the session in order to code the session as education of the patient and family. Unfortunately, we have been advised that meeting with the family without the patient present is not billable. We will usually document this education as being provided, but it doesn't count towards the time spent in direct patient care.

Another SLP also explained that, "Family support and training seems to get pushed aside when insurance only allows for a certain number of sessions and the patient and family's time is limited for therapy." In summary, many SLPs perceived to some extent that the environment of their work setting was one that supported involving family members to some degree by aiding their time to work with family members. Many SLPs also reported that their work environment specifically offered family members some supports such as educational materials. However, many SLPs also felt that lack of insurance reimbursement or other funding sources to address family members' needs was a barrier related to the work environment.

SLPs' perceptions of family members' and clients' beliefs and accessibility was another factor that affected their inclusion of family members. Most SLPs (80.9%) 'somewhat' or 'strongly' agreed that it is difficult for family members to attend therapy sessions due to their own personal obligations or schedules (item 6f). Few SLPs (23.6%) agreed to some extent that having family members in therapy sessions threatened the autonomy of their clients (item 6g), or that family members did not express a desire to participate in sessions (29.1%; item 6h). Regarding the opinions and preferences of their clients with PD, most SLPs (90.9%) 'somewhat' or ‘strongly’ agreed that they could easily gain permission from their clients to reach out to family members and include them in treatment (item 6i). However, only slightly more than one-third of SLPs (35.4%) agreed to some degree that their clients preferred to attend therapy sessions without family members present (item 6j). One SLP reported on this: “I find that the vast majority of patients prefer having their significant others attend therapy sessions and most family members take the time to do so.” Although not captured via the survey items, another SLP discussed policies and laws that can make it difficult to involve family members. However, these barriers can be overcome because of the willingness of her clients to allow her to speak with family members: “Privacy laws may prevent me from including family members and prevent me from reaching out to them; most patients agree to let me talk with family…” Overall, most SLPs felt that both family members and clients with PD would welcome family member involvement in treatment. They also believed that involving family members was not a threat to client autonomy. However, their perceptions about family members’ availability and concerns over privacy regulations suggest that these might be two factors that limit family member involvement.

SLPs’ opinions about the evidence base regarding involvement of family members and supporting their needs in treatment also influenced their ability to engage in this practice. Most SLPs (77.2%) ‘somewhat’ or ‘strongly’ agreed that there is strong evidence that family members have a role in treatment to support the goals of the person with PD (item 6k). Slightly more than half of SLPs (54.6%) agreed to some degree that there is an evidence base to guide them in specifically addressing the needs of family members (item 6l), and that family member goals are specifically part of the protocols of therapy programs that they have been trained to provide

(59.1%; item 6m). One SLP researcher questioned the current state of the evidence and offered ideas to further explore this topic:

> Evidence-based protocols are a critical element in predicting the success of our treatments. While, our clinical knowledge tells us to educate and offer families support in dealing with the challenges of PD, it would be very useful to report literature documenting the evidence of family engagement on treatment outcomes. What specific "family protocols" offer the most positive impact on patient outcomes?

In summary, SLPs held varying perspectives about the strength and usefulness of the current evidence base to influence their involvement of family members in the rehabilitation process. Most SLPs reported that there is a strong knowledge base demonstrating family members' role in treatment to some extent, but only about half of felt that it guided them on ways to specifically support the needs of family members. Many SLPs also reported that the therapy programs that they were trained to provide did include a component of meeting family members' needs.

SLPs' perceptions about resources that prepared them to work with family members was a fifth factor that affected their practice. There were seven questions on the survey inquiring about the helpfulness of various resources in preparing them to work with family members. The items were divided into topics that asked about perceptions of their preparedness, the clinical experiences they gained over time, different types of evidence they consumed, and different experiences they gained from their graduate training program. Table 7 summarizes SLPs' responses to these items. Survey items are organized according to SLPs' endorsement of 'very helpful' responses from highest to lowest.

Table 7. Frequencies and percentages of SLPs reporting on the helpfulness of resources to prepare them to involve family members in treatment.

Question Item: How **helpful or unhelpful** are the following resources related specifically to supporting families of adults with neurologic communication disorders?	**Frequency (Percentage)**
7a. Developing skills/experience over time from your own clinical practice	
Have not had/used	0 (0.0%)
Not helpful	0 (0.0%)
Somewhat helpful	12 (10.9%)
Very helpful	98 (89.1%)
7b. Attending continuing education events (e.g, web-based courses, ASHA conference, workshops, etc.)	
Have not had/used	1 (0.9%)
Not helpful	2 (1.8%)
Somewhat helpful	27 (24.5%)
Very helpful	80 (72.7%)
7c. Learning from colleagues about ways to support family members	
Have not had/used	2 (1.8%)
Not helpful	1 (0.9%)
Somewhat helpful	32 (29.1%)
Very helpful	75 (68.2%)
7d. Reading peer-reviewed research articles (including ASHA SIG articles)	
Have not had/used	9 (8.2%)
Not helpful	6 (5.5%)
Somewhat helpful	52 (47.3%)
Very helpful	43 (39.1%)
7e. Clinical practicum training completed during graduate school program	
Have not had/used	9 (8.2%)
Not helpful	18 (16.4%)
Somewhat helpful	54 (49.1%)
Very helpful	29 (26.4%)
7f. Reading non peer-reviewed publications (e.g., books, ASHA Leader, etc.)	
Have not had/used	6 (5.5%)
Not helpful	11 (10.0%)
Somewhat helpful	73 (66.4%)
Very helpful	20 (18.2%)
7g. Coursework completed during graduate school program	
Have not had/used	14 (12.7%)
Not helpful	27 (24.5%)
Somewhat helpful	61 (55.5%)
Very helpful	8 (7.3%)

In general, when responding to one survey item (not listed in any table) asking how prepared they felt in their career to address the specific needs of family members of clients with PD, 82.7% of SLPs reported feeling ‘very’ or ‘somewhat’ prepared. According to the data in Table 7, the clinical experiences that SLPs gained over time was perceived as the most helpful resource in preparing them to involve family members, as the entire sample of SLPs in this study (100%) endorsed that this was ‘somewhat’ or ‘very’ helpful (item 7a). One SLP commented on the value of time in enabling her to gain the experience needed to work with family members: “Well, I have been a clinician for MANY years, so, I imagine there is no substitute for experience.” Another also noted that “Much of the way to interact with families came from experience working with families…” SLPs also reported on the helpfulness of other resources in preparing them to involve family members in treatment. A majority of SLPs (92.7%) endorsed that attendance at continuing education events was ‘somewhat’ or ‘very’ helpful (item 7b). Moreover, many SLPs (86.4%) agreed that reading peer-reviewed research articles was a ‘somewhat’ or ‘very’ helpful resource (item 7d) as was reading publications that were not peer-reviewed (84.6%). Learning from colleagues about ways to support family members was also helpful to some extent, with 97.3% of SLPs endorsing this (item 7c). Regarding graduate school training, a majority of SLPs (75.5%) felt that their clinical practicum training (item 7e) and the coursework they completed (62.8%, item 7g) during their graduate school program were helpful to a degree, with lower proportions reporting that these experiences were ‘very’ helpful.

Overall, SLPs perceived that the clinical work experiences they gained over time as well as learning from colleagues were the most helpful resources in preparing them to work with families. Continuing education events and reading peer-reviewed articles were also helpful resources. On the other hand, the knowledge and clinical experiences they gained from their graduate program were less helpful in supporting them to engage in this practice.

Chapter 4. DISCUSSION

In this section, a summary of the findings from this study will be reported and connected with prior literature. Then, a discussion of the clinical implications of this study will be provided. Finally, limitations of this study as well as directions for future research will be described.

4.1 SUMMARY OF FINDINGS

The purpose of this mixed-methods study was to explore the nature and extent of family member involvement in rehabilitation to address communication disorders in people with Parkinson's disease. Specifically, family members' and SLPs' perspectives about family member involvement in treatment were explored to gain a preliminary understanding of how third-party disability might or might not be addressed in rehabilitation. There were three research questions for this study. The first inquired about how family members are currently involved in the treatment program targeting the person with PD. The second asked about how family members' needs in treatment are currently being met. The third explored factors that affect SLPs' involvement of family members in treatment.

There were several key findings from this study. First, family members and SLPs had divergent perspectives regarding family member involvement in treatment. Family members reported having little to no involvement, whereas a majority of SLPs reported involving most, if not all, family members of their clients with PD in treatment. For family members, limited involvement was influenced by reasons such as the high level of independence of the person with PD, lack of awareness of the option to attend treatment sessions, or personal work schedules or obligations that made attendance difficult. On the other hand, a majority of SLPs reported involving the family members of most, if not all, of their caseload of clients with PD. There may be several reasons for these differing views. One reason may be related to the small sample of family members, and that the SLPs who participated in this study may not have worked with the family members in this study. Another reason may be that many of the SLPs in this sample worked with family members of clients who are less independent than the clients represented by the family members in this study. A third reason may be that SLPs' consider that they are 'involving' family members if they extend an invitation to family members, perhaps done via the person with PD. Yet a suggestion raised by participants in this study was that such invitations may not be reaching family members. Perhaps the strongest possible reason to consider is that there may differences in family members' and SLPs' ideas about the meaning of family member involvement in treatment. Family members in this study seemed to convey that to them, involvement in treatment meant not only supporting the person with PD, but also having their own needs met. Given the patterns reported by SLPs in this study, involvement to them may mean largely a focus on having family members help the person with PD. A final possible explanation to consider would relate to an artifact of this study in that SLPs in this sample may have reported involving a high percentage of family members because of response bias (purposeful or not) influencing them to reflect positively on their clinical practices – although again because a direct comparison was not made between perceptions of involvement between clinician-family pairs, this point is conjecture. However, one SLP who participated in a cognitive interview during the piloting process of the survey instrument used in this study did suggest this response bias could be an influence.

Despite the divergent reports, a convergent finding was that when family members were included in treatment, it was primarily for the purpose of enhancing treatment outcomes to improve the communication abilities of the person with PD. Family members reported that their involvement in treatment was primarily to support communication for the person with PD such as by helping with completion of home exercises. From the SLPs' perspective, inclusion of family members consisted of various activities such as: consulting with them about the communication abilities of the person with PD; reaching out to family members and inviting them to attend at least a few treatment sessions; providing educational materials about the communication changes or some aspect of treatment; and training family members to help with home practice exercises. Many SLPs also felt that family members were open to attending treatment sessions, but family members' personal schedules were a potential a barrier. Despite this, many SLPs held views to suggest that they were receptive to including family members and meeting their specific needs, and family members and clients were also receptive to this idea. While there is limited literature regarding the involvement of family members in the rehabilitation process for communication disorders, Sherratt et al. (2011) reported similar findings about family members of people with aphasia. They noted that family members discussed limited time or experiences of exhaustion as reasons why they did not participate in treatment. Furthermore, family members in this study requested for more information from treatment, and this was in contrast to the findings that Forsgren et al. (2013) reported. They found that family members were either satisfied with the amount of information they received or felt that too much information was provided from treatment.

The second finding from this study revealed that there was also a range in the perspectives of family members and SLPs with regard to meeting the needs specific to family members in treatment. For some family members, treatment met their need for the person with PD to communicate more effectively and to be understood. However, family members needed more supports than what they received to enhance the communication abilities for the person with PD. To address this, they requested additional information beyond what they were given about the communication disorders or about treatment. This was consistent with the findings that Miller et al. (2011) reported regarding family members' desire for additional information.

Perhaps the most salient finding in the current study pertained to family members' own personal needs for help managing the challenging communication dynamics that existed between them and the person with PD. These family members' wishes for therapy are consistent with documentation of third-party disability in a prior study (Mach et al., under review). To address this, family members suggested that SLPs could provide them with strategies for communicating with the person with PD in a way that minimized displays and experiences of irritation or frustration. They also expressed a need to be referred for additional supports such as mental health counseling or support groups. SLPs reported on the different activities that they participated in to meet family members' needs in treatment, with some activities being more common than others. The primary activity that most SLPs participated in was consulting with most family members about how the communication changes in the person with PD affected their daily lives. However, only a small proportion of SLPs wrote goals specifically targeting the needs of family members, although they did report counseling family members with regard to coping with the communication changes in the person with PD in their daily lives. Many of the findings in this current study corresponded with the findings from prior literature. For example, Howe et al. (2012) and Miller et al. (2011) also found that family members wanted additional sources of professional or informal support to manage their own emotions. Furthermore, Sherratt et al. (2011) also reported that few SLPs had goals for family members of people with aphasia but many counseled family members to cope with the communication changes.

Although family members did not differentiate between the type of communication disorder when describing their involvement in treatment, a third finding from this study demonstrated similarities and differences in SLPs' practices when treating dysarthria versus cognitive-communication disorders. In general, a smaller proportion of SLPs included most, if not all, family members when treating cognitive-communication disorders than they did when treating dysarthria. Examples of some of the activities for which SLPs engaged family members less when the clients with PD had cognitive-communication disorders were consulting with family members about the communication abilities in the person with PD, involving them in conversation when goal setting, or directing families to additional supports such as mental health counseling or support groups. However, there were a few instances in which a higher proportion of SLPs involved family members of people with cognitive-communication disorders than they did with dysarthria. In these instances, more SLPs included family members in activities related to training of home practice programs, reaching out specifically to family members and providing them with opportunities to talk about their concerns without the person with PD present, and writing goals specifically targeting the needs of family members. One possible reason for this may be that cognition has a greater impact on family members that contributes to caregiver burden (Mosley et al., 2017), and SLPs may recognize this and attempt to support these family members in treatment.

The fourth key finding from this study demonstrated that there were several factors influencing SLPs' practice to involve family members in treatment. Regarding their views about this issue, findings seemed to suggest that a majority of SLPs held positive opinions about involving family members in treatment. They also had positive perceptions about family members' and clients' beliefs and preferences to include family members. However, SLPs held mixed opinions about the environmental characteristics of their work settings that influenced their practice. Many SLPs held the perception that their work setting supported their time to work with family members and provided supports specifically for family members. However, when asked about assistance in the form of support groups particularly on the issue of communication or swallowing disorders for family members, few SLPs indicated that these were offered at their work setting. Many SLPs also felt that limitations with insurance reimbursement made it difficult to include family members in treatment. These findings suggest that organizations are adopting some practices for family-centered care, but the range of practices may not yet be fully implemented. In connection to prior literature, Johansson et al. (2011) found that time constraints were reported as the most common reason SLPs did not include family members of people with aphasia in treatment. This conflicted with the findings from this current study because SLPs in this study reported that their work setting supported their time to involve family members, which suggests that time was not necessarily a constraint.

A final key finding was that the vast majority of SLPs perceived various resources as being helpful in preparing them to involve family members in treatment. Most helpful were the clinical experiences they gained over time. Learning from colleagues about ways to support family members and attending continuing education events were also rated as helpful. A majority of SLPs perceived that resources such as reading peer-reviewed research articles and reading publications that were not peer-reviewed were helpful in preparing them to involve family members. However, SLPs held mixed views about the evidence base. A majority of SLPs felt that there is strong evidence to demonstrate the role that family members have in treatment, but only about half believed that the evidence base guided their practice on ways to address the needs specific to family members. Finally, the clinical experiences and coursework from SLPs' graduate programs were the least helpful of resources that were asked in this survey to prepare them for involving family members in treatment.

4.2 CLINICAL IMPLICATIONS

Given experiences of third-party disability in family members of people with communication disorders associated with PD, a family-centered approach to treatment would be critical for improved outcomes from treatment for the person with PD as well as for family members (Mach et al., 2018). Prior literature supports this argument for family-centered care. Bamm and Rosenbaum (2008) explored the foundations of family-centered care in rehabilitation for adults, and the IPFCC (2017) also proposed that such care should be delivered to delivering such care for family members. Regarding the clinical implications from this current study, people with PD should continue to remain as the primary client of interest in treatment. However, rather than including family members as a secondary client primarily to support outcomes for the person with PD in the rehabilitation process, SLPs should consider shifting more attention towards family members as individuals with their own unique needs. One way to address this is by writing goals to target family members' needs for improving communication between them and the person with PD, similar to what is recommended for people with aphasia (Howe et al., 2012). While family members may already receive information about ways to support communication for the person with PD, they can also be provided with additional information in the form of education groups that reinforce their valuable role as the "interlocuter" (Miller et al., 2011, p. 186) in communication interactions. Further, information about how to support communication for the person with PD, as well as invitations to treatment sessions, should be communicated directly to family members. Arguably one of the most valuable ways to address experiences of third-party disability in family members of people with

PD is by first acknowledging that third-party disability exists. Then, SLPs can work with family members and the client with PD to address those experiences by developing ways to manage the challenging communication interactions that are present.

Questions remain, however, about the standard for involving family members in treatment. It may not be clinically feasible for SLPs to involve all family members of all of their clients for various reasons such as the independence level or severity of impairments in the person with PD and the availability of family members. Furthermore, not all family members experience third-party disability associated with the communication changes in PD. The preferences of the person with PD should also be respected such that if they do not want family members to be involved, then this should be honored. Finally, a shift in the healthcare system from an administrative and financial standpoint will be crucial to enforcing a family-centered approach to treatment that meets the needs of the person with PD as well as their family members.

4.3 LIMITATIONS

There are several limitations to this study. Findings were largely influenced by family member qualitative data because items for the SLP survey were developed based on preliminary analysis of family member data. Thus, findings from the survey may not have represented the full spectrum of SLPs' perspectives regarding their clinical practices to include family members in treatment because there may be issues that were not raised by family member participants.

Another limitation for this study relates to the methods for sampling. A convenience sample was used when recruiting family member and SLP participants. Thus, findings may not be representative of the population, and this affects generalizability of results. Regarding the sample of family members, since there were nine participants, there is the potential that saturation of findings was not reached. A deeper exploration into the experiences of family members throughout the rehabilitation process using different sampling methods and a larger sample size could ensure saturation of findings. Regarding the sample of SLPs, a comprehensive understanding of SLPs' practice patterns may not have been captured as a majority worked in outpatient hospital settings, but few worked in other settings such as home health agencies. This is important to understand because there may be differences in SLPs' practice patterns depending on the setting where they are employed. Furthermore, facilitators and barriers affecting SLPs' practice patterns may also differ depending on the setting. Thus, using more rigorous sampling methods would enhance depth of findings and increase generalizability of findings.

4.4 FUTURE DIRECTIONS

Multiple considerations should be made for future research. Because a survey method was used to gather information about SLPs' perspectives and practices regarding including family members in rehabilitation, future research can use qualitative methods to gain deeper insight into the experiences of SLPs in their clinical practice. Given that findings from surveys are limited to the questions asked, qualitative methods give researchers the opportunity to learn of SLPs' lived experiences in their daily clinical routines, including how they involve family members in treatment. SLPs can provide their viewpoints about addressing third-party disability through family member involvement in treatment in a manner that is open-ended, unlike the restricted findings gathered from survey question items. Furthermore, research should continue to involve family members and SLPs while also including other key stakeholders such as the person with PD, healthcare administrators, or policymakers. Engaging various key stakeholders in research allows for a more holistic picture about facilitators and barriers that influence SLPs' provision of family-centered care to address third-party disability. Finally, using research methodologies such as mixed-methods or community-based participatory research while including key stakeholders in the process will be crucial for development of interventions or programs that not only meets the needs of family members and people with PD to address third-party disability but that SLPs could also feasibly adopt and implement in their practice settings. By considering the above areas for future research, there can be improved treatment outcomes and healthcare policies can be influenced such that adoption of a family-centered approach to treatment can be reinforced.

There needs to be a shift towards family-centered care to address third-party disability as this is a current gap between research and practice. As one SLP commented: “Participating in this survey helped me to realize that I have neglected a very important part of treatment - seeing my patient as a whole person,” and one family member further elaborated, “It would be nice if it [speech therapy] was recognized as a family issue” (FM3).

REFERENCES

Bamm, E. L., & Rosenbaum, P. (2008). Family-Centered Theory: Origins, Development, Barriers, and Supports to Implementation in Rehabilitation Medicine. *Archives of Physical Medicine and Rehabilitation*, *89*(8), 1618–1624. https://doi.org/10.1016/j.apmr.2007.12.034

Carter, J. H., Stewart, B. J., Archbold, P. G., Inoue, I., Jaglin, J., Lannon, M., … Zoog, K. (1998). Living with a person who has Parkinson's disease: The Spouse's perspective by stage of disease. *Movement Disorders*, *13*(1), 20–28. https://doi.org/10.1002/mds.870130108

Cedarbaum, J. M., Stambler, N., Malta, E., Fuller, C., Hilt, D., Thurmond, B., & Nakanishi, A. (1999). The ALSFRS-R: a revised ALS functional rating scale that incorporates assessments of respiratory function. *Journal of the Neurological Sciences*, *169*(1–2), 13–21. https://doi.org/10.1016/S0022-510X(99)00210-5

Creasy, K. R., Lutz, B. J., Young, M. E., & Stacciarini, J.-M. R. (2015). Clinical Implications of Family-Centered Care in Stroke Rehabilitation. *Rehabilitation Nursing: The Official Journal of the Association of Rehabilitation Nurses*, *40*(6), 349–359. https://doi.org/10.1002/rnj.188

Creswell, J. W., & Plano Clark, V. L. (2010). *Designing and conducting mixed methods research* (2nd edition). Thousand Oaks, CA: Sage.

Forsgren, E., Antonsson, M., & Saldert, C. (2013). Training conversation partners of persons with communication disorders related to Parkinson's disease—a protocol and a pilot study. *Logopedics Phoniatrics Vocology*, *38*(2), 82–90. https://doi.org/10.3109/14015439.2012.731081

Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2013a). A qualitative investigation into third-party functioning and third-party disability in aphasia: Positive and negative experiences of family members of people with aphasia. *Aphasiology*, *27*(7), 828–848. https://doi.org/10.1080/02687038.2013.768330

Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2013b). Third-party disability in family members of people with aphasia: A systematic review. *Disability and Rehabilitation: An International, Multidisciplinary Journal*, *35*(16), 1324–1341. https://doi.org/10.3109/09638288.2012.735341

Greene, J. C., Caracelli, V. J., & Graham, W. F. (1989). Toward a conceptual framework for mixed-method evaluation designs. *Educational Evaluation and Policy Analysis*, *11*(3), 255–274.

Howe, T., Davidson, B., Worrall, L., Hersh, D., Ferguson, A., Sherratt, S., & Gilbert, J. (2012). 'You needed to rehab … families as well': Family members' own goals for aphasia rehabilitation. *International Journal of Language & Communication Disorders*, *47*(5), 511–521. https://doi.org/10.1111/j.1460-6984.2012.00159.x

Hsieh, H.-F., & Shannon, S. E. (2005). Three Approaches to Qualitative Content Analysis. *Qualitative Health Research*, *15*(9), 1277–1288. https://doi.org/10.1177/1049732305276687

Institute for Patient and Family-Centered Care. (2017). Advancing the Practice of Patient- and Family-Centered Care in Hospitals: How to Get Started. Retrieved July 3, 2018, from http://www.ipfcc.org/

Johansson, M. B., Carlsson, M., & Sonnander, K. (2011). Working with families of persons with aphasia: a survey of Swedish speech and language pathologists. *Disability and Rehabilitation*, *33*(1), 51–62. https://doi.org/10.3109/09638288.2010.486465

Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry.* New York, NY: Sage.

Lindkvist, K. (1981). Approaches to textual analysis. In *In K.E. Rosengren (Ed.) Advances in content analysis* (pp. 23–41). Beverly Hills, CA: Sage.

Mach, H., Baylor, C., Hunting Pompon, R., & Yorkston, K. (2018). Third-party disability in family members of people with communication disorders associated with Parkinson's disease. *Topics in Language Disorders*, Manuscript submitted for publication.

Martin, S. C. (2015). Psychosocial challenges experienced by partners of people with Parkinson disease. *Journal of Neuroscience Nursing*, *47*(4), 211–222. https://doi.org/10.1097/JNN.0000000000000141

McLaughlin, D., Hasson, F., Kernohan, W. G., Waldron, M., McLaughlin, M., Cochrane, B., & Chambers, H. (2011). Living and coping with Parkinson's disease: perceptions of informal carers. *Palliative Medicine*, *25*(2), 177–182. https://doi.org/10.1177/0269216310385604

Merriam, S. B. (2009). *Qualitative Research: A Guide to Design and Implementation* (3rd edition). San Francisco: Jossey-Bass.

Miller, N., Noble, E., Jones, D., Deane, K. H. O., & Gibb, C. (2011). Survey of speech and language therapy provision for people with Parkinson's disease in the United Kingdom: patients' and carers' perspectives. *International Journal of Language & Communication Disorders*, 100824014249025. https://doi.org/10.3109/13682822.2010.484850

Mosley, P. E., Moodie, R., & Dissanayaka, N. (2017). Caregiver Burden in Parkinson Disease: A Critical Review of Recent Literature. *Journal of Geriatric Psychiatry and Neurology*, *30*(5), 235–252. https://doi.org/10.1177/0891988717720302

Nund, R. L., Scarinci, N. A., Cartmill, B., Ward, E. C., Kuipers, P., & Porceddu, S. V. (2016). Third-party disability in carers of people with dysphagia following non-surgical management for head and neck cancer. *Disability and Rehabilitation*, *38*(5), 462–471. https://doi.org/10.3109/09638288.2015.1046563

Scarinci, N., Worrall, L., & Hickson, L. (2009). The ICF and third-party disability: its application to spouses of older people with hearing impairment. *Disability and Rehabilitation*, *31*(25), 2088–2100.

Scarinci, Nerina, Worrall, L., & Hickson, L. (2012). Factors Associated With Third-Party Disability in Spouses of Older People With Hearing Impairment: *Ear and Hearing*, *33*(6), 698–708. https://doi.org/10.1097/AUD.0b013e31825aab39

Sherratt, S., Worrall, L., Pearson, C., Howe, T., Hersh, D., & Davidson, B. (2011). “Well it has to be language-related”: speech-language pathologists’ goals for people with aphasia and their families. *International Journal of Speech-Language Pathology*, *13*(4), 317–328. https://doi.org/10.3109/17549507.2011.584632

Tashakkori, A., & Teddlie, C. (2003). *Handbook of Mixed Methods in Social and Behavioral Research.* Thousand Oaks, CA: Sage Publications.

Thommessen, B., Aarsland, D., Braekhus, A., Oksengaard, A. R., Engedal, K., & Laake, K. (2002). The psychosocial burden on spouses of the elderly with stroke, dementia and Parkinson’s disease. *International Journal of Geriatric Psychiatry*, *17*(1), 78–84.

Threats, T. (2010). The ICF framework and third party disability: application to the spouses of persons with aphasia. *Topics in Stroke Rehabilitation*, *17*(6), 451–457.

World Health Organization. (2001). *International Classification of Functioning, Disability and Health*. Geneva: World Health Organization. Retrieved from http://www.who.int/classifications/icf/icfbeginnersguide.pdf?ua=1

APPENDIX A: QUALITATIVE INTERIVEW GUIDE

Introduction

Hello, my name is Helen Mach and I am a doctoral student at the University of Washington. I would like to learn about the experiences and perspectives of family members who are living with a person with communication impairments associated with Parkinson's disease. I would also like to learn more specifically about how the communication challenges in your family member might impact you on a day-to-day basis. I am interested in this topic because I would like for speech-language pathologists to not only support communication in the person with Parkinson's disease, but also to involve family members in treatment and determine what SLPs can do to support the needs of family members as unique individuals in the treatment process.

There are no immediate benefits to family member participants. However, this data will be used to inform the practices of SLPs to better serve individuals with Parkinson's disease as well as family members during treatment. Risks of participating in this study may include sharing of stories that trigger difficult emotions.

We will make every effort to maintain confidentiality and anonymity to participants. Names of participants and any identifying information such as location of residence will be removed from audio recordings and interview notes.

Interviews will take approximately one to one and half hours long and will occur over one session. Consent to collect audio recordings via an audio recorded will be obtained before collecting the audio recordings. We would like to learn about your experiences about how the communication challenges in your family member with PD has impacted (or not impacted) you. Please feel free to share stories or give examples of situations as you participate in this interview.

Grand tour question: Describe to me what your experiences are like as your family member's communication has started to change.

Probe Areas

1. **Communication impact on family:** What does communication look like between you and your family member in your day-to-day life?
2. **Progress of communication changes:** Can you describe how the progression of the speech changes in PD has affected your communication with each other? Progression of communication challenges impacting your daily routine?
3. **Changes in day-to-day life:** How have changes in communication affected your daily routine (e.g., making accommodations to support the family member with PD) as PD has progressed?
4. **Perspectives about communication with family member with PD:** What are your thoughts (or feelings) about those experiences with communication?
5. **Support for communication:** Can you describe the types of support for communication you give to your family member with PD?
6. **Communication settings:** What does communication look like for you in social settings where your family member is also present? Home setting? Social settings/network? Out in the community running errands? Doctor's appointments?

7. **Coping/resilience with communication challenges:** In your interactions with your family member with PD, describe things you do differently, if any, to deal with the communication challenges.
8. **Speech treatment perspectives:** What did you find was particularly helpful/not helpful from speech therapy to meet your needs or desires as the family member?
9. **Speech treatment experiences:** What are your experiences with being or not being involved in speech therapy sessions? What types of support have you received for communication, if any, during therapy sessions?
10. **Therapist characteristics**: Can you describe interactions with SLPs that you found to be helpful or not helpful as part of treatment? Describe how they included or did not include you in therapy?
11. **Therapist recommendations:** If you could give recommendations to SLPs about how you would like (or not like) to be included in the treatment process, what might they be?
12. **Treatment content:** What ideas do you have about what you would like to be addressed from speech therapy for you as the family member? More education about PD? Strategies for communication? Etc.?

Ending: Is there anything else you would like to share about your experiences with living with a person with Parkinson's disease who has communication impairments associated with this condition?

APPENDIX B: DEMOGRAPHIC DATA COLLECTION FORM

Directions: There are **two questionnaires** to complete. The first questionnaire asks about **you** and the second one asks about **your family member with PD**. For each question below, please mark the answer that best describes you. You may also skip any question you do not feel comfortable completing.

Basic Information About Self

Age: ________

Gender:
☐ Male
☐ Female

Race/Ethnic Group:
☐ American Indian/Alaskan Native
☐ Asian
☐ Native Hawaiian or other Pacific Islander
☐ Black or African American
☐ White (Caucasian)
☐ Hispanic or Latino
☐ More than one
☐ Other: ______________________________

Relationship with person with PD:
☐ Spouse/long-term domestic partner
☐ Child
☐ Extended family member (please specify: ______________________________)
☐ Friend
☐ Other: ______________________________

In addition to your family member with PD, with whom do you currently live:
☐ I live with ONLY the person with PD
☐ Other family (e.g, children, other relatives)
☐ Friends
☐ Assisted Living or Adult Family Home
☐ Other: ___________________________________

Employment Status (Please check ALL that apply):

☐ Working full-time for pay outside the home
☐ Working part-time for pay outside the home

☐ Working for pay in home-based business
☐ Working as volunteer
☐ Working at home as a homemaker, stay-at-home parent, or care provider for other family members
☐ Attending school full-time
☐ Attending school part-time
☐ Retired
☐ Retired to provide care for family member
☐ Not working for other reasons: ____

What is/was your occupation? ____

Do you have any problems with your hearing? Please choose the statement that best describes you:

☐ I do not have problems with my hearing
☐ I do have problems with my hearing, but I do NOT wearing hearing aids or use other assistive devices
☐ I do have problems with my hearing, and I DO wearing hearing aids or use other assistive devices

Do you have any other medical conditions that, in your opinion, affect your participation in day-to-day activities?

☐ No
☐ Yes. Please describe: ____

Basic Information About Your Family Member with PD

Age: ________

Gender:

☐ Male
☐ Female

Race/Ethnic Group:

☐ American Indian/Alaskan Native
☐ Asian
☐ Native Hawaiian or other Pacific Islander
☐ Black or African American
☐ White (Caucasian)
☐ Hispanic or Latino
☐ More than one
☐ Other: _______________________________

Employment Status of family member (Please check ALL that apply):

- ☐ Working full-time for pay outside the home
- ☐ Working part-time for pay outside the home
- ☐ Working for pay in home-based business
- ☐ Working as volunteer
- ☐ Working at home as a homemaker, stay-at-home parent, or care provider for other family members
- ☐ Attending school full-time
- ☐ Attending school part-time
- ☐ Retired
- ☐ Retired to provide care for family member
- ☐ Not working for other reasons: ____

What is/was your family member's occupation? ____

What is the primary method of communication your family member uses to communicate?

- ☐ Speech
- ☐ Writing
- ☐ Augmentative device such as communication board or notepad
- ☐ Computerized augmentative device
- ☐ Other devices or strategies: ____________________________________

Does your family member have any problems with hearing? Please choose the statement that best describes him/her:

- ☐ He/she do not have problems with his/her hearing
- ☐ He/she does have problems with his/her hearing, but he/she does NOT wearing hearing aids or use other assistive devices
- ☐ He/she does have problems with his/her hearing, and he/she DOES wearing hearing aids or use other assistive devices

Which statement best describes the **speech** of your family member with PD? (Check ONE box.)

- ☐ Normal
- ☐ Sounds different but people understand him/her
- ☐ Sometimes have to repeat words to be understood
- ☐ Use gestures, writing or drawing to help people understand his/her speech
- ☐ Not understandable; He/she does not use speech for communication

When was your family member diagnosed with PD? ____________________________________

When did your family member pursue speech therapy? __________________________________

Approximately how long did speech therapy last (e.g., one month, 6 months, etc.)?

____

Please describe the general content of the speech therapy sessions (e.g. LSVT, worked on voice, articulation of sounds, finding words, etc.).

____

____

____

APPENDIX C: QUALITATIVE CODEBOOK

Titles of Codes and definitions are reported below:

Communication disorder characteristics
Characteristics of the communication disorders of the IwPD. (Note: no need to recode in same interview if comes up multiple times)

Communication disorder impact on family
Instances in which the communication disorder impacts (or doesn't impact) the family member. (e.g., light sleeping in order to hear person with PD in middle of the night). Also includes any emotional impacts. Can double code with "strategies for communication" only if family members report an emotional reaction in having to use strategies to support communication (e.g., frustrated with having to translate for IwPD).

Communication disorder impact on the IwPD
Family member perceptions about the impacts including emotional or psychological impacts (e.g., confidence, autonomy, independence, withdrawing, isolating, etc.) of the communication disorder on the IwPD.

Communication Situations
Any descriptions the family member provides about communication encounters or different types of social communication situations

Family involvement in speech Tx
Any experiences family members report about speech therapy including interactions with SLPs, practicing with IwPD outside of Tx sessions at home, etc. Also includes family discussion of no involvement with Tx sessions, etc.

Family member opinions about speech Tx
Includes any family member’s thoughts or perceptions about speech Tx itself and/or about the IwPD’s experiences or participation in speech Tx as well as tx outcomes for themselves and/or the IwPD (e.g., IwPD continues to use the speech strategies and they really help). Also includes family member comments about personalities, expertise, skills, traits (including lack thereof), etc. of SLPs. Also includes traits that family members would like to see from SLPs to include families in tx. Anything family members would like to see of speech tx will be coded under this.

Family suggestions for improvement
Any suggestions family members have to improve speech tx for the IwPD and suggestions to include family members into speech tx.

Other influences on communication
Can include health conditions of either the family member or IwPD that affect communication, environmental factors, the need for hearing aids, other communication partners besides the dyad

of IwPD and the family member, etc. Any non-speech factors (e.g., personality of IwPD) that affect communication.

Speech Tx content for IwPD

Content of therapy to target communication or cognition specifically for the IwPD. Family member comments that they are unsure about content is also included here.

Starting speech Tx

Anything about how family and/or IwPD found out about speech tx, decisions to start speech tx, process of getting started, etc.

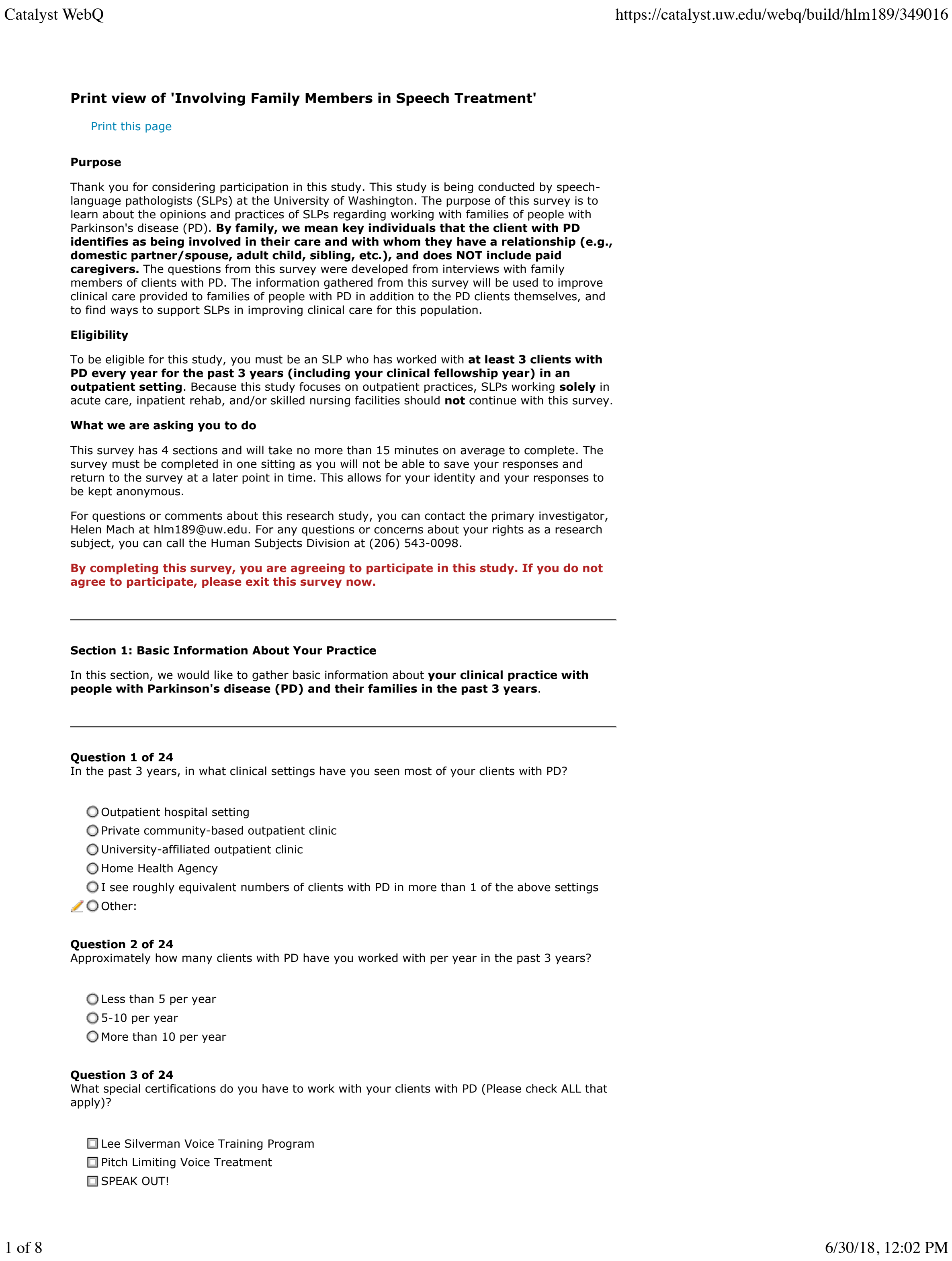
Strategies for communication

Any strategies families use to manage or support communication (including either speech or cognition) between themselves and/or other communication partners with the IwPD. Also includes ways that family members try to protect the dignity or autonomy of the IwPD for communication. If family member discusses strategies in a way that emotionally impacts them (e.g., frustrated they have to do that), then double code with CD impact on family member.

Swallowing issues

Comments family member makes about swallowing difficulties (be sure to double code if it overlaps with communication in any way).

APPENDIX D: SLP SURVEY



Print view of 'Involving Family Members in Speech Treatment'

Print this page

Purpose

Thank you for considering participation in this study. This study is being conducted by speech-language pathologists (SLPs) at the University of Washington. The purpose of this survey is to learn about the opinions and practices of SLPs regarding working with families of people with Parkinson's disease (PD). **By family, we mean key individuals that the client with PD identifies as being involved in their care and with whom they have a relationship (e.g., domestic partner/spouse, adult child, sibling, etc.), and does NOT include paid caregivers.** The questions from this survey were developed from interviews with family members of clients with PD. The information gathered from this survey will be used to improve clinical care provided to families of people with PD in addition to the PD clients themselves, and to find ways to support SLPs in improving clinical care for this population.

Eligibility

To be eligible for this study, you must be an SLP who has worked with **at least 3 clients with PD every year for the past 3 years (including your clinical fellowship year) in an outpatient setting**. Because this study focuses on outpatient practices, SLPs working **solely** in acute care, inpatient rehab, and/or skilled nursing facilities should **not** continue with this survey.

What we are asking you to do

This survey has 4 sections and will take no more than 15 minutes on average to complete. The survey must be completed in one sitting as you will not be able to save your responses and return to the survey at a later point in time. This allows for your identity and your responses to be kept anonymous.

For questions or comments about this research study, you can contact the primary investigator, Helen Mach at hlm189@uw.edu. For any questions or concerns about your rights as a research subject, you can call the Human Subjects Division at (206) 543-0098.

By completing this survey, you are agreeing to participate in this study. If you do not agree to participate, please exit this survey now.

Section 1: Basic Information About Your Practice

In this section, we would like to gather basic information about **your clinical practice with people with Parkinson's disease (PD) and their families in the past 3 years**.

Question 1 of 24
In the past 3 years, in what clinical settings have you seen most of your clients with PD?

○ Outpatient hospital setting
○ Private community-based outpatient clinic
○ University-affiliated outpatient clinic
○ Home Health Agency
○ I see roughly equivalent numbers of clients with PD in more than 1 of the above settings
○ Other:

Question 2 of 24
Approximately how many clients with PD have you worked with per year in the past 3 years?

○ Less than 5 per year
○ 5-10 per year
○ More than 10 per year

Question 3 of 24
What special certifications do you have to work with your clients with PD (Please check ALL that apply)?

☐ Lee Silverman Voice Training Program
☐ Pitch Limiting Voice Treatment
☐ SPEAK OUT!

☐ None
☐ Other:

Question 4 of 24
With what percentage of your clients with PD **do you use** the following programs?

Please use this chart to help guide you in your responses.

None	None of your clients
Few	25% or less of your clients
Many	Approximately 50% of your clients
Most	75% or more of your clients
All	All of your clients

Rows
Lee Silverman Voice Training Program
Pitch Limiting Voice Treatment
SPEAK OUT!

○ None
○ Few (≤25%)
○ Many (Approx. 50%)
○ Most (≥75%)
○ All

Question 5 of 24
Please describe other programs you use that were not listed in the previous question (if any). Also indicate with what percentage of your clients with PD you use these other programs.

Section 2: What You Do/Don't Do in Your Practice with Family Members

In the following sections, we will ask about your clinical practices in the areas of dysarthria, cognitive-communication, AAC, and dysphagia with your clients with PD. In each section, we will first ask about the percentage of clients for whom you write goals in that area. Then, we will ask a series of questions about your work specifically related to working with family members if they apply.

Please answer these questions based **on the percentage of ALL clients with PD with whom you work** regardless of what goals you are working on or whether or not family are involved.

We acknowledge that family involvement in therapy can vary widely for many reasons. For example, you may or may not have the opportunity to see family members, you may have limited resources, there is variability in the clinical needs of your client with PD (e.g, severity, life situations), etc. Regardless, we just want to get an **accurate idea of what happens in your practice**. This will help us consider what percentage of **all** your clients with PD **actually receive** these services. In section 3, we will ask you questions about factors that make it easy or difficult to involve families in treatment.

Question 6 of 24
For approximately **what percentage of your clients do you write goals** to specifically address **management of dysarthria (including voice concerns)**?

Please use this chart to guide you in your responses.

None	None of your clients
Few	25% or less of your clients
Many	Approximately 50% of your clients
Most	75% or more of your clients
All	All of your clients

	Logic destinations
○ None	➪ Question 8: For approximately what perc...
○ Few (≤25%)	➪ Don't skip (default)
○ Many (Approx. 50%)	➪ Don't skip (default)
○ Most (≥75%)	➪ Don't skip (default)

○ All	⇨ Don't skip (default)
No response	⇨ Don't skip (default)

Question 7 of 24
When working with your clients on goals related to **dysarthria (including voice concerns)**, with what **percentage of your clients** do you do the following?

Please use this chart to help guide you in your responses.

None	None of your clients
Few	25% or less of your clients
Many	Approximately 50% of your clients
Most	75% or more of your clients
All	All of your clients

Rows

I ask family members about how their communication is going with my clients with PD.

I ask family members how communication is going between my clients with PD and other people.

I ask family members how their everyday lives have changed because of the dysarthria in my clients with PD.

I reach out specifically to family members to provide them with opportunities to talk with me separately about their concerns.

I specifically reach out to family members to invite them to attend at least a few therapy sessions.

I include family members in the conversation when choosing goals for my clients with PD in treatment.

I write goals specifically targeting the needs of family members.

I work together with family members and my clients with PD on how to avoid or fix communication breakdowns in everyday life.

I train family members to help with home practice for treatment carryover.

I provide educational materials to family members regarding communication changes and/or therapy for my clients with PD.

I counsel family members regarding coping with the communication changes in my clients with PD in their everyday lives.

I direct families to additional supports/resources (e.g., mental health counseling, support groups, respite care, community resources, etc.) when appropriate.

I recommend to older family members to have their hearing checked.

○ None
○ Few (≤25%)
○ Many (Approx. 50%)
○ Most (≥75%)
○ All

Question 8 of 24
For approximately **what percentage of your clients do you write goals** to specifically address management of **cognitive-communication disorders**?

Please use this chart to guide you in your responses.

None	None of your clients
Few	25% or less of your clients
Many	Approximately 50% of your clients
Most	75% or more of your clients
All	All of your clients

	Logic destinations
○ None	⇨ Question 10: For approximately what perc...
○ Few (≤25%)	⇨ Don't skip (default)
○ Many (Approx. 50%)	⇨ Don't skip (default)
○ Most (≥75%)	⇨ Don't skip (default)
○ All	⇨ Don't skip (default)
No response	⇨ Don't skip (default)

Question 9 of 24

When working with your clients on goals related to **cognitive-communication**, with **what percentage of your clients** do you do the following?

Please use this chart to help guide you in your responses.

None	None of your clients
Few	25% or less of your clients
Many	Approximately 50% of your clients
Most	75% or more of your clients
All	All of your clients

Rows
I ask family members about how their communication is going with my clients with PD.
I ask family members how communication is going between my clients with PD and other people.
I ask family members how their everyday lives have changed because of the cognitive difficulties in my clients with PD.
I reach out specifically to family members to provide them with opportunities to talk with me separately about their concerns.
I include family members in the conversation when choosing goals for my clients with PD in treatment.
I write goals specifically targeting the needs of family members.
I work together with family members and my clients with PD on everyday cognitive-communication challenges.
I train family members to help with home practice for treatment carryover.
I provide educational materials to family members regarding cognitive-communication changes and/or therapy for my clients with PD.
I counsel family members regarding coping with the cognitive-communication changes with my clients with PD in their everyday lives.
I direct families to additional supports/resources (e.g., mental health counseling, support groups, respite care, community resources, etc.) when appropriate.

○ None
○ Few (≤25%)
○ Many (Approx. 50%)
○ Most (≥75%)
○ All

Question 10 of 24
For approximately **what percentage of your clients do you write goals** to specifically address management of **alternative-augmentative communication (AAC)**? (By AAC, we mean any high or low tech devices as well as low tech communication boards, picture exchange systems, etc.)

Please use this chart to guide you in your responses.

None	None of your clients
Few	25% or less of your clients
Many	Approximately 50% of your clients
Most	75% or more of your clients
All	All of your clients

	Logic destinations
○ None	⇨ Question 12: For approximately what perc...
○ Few (≤25%)	⇨ Don't skip (default)
○ Many (Approx. 50%)	⇨ Don't skip (default)
○ Most (≥75%)	⇨ Don't skip (default)
○ All	⇨ Don't skip (default)
No response	⇨ Don't skip (default)

Question 11 of 24
When working with your clients on goals related to **AAC**, with **what percentage of your clients** do you do the following?

Please use this chart to help guide you in your responses.

None	None of your clients
Few	25% or less of your clients

Many	Approximately 50% of your clients
Most	75% or more of your clients
All	All of your clients

Rows

I ask family members about how their communication is going with my clients with PD when using AAC.

I ask family members how communication with AAC is going between my clients with PD and other people.

I ask family members how their everyday lives have changed by the need to use AAC.

I reach out specifically to family members to provide them with opportunities to talk with me separately about their concerns with communication using AAC.

I involve family members in selection and customization of AAC approaches.

I train family members and my clients with PD together on how to use AAC.

I work together with family members and my clients with PD to use AAC in everyday life.

I counsel family members regarding coping with severe communication problems.

I direct families to additional supports/resources for AAC (e.g., websites, support groups, community resources).

I refer clients to see an AAC specialist when appropriate.

○ None
○ Few (≤25%)
○ Many (Approx. 50%)
○ Most (≥75%)
○ All

Question 12 of 24
For approximately **what percentage of your clients do you write goals** to specifically address management of **dysphagia**?

Please use this chart to guide you in your responses.

None	None of your clients
Few	25% or less of your clients
Many	Approximately 50% of your clients
Most	75% or more of your clients
All	All of your clients

	Logic destinations
○ None	⇨ Section 3: Factors That Aff...
○ Few (≤25%)	⇨ Don't skip (default)
○ Many (Approx. 50%)	⇨ Don't skip (default)
○ Most (≥75%)	⇨ Don't skip (default)
○ All	⇨ Don't skip (default)
No response	⇨ Don't skip (default)

Question 13 of 24
When working with clients on goals related to **dysphagia**, with **what percentage of your clients** do you do the following?

Please use this chart to help guide you in your responses.

None	None of your clients
Few	25% or less of your clients
Many	Approximately 50% of your clients
Most	75% or more of your clients
All	All of your clients

Rows

I ask family members about how dysphagia in my clients with PD affects their interactions with each other.

I ask family members how their everyday lives have changed because of the dysphagia in my clients with PD.

I reach out specifically to family members to provide them with opportunities to talk with me separately about their concerns.

I specifically reach out to family members to invite them to attend at least a few therapy sessions.

I include family members in the conversation when choosing goals for my clients with PD in treatment.

I write goals specifically targeting the needs of family members.

I work togther with my clients with PD and family members on how to manage swallowing concerns in everyday life.

I provide educational materials to family members that are tailored to the specific symptoms of dysphagia experienced by my clients with PD (e.g., modified diets, aspiration precautions, swallowing exercises).

I counsel family members regarding coping with dysphagia in my clients with PD in their everyday lives.

I direct families to additional supports/resources (e.g., mental health counseling, support groups, respite care, community resources, etc.) when appropriate.

○ None
○ Few (≤25%)
○ Many (Approx. 50%)
○ Most (≥75%)
○ All

Section 3: Factors That Affect Inclusion of Family Members

You are half way through this survey.

The following section is intended to gain information about factors that make it easy or difficult for SLPs to include family members into therapy sessions.

Question 14 of 24
How **helpful or unhelpful** are the following resources related specifically to supporting families of adults with neurologic communication disorders?

Rows

Coursework you completed during your graduate school program

Clinical practicum training you completed during your graduate school program

Reading non peer-reviewed publications (e.g., books, ASHA Leader, etc.)

Reading peer-reviewed research articles (including ASHA SIG articles)

Attending continuing education events (e.g, web-based courses, ASHA conference, workshops, etc.)

Learning from colleagues about ways to support family members

Developing skills/experience over time from your own clinical practice

○ Very helpful
○ Somewhat helpful
○ Not helpful
○ Have not had/used

Question 15 of 24
How **prepared or unprepared** have you felt in your career to address the specific needs of family members of clients with PD?

○ Very prepared
○ Somewhat prepared
○ Neutral
○ Somewhat unprepared
○ Very unprepared

Question 16 of 24
Does your setting offer support groups for family members specifically focusing on communication and/or swallowing issues?

○ Yes
○ No

Question 17 of 24

Please rate the extent to which you **agree or disagree** with each of the following statements about working with families of clients with PD.

Rows

I feel confident supporting the needs of family members as part of the treatment process.

I believe it is appropriate to have goals specifically for family members to support their needs in living with the communication changes in my clients with PD.

My setting supports my time to work with family members (e.g., productivity adjustments, scheduling, etc.)

Limitations in insurance reimbursement or other funding makes it difficult for me to directly address the needs of family members in treatment.

My setting provides supports specifically for family members (e.g., offering support groups, educational classes, educational materials).

I can easily get permission from my clients with PD to reach out to their family members and involve them in treatment.

Family members do not express the desire to participate in speech therapy.

Having family members in therapy sessions interferes with the autonomy of my clients with PD.

My clients with PD do not want the family members in the therapy sessions.

It is difficult for family members to attend therapy sessions due to their own personal obligations or schedules.

There is a strong evidence base to support the role of family members in treatment.

There is an evidence base to guide me in addressing the needs of family members.

Addressing family member goals are specifically part of the protocols of the therapy programs I have been trained to provide.

- ○ Strongly agree
- ○ Somewhat agree
- ○ Somewhat disagree
- ○ Strongly disagree
- ○ Unsure

Question 18 of 24
Please tell us a little bit more about any other thoughts that came to mind as you completed this survey. Any other comments or thoughts (especially those not covered in this survey) you have will help us gain a better understanding about your opinions regarding addressing the needs of families of your clients with PD, your clinical practices to engage in activities to support and include families in treatment, as well as supports and barriers that influence your ability to engage in these activities.

Section 4: A Little More Information About You

In this final section, we would like to gather a little more basic information about you.

Question 19 of 24
My age in years is:

Question 20 of 24
My gender is:

- ○ Male
- ○ Female
- ○ Transgender
- ○ Third gender/non-binary
- ○ Prefer not to answer
- ○ Other:

Question 21 of 24
My race is (Please select all that apply):

- ☐ American Indian/Alaskan Native
- ☐ Asian

☐ Black/African American
☐ Hispanic
☐ Native Hawaiian or other Pacific Islander
☐ White/Caucasian
☐ More than one
☐ I prefer not to answer
☐ Other:

Question 22 of 24
The highest degree I have earned is (Please select all that apply):

○ Bachelor's
○ Master's
○ Clinical Doctorate
○ Doctorate of Philosophy

Question 23 of 24
The number of years of experience I have as an SLP is:

○ <5 years
○ 5-10 years
○ 11-20 years
○ 20+ years

Question 24 of 24
The state where I am currently employed is (If you don't live in the U.S., please indicate what country you live in):

You have reached the end of this survey. If there are other SLPs you know who are eligible to complete this survey, please feel free to pass it along. A link to this survey is as follows: https://catalyst.uw.edu/webq/survey/hlm189/349016

THANK YOU FOR YOUR RESPONSES!