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Exploring the Experiences of Communication Partners of People with Parkinson's Disease: A Qualitative Study

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Exploring the Experiences of Communication Partners of Persons with Parkinson's Disease:

Qualitative Interviews

Minnesota State University Moorhead

By

Jacqueline Bell

In Partial Fulfillment of the

Requirements for the Degree of

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Speech-Language Pathology

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ANNOUNCEMENT OF ORAL EXAMINATION

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Qualitative Interviews

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Thesis Abstract

The purpose of this phenomenological qualitative study was to explore interactions between persons with Parkinson's disease (PD) and their communication partners. People with PD experience difficulties that can have a profound effect on their ability to communicate. This qualitative study explored the thoughts and feelings of primary communication partners of people with PD. The primary communication partners were interviewed using open-ended questions. The seven participants identified and detailed how declines in communication due to PD have resulted in changes in daily life, including; social participation, daily tasks, and psychosocial well-being. Commonalities that communication partners experienced will aid speech-language pathologists to better understand the effects that PD has on communication.

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Chapter 1

Introduction

According to the Parkinson's Foundation (2018), approximately one million Americans and ten million people worldwide are diagnosed with Parkinson's disease (PD). The direct cause of PD is unknown, however, researchers suggest there are direct connections between a genetic predisposition and exposure to environmental factors (Bayles & Tomoeda, 2014). Symptoms of PD can vary among persons with PD, but seem to be caused by a reduction of dopamine in the area of the brain known as the substantia nigra (Yorkston, Miller, & Strand, 2004).

The American Speech-Language-Hearing Association (ASHA, n.d.) has outlined the scope of practice for a speech-language pathologist (SLP) as being able to treat speech, voice, cognitive communication, and swallowing, which are all areas that can be affected by Parkinson's disease. Every case of PD is different and symptoms among patients vary greatly. Recent researchers suggested three onset groups; young onset (≤ 50 years), middle onset (50-69 years), and late onset (≤ 70 years), with the largest group (51%) being in the middle onset group (Mehanna, Moore, Hou, Aliya, & Lai, 2014). No matter the stage in life, PD has a profound effect on a person's ability to communicate (Tippett, Mari, & Rao, 2009).

It can be assumed that each person with PD has at least one primary communication partner, if not more. Whether it is a spouse, parent, child, or friend; the effect on communication is a significant life change for many communication partners. The knowledge SLPs can gain from communication partners of person's with PD is highly valuable in speech-language therapy. Interviewing communication partners allows researchers to learn about the communication difficulties that occur, which strategies have been beneficial and which ones have not, and how

SLPs can better improve communication between people with PD and their communication partners.

A limited number of qualitative studies in the area of PD and communication have been performed. A study by Eriksson, Hartelius, and Saldert (2016) explored certain characteristics observed in conversations with people with communication disorders, including persons with PD. There are also other experimental designs that explore specific repair strategies used for people with PD and other diseases and disorders that cause communication disorders (Griffiths, Barnes, Britten, & Wilkinson, 2015). Due to the limited number of studies, further exploration of the issues related to communication partners of people with PD appears warranted.

The purpose of this qualitative study was to gain information about experiences in communication between communication partners and persons with PD. Information about communication breakdowns, strategies used, and changes in communication could facilitate new ways to approach speech-language pathology intervention for persons with Parkinson's disease.

Chapter 2

Review of Literature

Parkinson's Disease

PD is a progressive disease of the central nervous system, specifically affecting the part of the brain known as the basal ganglia (Yorkston, Miller, & Strand, 2004). PD symptoms are caused by a decrease of dopamine (usually about 50% decrease) in the substantia nigra (Bayles & Tomeoda, 2014). The decrease of dopamine causes a chemical imbalance in the brain that results in the symptoms that classify this disease. There are three symptoms that are associated with PD and are considered the “classic triad of symptoms”: tremor, bradykinesia, and rigidity (Yorkston et al., 2004, p. 87). Other symptoms of PD include difficulty sleeping, difficulty with communication, swallowing, dementia, and depression (Bayles & Tomoeda, 2014). A PD diagnosis is fairly common, with an estimated 1% over the age of 50 exhibiting symptoms of the disease and an estimated 50,000 Americans diagnosed each year (Yorkston et al., 2004). The number of people in America with PD is expected to double by the year 2040 because of the growing elderly population (Bayles & Tomoeda, 2014).

Parkinson's disease treatment. Parkinson's disease is currently treated through a multi-faceted approach comprised of pharmacological intervention, surgical procedures, and behavioral therapy (Yorkston et al., 2004). Pharmacological interventions are prescribed to patients with PD in order to improve symptoms of depression and anxiety by offsetting the decreased production of dopamine (Rabinstein & Shulman, 2000). Dopamine replacements have become the most common drug treatment for PD. Levodopa is a drug that promotes dopamine in the brain (Yorkston et al., 2004). It is commonly used in the treatment of PD because it is a

medication that crosses the blood-brain barrier and degrades into dopamine (Yorkston et al., 2004). However, this type of drug often is accompanied by side effects such as nausea, dyskinesia, hallucinations, and insomnia (Rabinstein & Shulman, 2000). Anticholinergic drugs can provide some relief of PD symptoms, but they often include difficult side effects such as dry mouth, blurred vision, constipation, and incontinence (Yorkston et al., 2004).

There are also surgical procedures that have been used to manage symptoms for PD. One option is a procedure called a thalamotomy (Yorkston et al., 2004). Thalamotomy is a procedure where an electric current is used to destroy tissue in the brain, specifically the area called the thalamus (Yorkston et al., 2004). Another surgery performed is deep brain stimulation (DBS). In this case, a small electrode is placed in order to interrupt signals to the areas of the brain that are affected by the disease (Rowland et al., 2015). DBS can benefit PD patients that experience motor control symptoms but is most effective when used along with pharmacological interventions (Rowland et al., 2015). Restorative techniques are another option for managing PA but are still in experimental stages (Yorkston et al., 2004). Restorative techniques that are still being researched include tissue transplants and gene therapy. A clinical trial performed in 2015 tested the use of gene therapy along with DBS and the researcher's viewpoint was that the two interventions done simultaneously offered scientific, ethical, and financial advantages (Rowland, et al., 2015).

Behavioral therapy has also proven to be a reliable method of managing PD symptoms, especially along with pharmacological intervention: "Rehabilitation efforts, including physical and occupational therapy programs, are adjuncts to appropriate drug management. The goal of all these programs is to enhance and maintain the level of function of individuals with Parkinson disease" (Yorkston et al., 2004, p. 95). While physical therapy and occupational therapy focus on

maintaining large and small motor movements in patients with PD, speech-language therapy also targets areas of behavioral therapy (Yorkston et al., 2004). Speech-language pathologists (SLP's) can provide counseling, cognitive-communicative, motor speech, swallowing, and social communication behavioral therapy for people with Parkinson's disease (Duffy, 2013; Eriksson, Hartelius, & Saldert, 2016; Yorkston et al., 2004). The American Speech-Language and Hearing Association (ASHA) provides a descriptive scope of practice for these areas (Tippett et al., 2009). ASHA provides clear guidelines on the role an SLP serves for persons with PD in treating cognitive communication and swallowing impairments in the areas of dysarthria, voice, cognitive communication impairment, dysphagia, and counseling/education (Tippett et al., 2009).

SLP's Scope of Practice in Parkinson's Disease Therapy

Dysarthria. Dysarthria is a generalized term that is used to describe a neurological change in speech (Duffy, 2013). Dysarthria is described as: "A collective name for a group of neurologic speech disorders that reflect abnormalities in the strength, speed, range, steadiness, tone, or accuracy of movements required for the breathing, phonatory, resonatory, articulatory, or prosodic aspects of speech production" (Duffy, 2013, p.4). However, there are specific types of dysarthria that characterize motor speech disorders. The category of dysarthria found in PD is hypokinetic dysarthria and is perceptually characterized by short rushes of speech and poor articulation, resulting in a decrease of speech intelligibility (Lowit, Marchetti, Corson, & Kuschmann, 2018). More specifically, people with PD exhibit speech short rushes of speech that is quiet or can be described as "weak" sounding, monotone voice, decreased articulation difficulties beginning a phrase, and stuttering (Hartelius & Svensson, 1994). These perceptual speech characteristics are a result of rigidity of muscle movements caused by the disease and

effects speech production due to changes in respiration abilities (Duffy, 2013; Mehanna & Jankovic, 2010).

Perceptually, there are changes in the voice of a person with PD's voice that provides a connection between dysarthria and voice. Due to the rigidity of muscles that cause aspects of dysarthria, it also causes a bowing of the vocal folds in about half of people with PD (Yorkston et al., 2004). The bowing of the vocal folds is a structural change that causes a functional shift in the voice of a person with PD. Perceptual characteristics of bowed vocal folds include a breathy voice, reduced loudness, and monotone speech (Yorkston et al., 2004). With treatment to improve phonatory efforts and improve voice quality, the bowing improves (Boone, McFarlane, Von Berg, & Zrick, 2014). Behavioral therapy is most important to train a person's self-awareness in changes of voice. Due to the changes in the basal ganglia control circuit, self-awareness is reduced (Duffy, 2013). As a result, the person with PD may not be aware of the changes in their voice (i.e., reduced loudness or reduced articulation).

Assessment of dysarthria. All of these aspects of dysarthria, voice, and self-awareness are accounted for when an SLP is assessing a person with PD. The average vocal loudness level of a person with PD is often recorded when the person is reading words and phrases, as well as in conversational speech (Yorkston et al., 2004). Self-awareness of speech production is related to a circuit in the brain that can be impaired by PD (Bayles & Tomoeda, 2014). Self-awareness is assessed by asking the person with Parkinson's disease to talk louder, and measuring decibel levels during that attempt. If the person with PD demonstrates the ability to adjust productions of speech, it is most likely not a physical deficit, but changes in their cognition that are affecting their vocal loudness (Yorkston et al., 2004). Intelligibility at the conversational level is often estimated during assessment and is imperative to distinguishing the severity of dysarthria

(Yorkston et al., 2004). Diadochokinetic rates is a timed speech task that is used to assess the speed and precision of articulatory movements and can display a decreased range of movement as it relates to speech mechanisms (Duffy, 2013). Measures of jitter and shimmer in voice are measured vocal fold vibration, and a person with PD may exhibit high jitter and shimmer due to decrease motor control (Duffy, 2013). Perceptual characteristics of speech (e.g., vocal quality, pitch, monotone speech, imprecise consonants, and rate) and type of breathing being utilized (i.e., diaphragmatic vs. clavicular) are also important to note during assessment.

Cognitive-communicative impairment. Dysarthria and voice is one aspect of PD that affects communication. Changes in cognition also have effects on communication. Cognition is a general term that refers to a person's ability to process and store information (Bayles & Tomoeda, 2014). When changes in cognition affect a person's ability to communicate, the term cognitive-communicative impairment is used to describe this type of communication impairment (Bayles & Tomeoda, 2014). Dementia associated with PD is characterized by deficits in anticipation, planning, memory, language, and visuospatial skills (Yorkston et al., 2004). Levels of cognitive deficits vary greatly between persons with PD, but it is estimated that 10%-30% of people with advanced PD experience dementia (Rabinstein & Shulman, 2000).

Assessment of cognition. SLP's assessment of cognition will usually include a screening, and then one or more standardized assessment if warranted. Common standardized tests and screeners used to assess cognition in PD are the Montreal Cognitive Assessment (MOCA), the Boston Naming Test, and the Mini-Mental State Examination (MMSE) (Tippett et al., 2009). Informally assessing word retrieval abilities and an oral mechanism exam are also part of Parkinson's Disease-Related Dementia (PDD) diagnoses (Tippett et al., 2009). The Movement Disorder Society (MDS) Task Force created diagnosing criteria for PDD that includes; a MMSE

score equal or less than 26, changes in cognition must be affecting activities of daily living, at least two significant impairments in cognition must be found in subtests of the MMSE and the MOCA (e.g., clock drawing, word recall, lexical fluency) (Bayles & Tomoeda, 2014).

Dysphagia. Dysphagia is the term used for a disorder in swallowing and is explained as a physiological change in the muscles needed for swallowing (Groher & Crary, 2016).

Specifically, in PD, dysphagia can appear at any stage of the disease and all three stages of the swallow (oral, pharyngeal, and esophageal) may be affected (Yorkston, et al., 2004). Swallowing is assessed informally by interviewing family members, interviewing the patient, and performing a bedside swallowing exam in order to determine if signs/symptoms of dysphagia or aspiration are present (Tippett et al., 2009). If further assessment is needed, a videofluoroscopic swallow study can be performed. A videofluoroscopic swallow study allows an SLP to view a moving x-ray of a patient's swallow and assess whether a diagnosis of dysphagia and intervention is appropriate (Groher & Crary, 2016). Although dysphagia is often associated with PD, for this research, the focus is on communication, including both motor speech and cognitive communication. Therefore, dysphagia will not be discussed in future sections.

Counseling/Education. An SLP may provide counseling for the person with PD and his or her caregiver in the areas of motor speech, cognitive communication deficits, dysphagia, communication strategies, use of AAC, and acceptance of disease (Eriksson et al., 2016; Tippett et al., 2009). There are also local and national support contacts that can be recommended to a person with PD and their caregivers that provide counseling and education (Parkinson's Foundation, 2018). If necessary, an SLP may refer a person with PD to an otolaryngologist, occupational therapist, physical therapist, or other professionals to assist in other deficits outside of an SLP's scope of practice that occur in PD (Tippett et al., 2009).

Communication Difficulties exhibited by persons with PD

Communication difficulties related to dysarthria. Deviant speech characteristics provide a way to distinguish between the different types of dysarthrias (Duffy, 2013). As noted above, hypokinetic dysarthria is the type of dysarthria characterized by the changes in speech noted in people with PD (Yorkston et al., 2004). The speech characteristics distinguishing hypokinetic dysarthria include; monopitch, reduced loudness, increased overall rate, short rushes of speech, inappropriate pausing, rapid alternating motion rates (AMR's), and imprecise consonants (Duffy, 2013).

Intelligibility. Combining these speech characteristics associated with hypokinetic dysarthria, result in impaired speech intelligibility. Speech intelligibility is judged by a listener, and if impaired, has a large impact on communication (Duffy, 2013). An SLP will often assess intelligibility using a standardized assessment, calculating a percentage by recording a language sample or even informally judge intelligibility by using a trained ear (Duffy, 2013). An intelligibility rating scale can be helpful for SLP's to administer to communication partners in order to further identify levels of impairment in persons with PD. Duffy created an intelligibility rating scale for motor speech disorders that outlined levels of speech impairments in environments and provides a rating on a scale of 1-10 (Duffy, 2013). The rating scale is subjective and does not provide a detailed rating. The rating scale provides SLPs and other professionals an approximation of the level of speech intelligibility impairment as judged by a common communication partner. While the information from this rating scale is important for judging speech intelligibility, the communication partner may also be providing judgment of comprehensibility in the process. As intelligibility measures comprehension of each individual

phonemic production, comprehensibility also takes into account what is understood given other information (e.g., context, facial expressions, and gestures) (Duffy, 2014).

Cognitive communication impairment due to dementia.

Executive functioning. People with PD that experience cognitive communication impairments most commonly have difficulties in the areas of executive functioning, memory, and visual-spatial functioning (Bayles & Tomoeda, 2014). Executive functioning is skills in information processing and performing everyday activities related to using previously learned information (Bayles & Tomeoda, 2014). Executive function skills include processing sensory information, decision making, planning and carrying out everyday activities, and planning and sequencing speech (Troche & Altmann, 2012). Specifically in planning and sequencing speech, people with PD display difficulties with word finding and category naming (or word fluency) (Bayles & Tomeoda, 2014).

Delayed mentation. Word finding and word fluency have been a topic of research in order to further explore a characteristic explained as slowness of thinking (Troche & Altmann, 2012). Past research has explained the phenomena as deficits in language comprehension, however, several researchers view symptoms as slowed processing of receptive and expressive information (Bayles & Tomoeda, 2014; Murray, 2008; Troche & Altmann,). As a result, characteristics of communication in people with Parkinson's reported include; inability to anticipate, slowed initiation (especially spontaneously), impaired shifting from one topic to the next, and an inability to generate wanted words or phrases (Yorkston et al., 2004).

Visuospatial functioning. People with Parkinson's disease report deficits in visuospatial functioning in the areas of orientation, space perception, color discrimination, and contrast

(Bayles & Tomeoda, 2014). Deficits in these areas can cause communication breakdowns and affect learning capabilities. Visuospatial deficits are sometimes heightened when patients experience difficulties with attention, or hallucinations (Bayles & Tomoeda, 2014).

Memory. Difficulties in memory are also associated with PD associated dementia. People with PD experience difficulties with procedural learning tasks, recognition tasks, and prospective memory tasks (Bayles & Tomoeda, 2014). A study performed in 2016 interviewed people with PD about their difficulties with communication (Yorkston, Baylor, & Britton, 2016). Participants reported recalling information while communicating was no longer natural, but more a task. One participant described he felt as if he “needed to think about speaking” when recalling information (Yorkston, et al., 2016).

Dementia in people with PD may not always be present. When it is present, the effects and symptoms observed vary in each case. People with PD related dementia may present with only one of the main areas of dementia listed, for example, minor difficulties with memory that worsen over time (Bayles & Tomoeda, 2014). Some people with PD may present with all three areas (executive functioning, memory, and visuospatial functioning). Some people with PD may not present with all dementia areas for a long time, but often experience some difficulties with dementia at some point.

SLP Intervention for Communication of Persons with PD

Behavioral management approaches. When it comes to communication, SLPs provide intervention, labeled as behavioral management approaches, for communication difficulties in persons with PD. In behavioral management therapy, SLP's take either a speech-oriented

approach, a communication orientated approach, or both. (Bayles & Tomoeda, 2014; Yorkston et al., 2016).

Speech orientated approaches. Speech orientated approaches focus on changing or improving a patient's speech in order to improve intelligibility and efficiency of communication (Duffy, 2013). Improving communication with a speech orientated approach usually means the therapist is doing one of two things: improving physiological support or compensation (Duffy, 2013). Physiological support is attempting to reduce the actual impairment present by improving the physiological support associated with the changes in speech. It is common to use this approach in cases where patients present with a type of dysarthria and may include exercises to strengthen muscles used for speech. Compensation for communication in speech refers to the patient learning to compensate for a physiological change in their voice (Duffy, 2013). Compensation methods for speech are common in progressive disease therapy and may include respiratory training, posture change, articulation therapy, and pacing and speech rate training (Duffy, 2013).

Lee Silverman Voice Training (LSVT LOUD). This behavioral management approach is designed to actually change behaviors in phonatory and respiratory functions (Sapir et al., 2002). Due to the changes in the basal ganglia control circuit, PD patients' self-awareness is reduced for the changes in their own vocal loudness and articulation (Duffy, 2013). The LSVT LOUD program is outlined as an intensive four times a week for four weeks therapy program, along with at home programming. A randomized control trial compared 22 participants who participated in LSVT LOUD treatment with 13 participants in respiratory treatment program (RET) (Sapir et al., 2002). The researchers concluded that patients with PD that undergo LSVT

LOUD training demonstrated speech with more energy and better quality that was maintained for at least 1 year after completing therapy (Sapir et al., 2002).

A non-experimental study outlined several authors' research and professional experience on the benefits of LSVT LOUD. The authors' opinion was that LSVT LOUD was a successful program due to its intensity of neural plasticity training of a single task: maintaining louder speech production (Fox et. al., 2006). The researchers also suggested LSVT LOUD may contribute to improvement in other areas such as swallowing and physical body movements, however, further research is needed in order to confirm these claims (Fox et. al., 2006).

Rate management. Delayed Auditory Feedback (DAF) may be used as a long-term or short-term benefit and is a small, portable device that provides a feedback of the speaker's voice in an effort to slow the speaker's overall rate and/or improve fluency (Yorkston et al., 2016). An experimental design study with 9 selected participants all with PD reported on the success of DAF. (Wang, Metman, Bernard, 2008) Conclusions were that the participants with PD displayed an improvement of intelligibility and rate during conversational speaking tasks, but not during reading tasks (Wang, et al., 2008). Small voice amplifier devices may also be used during specific speaking situations in order to increase the speaker's volume (Yorkston et al., 2016).

There are also several ways to target rate management without the use of prosthetics. A few options include; hand or finger tapping, incorporating rhythm to words, pacing board, or providing visual feedback of rate (Duffy, 2013).

Communication orientated approaches. Communication orientated approaches focus on improving communication for an individual patient. These approaches may include speech training for a specific listener or communication partner, learning strategies to improve

communication (e.g., rephrasing, asking questions, or improving the environment for communication), or even the patient learning self-advocacy skills (Duffy, 2013). A communication orientated approach is tailored for a specific patient's needs and is usually adjusted throughout therapy.

An example of a communication-oriented approach was described in a recent study. A training program for communication partners of people with PD and other related disorders was designed and researched. Forsgren, Antonsson, and Saldert (2013) explored the communication program called Supporting Partners of People with Aphasia in Relationships and Conversation (SPPARC). Using a case-control study design, the researchers altered the SPPARC program and applied it to three couples with PD and their communication partners. The study consisted of a three week training period (one session per week) with data taken before and after using multiple standardized assessments. Two of the participants reported the information in the training was sufficient, and one participant felt there was too much information provided (Forsgren et al., 2013). Of the six participants, four participants reported a slight improvement in communication was noted compared to before the training. Comprehensibility was measured before, after, and during a follow-up appointment, where a small increase in comprehensibility was noted between the person with PD and their communication partner (Forsgren et al., 2013). However, the results of the study were somewhat inconclusive, stating the training program had "at least partly met their [participants] current needs" (Forsgren et al., 2013, p. 86).

Augmentative and Alternative Communication (AAC). Augmentative and alternative communication (AAC) can be used as a behavioral management approach as a way to compensate, or supplement when speech or communication is impaired (Duffy, 2013). Specifically, in PD and other progressive diseases, AAC is helpful for patients with severe

dysarthria. If patients are physically and cognitively able to operate a device or another form of AAC, it was recommended by ASHA (n.d.) that the patient seek advice and support for using AAC from an SLP. A survey of 30 SLPs performed in 1999 by Armstrong, Jans, and MacDonald reported that a majority of the SLPs interviewed in the study reported successful implementation of AAC in people with PD. The authors concluded that success of AAC implementation in patients with PD depended on the patient's level of cognition, stage of disease at the time of implementation, eye-hand coordination and motor control, family/caregiver support and motivation, and patient's motivation (Armstrong et al., 1999).

Despite the many benefits of AAC, patients with PD may have resistance in using AAC devices (Armstrong et al., 1999). People with PD and their spouses (or communication partners) considering AAC have reservations with the technology aspect and learning how to use it (Beukelman & Mirenda, 1998). Unfortunately, when most patient's with PD need AAC the most, is towards the end of the progression when cognitive impairments are advanced and may interfere with the effective use of AAC. (Armstrong et al., 1999.) This is why it is recommended for SLP's to as soon as possible, and start training patients in AAC early in the progression of the disease (Duffy, 2013).

Effects on Communication Between Persons with PD and Their Communication Partners

There were no specific studies located that described the difficulties communication partners of people with PD experienced in communicating with their loved one. However, one study described the reports of persons with PD. The researchers explained the strategies used by communication partners of people with PD (Carlsson, Hertelius, & Saldert, 2014). The researchers performed a cross-sectional study which observed conversations between seven

different couples where one spouse had a communication disorder due to PD or stroke-induced aphasia. The focus of the study was to observe communication strategies used and which qualities in the communication partners made them a better communicator. The researchers found three themes in the conversations: No participation in repair, request for clarification or modification and providing candidate solutions. The type of conversation repair used was believed to be dependent more on the spouse's type of personality and ability to communicate, rather than the type of communication disorder (Carlsson, et al., 2014). The researchers believed the spouse who was a better communicator demonstrated the ability to support his/her partner's communication and the ability to make inferences when communicating (Carlsson et al., 2014). The researchers stated the study provided important information about communication strategies, however, the study should be trialed on a larger group of participants in order to provide valid information (Carlsson et al., 2014).

Further Research Needed

Further research is needed in order to gain information about the experiences and perspectives of communication partners of people with PD encountered in daily communication. Qualitative research is most appropriate in order to gain this information due to its overall ability to describe the participants' daily lives and social interactions (Damico & Simmons-Mackie, 2003). In this case, the social phenomenon observed would be communication, the participants of the study are communication partners of people with PD. The study is focused on exploring the experiences and perspectives of communication partners of people with Parkinson's disease.

Chapter 3

Methods

Purpose of the Study

The purpose of this study was to explore the quality of interactions between people with PD and their communication partners through interviewing communication partners. The participants discussed communication patterns, difficulties, and strategies found in interactions between themselves and people with Parkinson's disease.

Research Design

This study used a qualitative design in order to collect information about the participants' feelings and experiences of communication with persons with PD. The phenomenological theory was used as the type of inquiry for this study. The phenomenological theory is characterized by exploring and reflecting on the "real-life" experiences of the participants in order to understand their thoughts, feelings, and attitudes towards a certain phenomenon through observations and interviews (Maxwell & Satake, 2006). This type of design was carried out with open-ended interview questions, probe questions, and collecting demographic data. Additional general questions were used as necessary for clarification or to encourage the expansion of responses (e.g., "could you tell me more?" or "Could you provide an example?"). In addition, the question on swallowing disorders was included for future analysis by the primary researcher, but at this time, was not included in the results as it was beyond the scope of this study. This study was approved by the Minnesota State University Moorhead Institutional Review Board on May 21, 2018.

Participants

The inclusion criteria for the participants of the study was primary communication partners of persons with PD who were at any level of severity of communication impairment. A primary communication partner for the study was defined as an adult (18 or older) who interacted with the person with Parkinson's disease at least 2-3 times a week and identified themselves as a primary communication partner.

Exclusion criteria were if a participant with PD was previously diagnosed with another neurological condition such as a stroke, head injury, or Alzheimer's disease. If dementia was present but related to the PD however, that participant was not excluded, as that was within the scope of the communication disorders under study.

Recruitment

Participants were recruited by distributing a written recruitment form about the study that shared the researcher's contact information in order to set up an interview or to receive further information about the study. Purposive sampling was practiced in order to target a specific group of individuals that represented the attitudes of a larger group (Maxwell & Satake, 2006).

Purposive sampling was performed by emailing the information about the study to local and state PD foundations and support groups. The researchers asked that the information about the study be shared with anyone with PD and their families and/or caregivers. The researchers attended support group meetings to explain the study and distributed the recruitment forms. Six area medical sites that did not require extensive institutional review board (IRB) applications, such as the researcher's university speech-language-hearing clinic, private practices, and long-term care facilities that served adult neurological clients were contacted for the study. A letter of

agreement on the organization letterhead was requested prior to approaching the person to distribute the study information to potential participants. In most cases, this was the SLP, but in some instances, there were also related professionals who served as gatekeepers. The researchers provided the practices/facilities with the study information and asked that he/she share the forms with clients with PD and their families and/or caregivers. In addition, recruitment forms were posted on bulletin boards in public places such as local grocery stores or area churches. The participants then contacted the researcher. When participants matching the inclusion criteria were identified, snowball sampling technique was also utilized in order to gain additional participants through personal networks. This facilitated word of mouth recruitment technique.

Two participants were located through the researcher's university speech-language-hearing clinic, however, only one interview was used due to the application of exclusion criteria. Two of the participants were recruited through a local church where a poster was displayed. Several of the participants were recruited by the researcher attending a PD choir and presenting the information about the study. However, only three of these interviews were analyzed after exclusion criteria were applied. One participant was recruited using word of mouth recruitment technique. A total of seven communication partners participated in the study: six were a spouse to a person with PD and one participant was a child of a person with PD. Three of the participants shared they suspected they had hearing loss but did not have a diagnosis. They did not have difficulty perceiving spoken speech during the interview.

Additional participants were recruited until it was determined a saturation of themes was present during the data analysis stage described below. Saturation of themes was described by Krueger and Casey (2015) as a determination by the researchers after a number of interviews had

been analyzed that no additional information was identified during the most recent interviews and it was likely recruitment of participants was sufficient (Kruegar & Casey, 2000).

Data Collection

Participants were given the option to complete the interview by coming to a neutral site such as the university clinic or to have the researchers come to the participant's home. Six opted for a face-to-face interview. One participant requested a phone interview, which was granted. Before the interview was completed, the communication partner was asked to complete a section of the widely used public domain tool: Unified Parkinson's Disease Rating Scale (Martignoni, Franchignoni, Pasetti, Ferriero, & Picco, 2003). The rating scale included six sections, however, for the purpose of this study, only section VI (Schwab and England Activities of Daily Living Scale) was administered. The rating score is included in Appendix C. Section VI allowed the communication partner to select a percentage (with descriptions and examples) of how independent the person with PD performed activities of daily living. This provided the context of the range of the extent of the effects of PD for those participating in the study. This aided analysis of the results of the study.

Other additional demographic data was collected for each participant and the person with PD for additional context. Pertinent demographic data of the communication partner included; age, gender, level of education, coexisting hearing impairments, vision impairments or glasses, and relationship to the person with Parkinson's disease. Demographic data pertaining to the person with PD included; age, gender, level of education, coexisting hearing or vision impairments, list of current medications, and years since PD diagnosis. In the course of gathering

this information, if the inclusion criteria were not met, the interview did not proceed. Full demographic information is presented below in Table 1.

Table 1.

Demographic Data

Participant	A	B	C	D	E	F	G
Age	73	74	77	71	77	76	47
Gender	M	F	F	F	F	F	F
Hearing/ Vision Impairment	Vision impairment in one eye (corrected)	Slight self- diagnosed hearing loss	N/A	N/A	Slight Self- diagnosed Hearing loss	Slight self- diagnosed hearing loss	N/A
Education	Associates Degree	B.S.	Ph.D.	Junior College	B.S.	1 year of College	Junior College
Years Since Person with PD Diagnosed	8	20	4-PD, 6-Lewy Body Dementia	6	9	12	4
Relationship to Person with PD	Spouse	Spouse	Spouse	Spouse	Spouse	Spouse	Daughter
ADL Scale Rating	30%	50%	20%	50%	60%	50%	10%

*Participant B had a prior diagnosis of Lewy Body disease (LBD) and a more current diagnosis of PD. Similarities of symptoms in both PD and LBD make affirmative diagnosing difficult (Bayles & Tomoeda, 2014). The participant was included in the study due to the more recent diagnosis of PD.

Before any formal interviews were completed, the first researcher performed a mock interview. A mock interview allowed the researcher to develop interview skills, identify additional follow-up probe questions that could have arisen, and assessed the clarity of the interview questions to be sure they elicited the information related to the aim of the study. The mock interview participant was not a communication partner of a person with PD, but someone in a similar age range with the diagnosis of dementia. The co-investigator provided feedback and analysis of the mock interview transcript. The question content was judged to be effective as designed. Some suggestions were provided by the second more experienced researcher for more frequent use of neutral probe questions to elicit an expanded response in future interviews.

Each participant in the study was interviewed. All the questions listed were asked, and the additional probe questions were asked based on the participant's responses. See Appendix B for the interview and probe questions. All responses were audio recorded and then later reviewed and typed word for word into printed transcripts. Then the transcripts were verified by the participants in a follow-up phone call or email.

Analysis

The methods used for data analysis were tape-based analysis. Tape-based analysis approach was executed by listening to sound recordings and writing transcripts of interviews (Krueger & Casey, 2015). A full transcript was typed out word for word to show all questions asked by the researcher and all responses from the participants. The researchers chose to use word for word transcriptions to obtain study credibility, which refers to representing the participants' true feelings and "real-life" experiences (Maxwell & Satake, 2006).

The participants were asked to affirm their responses to the questions in the interview to ensure the confirmability of the study. Confirmability is a procedure used to eliminate bias by increasing the accuracy of the data (Maxwell & Satake, 2006). They were also asked to share any additional information they wanted to include after they finished the follow-up verification.

After all the interviews were conducted and verified, the data was analyzed in order to compare responses and discover similarities and/or differences between participants. The researchers analyzed the word for word transcripts by using the long-table approach. The long-table approach is a way of organizing and coding the data from transcripts in order to categorize and identify themes (Krueger & Casey, 2015). Each transcript was color-coded to identify between each participant's quotes. The lines of the transcripts were numbered and then each transcript included a different stripe to identify gender, hearing loss, more than 10 years since diagnosis, below 50% on the ADL scale, the participant with Lewy Body disease and PD, and the participant who was a daughter. This was done to see if certain themes pertained to certain subgroups within the participants, and to put the quotes into context during analysis.

Using the word for word transcriptions, the researcher and supervisor coded the interviews in order to discover themes within the data. The themes were discovered by identifying recurrent patterning in the transcripts, or reoccurring patterns within the experiences provided by multiple participants (Maxwell & Satake, 2006). The researcher also utilized triangulation by considering all professional opinions of the primary researcher throughout the research process and thesis committee members in order to provide the most valid study with the most reliable information (Maxwell & Satake, 2006).

In addition, the principal investigator retained the data for the swallowing questions for future analysis. This data will not be included in the current study but will be stored with the transcripts utilizing IRB procedures for later analysis in a future study.

Chapter 4

Results

The participants in the study shared their experiences of being a primary communication partner to someone with PD. The data from the interviews was analyzed and themes that emerged are explained. Direct quotes from the participants are italicized to emphasize when their own words were included.

Communication Declines Noted

Communication declines in multiple areas were noted by all seven participants. In this study, communication is used as a broad term and refers to expressing wants and needs, by any means, from a person with PD to a communication partner (expressive language). It also refers to how the person with PD perceives information from their communication partner (receptive language).

Receptive language. One participant shared her thoughts about difficulties with receptive language. *“Many times, when we’re talking, and I think that it’s every day, it’s like we’re on two separate waves. He hears one line of information while I’m transmitting another line of information.”*

Expressive language. Participants detailed a number of expressive language difficulties experienced when communicating with the person with PD.

Delayed response. Three participants specifically outlined the receptive language difficulties they encountered as more of a delayed response to communication. More participants

outlined their communication declines as expressive language difficulties than as receptive difficulties.

“He would voice things, but now he says that it’s hard for him because he says the conversation goes faster than what he can think of what he wants to say and share it with everybody. By the time he finally has it figured out, the topic has gone to something else before he has time to add what he was going to add.”

One wife stated, *“Their thought process is so slow, by the time he answers my question, I forgot what I asked. He has really gotten slow. Much slower to react to what you ask him.”*

Limited communication exchange. Five of seven participants reported a decline specifically in how much the person with PD engaged in communication. A female participant recalled their spouse saying about going to a small group discussion at church, *“I had something to say, but I just couldn’t get it out, I just couldn’t get it.”* Another described going to a Christmas party for persons with PD, *“I don’t think he said two words the whole time. None of the men with Parkinson’s talked. They really kind of lose their communication. I think they just all feel like they can’t get the words out that they want.”* A wife of a partner in a state of decline described communication being reduced to only one or two words. *“He is unlikely to say a word. Once in a while, for example, he was asked a week ago, “Would you like ice cream or cake?” He said, “both” but otherwise he doesn’t talk.”* Several participants described communication dwindling to no speech at all, *“Sometimes he will understand that you are trying to ask a question and he tries to answer but he can’t.”*

Motor speech. Several participants described how a decline in motor speech had an effect on the ability to communicate wants and needs. Participants used words such as,

“mumbles, can't understand her, enunciation” and, *“He mumbles and stumbles on his words sometimes.”* Another participant described it as, *“He has a breathy quality to his voice.”* All aspects of motor speech impairment made communication with the person with PD more difficult.

Many participants described how the lower volume aspect of the voice made it more difficult to communicate. Changes in vocal volume were described as, *“he speaks quite softly, no timber in his voice.”* A wife reported, *“I can't hear him, I can't understand him. I ask him to repeat often.”* Two participants described how the person with PD did not seem to realize the change in volume. *“Parkinson's people have a light voice. They think they are talking loud but they aren't. I have real communication issues with that.”* Another participant with a similar response,

“When I don't catch what he is saying and I ask him to speak louder, the next time he says the same thing the volume doesn't change. It all stays the same. I could ask him to repeat it three times but it all stays the same. It stays the same level.”

Problematic and helpful situations. Five of the seven participants described situations where communication seemed to be more difficult. The one male participant noted several times that communication is always better in the morning compared to the evening. *“I'd say 4' clock on, starting to get tired and the day kind of winds down. Mornings are always the shiniest time.”* Other situations reported to be more problematic included when speaking in the car. *“He's trying to tell me something while looking out the window. I can understand him if he's looking at me.”* Two other participants reported difficulty when the topic of conversation was unknown.

“He will be in one place and I will be in another in the same room and I’m working on something and he’s just being observant and he’ll say, “Oh the leaves are falling down like snow.” Which is just something random and I’ll hear some of the words but I can’t figure out what he’s totally talking about.”

A female participant reported talking on the phone to be more difficult, *“I’m hearing from other people that talk to him on the phone that it’s difficult to understand him.”* However, a male participant reported, *“She is better on the telephone than she is speaking to me.”* In addition, two of the participants reported communication being better when it is one on one vs. in a group. *“The folks that I have noticed that come to visit and sit down and talk to him one on one, have been most successful in having him establish eye contact and maybe show some emotion.”*

Progressive decline. Six of the seven participants described how the communication difficulties became worse across time. Some described a gradual change. *“He’s gradually getting harder to understand. His voice has gotten softer. He doesn’t speak as clearly as he used to,”* and another, *“It just gets more difficult as the disease progresses.”* Two participants described the decline as more of a *“rapid decline”* and even a *“sharp drop in his ability to communicate.”*

Declines in Cognition

Several participants noted changes in the areas of attention, thinking, and memory. Some participants outlined difficulties in multiple areas of cognition.

Changes in attention and thinking.

Performing daily tasks. One participant specifically noted changes in the attention of the person with PD. More often, five participants described noting changes in the cognitive area of thinking. Participants reported a decline in thinking skills affected daily activities such as driving, writing, and using a calendar.

“He has a mild cognitive decline. I think it’s happening more and more. He’s having problems with details. Like the calendar, he looks at the calendar up and down instead of across. That’s kind of significant I think. Then he will get to the bottom and say, “Where do I go now? Do I start back at one?” So, that kind of planning, time, is very difficult for him.”

Another participant, *“Seems to be a problem in the area of time, keeping track of the days of the week, keeping track of pills.”*

Organization of thinking. Four of the seven participants described the changes in cognition as,

“He has a hard time formulating the thoughts he wants to say, and this is like getting into some conversation like an opinion on things. He has a hard time voicing that, putting that into words and getting that out. I think sometimes he just gives up because it’s hard to spit it out and say it.”

Quotes from other participants included, *“He starts telling me something but he can’t get it out. He can’t finish it. He has to wait a while until his brain is working right.”* And another shared, *“In terms of just keeping his thoughts together and being able to explain what’s coming next, keeping that fluency is much more difficult.”*

Memory. Three of the seven participants also reported a decline in memory, specifically memory of events and people. *“Yes, every hour I have to repeat things, “when are we going to the doctor?” every hour. Those things just don’t stick with him.”* More severe difficulties with memory were also reported, *“His memory comes and goes. Like I said, sometimes he recognizes me when I come in and other times he won’t.”*

Participation in Life Events

Communication partners were asked if difficulties in communication limited participating in events for themselves or the person with PD. Responses varied, but all participants reported a change in participation.

Maintained and gained participation. Three of the seven participants noted a minimal decline in participation. *“We still go visit people.”* The male participant noted his wife has even increased in doing some activities. *“We try to keep going. Like the choir, that could be a blessing. We increased activity there.”*

Reduced participation. All other participants reported reduced participation in activities such as visiting people, nursing home activities, and groups/meetings. *“We don’t go visiting at all anymore because it’s just the trip there and back, he doesn’t seem to enjoy it because he doesn’t visit anymore.”*

Barriers to participation. Several participants explained that they have not reduced participation in certain events, but PD has provided barriers to participation. *“Everything is an effort. It is really work to get ready to go.”* Several of the participants described barriers due to mobility constraints.

“He’s willing to do most anything. Part of it is, by the time you get everything set up and ready to go, he says, “I have to go to the bathroom.” That’s another 15-20 minutes. Nothing is easy anymore. We use to be very spontaneous people.”

Occurrence of Training/Therapy

Two of the seven participants reported having a type of training or therapy in order to improve communication with the person with PD. A few of the participants stated they did not have any training or therapy but then expressed more about the topic.

Communication partner having training or therapy. A wife who had participated in multiple trainings and therapies outlined her opinions of the events. She described attending one educational seminar organized by a local hospital when her husband was first diagnosed with PD.

“So that was a daylong seminar and there were many speeches about the progression of Parkinson’s, and the kinds of medications used, some of the therapies, like the physical therapy and the LOUD therapy and then some researched based types of things about the progression of the disease. It was overall very helpful to give me a picture of what I was beginning to experience and what was coming along.”

Another participant reported she learned a few communication techniques but did not find them to be useful. *“I’m not real good, I don’t know what they call it, but repeating some of the words back to the person that said it. I like to have conversation with people but I’m probably not a technique user.”*

LSVT LOUD therapy. One participant described how she had attended LOUD seminars with her husband and her opinion of that experience.

“Well I went to the LOUD seminar, I would take him to the LOUD seminar, so we would both go and that would take place over a period of a number of weeks and we did that two times. So, I think the therapy relating to the LOUD therapy was helpful for me as the caregiver and it was certainly helpful for him because our goal was to keep him communicating as long as we could.”

Communication partner had not had training or therapy. Several participants reported that they had never attended any training or therapy for improved communication. One participant said, *“No, but I wish.”* One of the more advanced stage participants had a similar response. *“It would have been great if I could have learned some better ways to communicate. That’s not offered and I know that these facilities can’t, but it would be a great tool if they could.”* Another participant considered the benefits of attending therapy with her husband. *“I imagine I could go to his classes with him, I don’t know if that would be helpful at all.”*

Support groups regarded as helpful. A strong theme that came through the interviews was the usefulness of support groups for the communication partners of people with PD. Multiple participants reported instances of attending support groups with positive experiences. One wife described the caregiver support groups she had attended.

“I go to every caregiver’s thing that is offered in the area. You might pick up on a thing from another person there, but not much from the speaker that is there. You get more from the experience. That’s what helps. The thing about having a support group of other spouses of Parkinson’s patients is that you can say anything at all and they have either heard it or will hear it and they don’t judge. It’s just so easy.”

Another participant described a similar experience with her support group. Both participants found benefits in sharing with others experiencing the same feelings.

“We all have to bring our husbands to their class so we sit and have coffee. Sometimes we walk, sometimes we sit and visit, sometimes we walk and talk, and it’s really good for us. It’s really helped a lot, knowing that you’re not the only one going through this. We all have concerns and the same frustrations.”

Training or therapy for a person with PD. Six of the seven participants reported that the person with PD attended a training or therapy at some time since his/her diagnosis. The participants then described the benefits of the trainings, as well as the areas that were not as successful.

Effective trainings and therapies. Two specific therapies were described by multiple participants, a choir for persons with PD, and LSVT LOUD therapy. Participants went into detail about the benefits the person with PD received from attending these interventions.

Choir. A male participant reported his wife enjoyed choir so much that she attended one in their home town and then also one where they vacation for the winter. *“She sings all the time. Seems like when she sings, you can understand her better than speaking. And that’s pretty common.”* Another participant said both she and her husband attended a Parkinson’s choir. *“Which is something to help keep those voices, gives them an opportunity to work on keeping the strong, which is a good thing.”*

LSVT LOUD. Five of the seven participants reported positive experiences with having the person with PD attend an LSVT LOUD therapy, however, the participants did not describe many specific changes they noted. One participant reported his wife *“tries to enunciate better”* as a

result of the therapy. At least three of the participants reported the person with PD needed to attend more than one session for what was described as a “*refresher.*”

Trainings and therapies not effective. Two participants reported noticing no change in communication after attending the LSVT LOUD program.

“For me, when you get therapy, and I realize he has a progressive disease, but the ultimate goal of therapy is usually to improve a little bit. But for “C”, it has kind of gone the other way. I know they teach a lot of things at the speech classes but I can’t really notice any changes or improvements from going. But possibly if he didn’t go to speech, it would be a lot worse. You know, I don’t know that.”

It should be noted that the same two participants that reported the LSVT LOUD program to not be effective for their spouse, were also the two that reported a lack of practice by their spouse. *“One of the things that go along with the program is practicing at home. Which is something that doesn't happen.”*

“In talking to other caregivers, they say their spouses don't practice at home either. I think motivation is a big thing and you can do the things when you have a therapist there guiding you. But for some reason, it just doesn't seem to carry over into real life.”

Communication Strategies Used by Communication Partners

Participants shared strategies they used to better communicate with the person with PD. Three participants described having to utilize strategies to compensate for cognitive deficits.

Cognitive strategies. Repetition of information was a common theme in this area. *“15 times or more a day he will ask, “What do we do today?” Then I’ll go through it again.”*

Participants described using calendars as a strategy for communication. *"Our calendar is pretty busy, pretty filled in. Every single month. So I have started taking a day at a time and putting the day, and then the date at the top, in chronological order, what we're doing that day."*

One participant whose communication partner with PD experienced advanced cognitive deficits found the use of pictures to be helpful.

"Starting a few years ago I made some Shutterfly books. I think the first one was for his 75th birthday. Knowing that he was getting dementia, I made the book for his birthday called "Still Cooking at 75." I had pictures of all the turkeys, he was a nutritionist, so this was something that was pretty exciting and about his favorite hobby...So this has been one main way to keep him in touch."

Communication strategies. Several participants described strategies they used on a daily basis to better communicate with the person with PD.

Nonverbal communication. Participants discussed small signals or gestures they use to communicate. *"Little signs or signals (points up) you know, louder."* Another, *"Sometimes I just sit there and hold his hand. I do a lot more hugging or put my arm around him so he knows I'm there."*

Face to face communication. Several participants also described the importance of proximity to the person with PD. *"Need to be more face to face when speaking to each other."* The male participant also reported the same with his wife. *"You look right at her and get close and then she's more alert."* Furthermore, two participants described the importance of gaining the other's attention in order to talk to them face to face. *"I will tell him if he needs to talk to me, he needs to get my attention first,"*

Prompting strategies. Some of the participants found it beneficial to coin certain phrases to remind their person with PD of a communication strategy. *"I say what they tell him in the LOUD class, "stop, speak with intent, or "speak with purpose". Another phrase used was, "Stop, start that again."*

Communication Strategies used by Person with PD

The participants also outlined strategies they have viewed the person with PD used to better communicate.

Carry-over from therapy. Participants described strategies that were learned from attending a therapy. *"The "speak with purpose and intent" thinking, it sometimes helps him to get things out and clearer."* Participants described when the person with PD was conscious of the strategies learned. *"She's working at it or is conscious of it."* And, *"He will start out and repeat the same four words and then stop because he is aware he is doing that and then start with more intent."*

Gestures. Three participants described the person with PD using gestures as a way to communicate. *"Signals"* and, *"Squeezes my hand."* Another participant said that communication could be as little as a facial expression. *"Facial expressions. He will smile and that's about all we really get out of him."*

Communication/Interaction Style

Communication partners described how their interaction or communication style affected communication.

Barriers to communication. Two spouses discussed how their own lack of listening created difficulties in communication. *"I see myself listening less. He knows what he's thinking about, but I have no idea what he's talking about. I sometimes just let those things go by rather than have him repeat them."* Another wife gave a similar response. *"I maybe don't listen to him as well as I should because the conversation doesn't get as involved as I like it to be so I sometimes just give up and don't do it."*

Furthermore, both of the participants in the previous quotes described themselves as having a lack of patience. *"We know they can't help it that they have Parkinson's and there's nothing they can do about it. Just have to be more patient and kind of let things go, but it's hard some days."*

Facilitators of communication. Just as some personal characteristics provided barriers to communication, some characteristics fostered communication. Two participants found benefits of being teachers in the past. *"I talk louder."* And the other participant, *"I think the kindergarten training helps us [with patience]."* Another participant described another important quality she possessed. *"I noticed him starting to fall and trip on things so I made a quick decision to sell our house. So suddenly I had to become quite decisive and bossy."* One wife described the importance of familiarity. *"We've been married for 54 years. I feel that I know him well enough to know if he is uncomfortable or agitated, or whatever."* One participant noted several times in her interview that she had a sense of humor that helped her to have a better relationship with her husband.

"I discovered a sense of humor that had been buried for a long time. I was never sensitive or anything like that but I'm just able to see the humor in things now and laugh"

about it... You can be a smartass about things that really are funny... It's not malicious, we don't mean to be malicious, but we are just trying to get rid of stress."

Psychosocial Effects

One of the largest themes derived from the interviews was the number of response that contained information about the feelings of the participants and the persons with PD. The responses reflected the impact that PD has had on the psychosocial well-being of the people involved.

Communication partners.

Changes in relationship. Several spouses described how PD has changed the relationship between them and the person with PD. One discussed how they use to spend their time. *"We used to sit in the evenings and watch the news and just talk about everything. That's hard, the changes."* Another spouse gave a detailed response on how communication has changed their relationship.

"Then in turn, as far as a communication partner, a spouse, it [formulating thoughts] makes it harder because you no longer know what's going on in their mind. So, you lose that communication, feelings, and thoughts that you shared in your married life earlier. The other day I told him, "Now, I don't even really know what you're thinking," So, it just kind of changes the relationship because you can't communicate the way that you use to I guess."

Negative emotions. Several different negative emotions caused by a response to PD were described by the participants. Two participants specifically noted **frustration**. *"I know they can't help it, but it's still frustrating."* Another participate conveyed **irritation**. *"I tend to be more*

irritated than compassionate. Irritation on my part that he's not remembering [events and calendar]. One participant commented, *"Wears me out"* when talking about all the activities they needed to take their spouse. The male participant described feeling **angry** at times.

"I have a tendency to holler or get angry and say something you shouldn't. Which you always regret afterward but you can't take it back...You're more angry at the illness than you are at the person but it doesn't sound that way."

Relating to similar experiences. Two of the participants specifically discussed how they found comfort in someone else feeling the same as how they felt. *"I feel a little better that it's not just me [that can't understand him]."*

"I remember one of the first meetings I went to, she said, "I feel like a slave, I do this, and I do this," I looked at her and I said, "What did you say? That's exactly how I feel!" and I thought to myself, "Hm, someone feels the same way I do."

Desire to maintain social activities different from the person with PD. One participant whose spouse had experienced advanced stages of disease outlined her feelings to maintain her own social activities.

"I feel like I'm leading a double life because I want to be with him as much as I can but my life is filled with many other things...So I guess I'm thinking we are kind of going on parallel tracks, the years that I have until maybe I suffer something that would cause me to have limitations, so I guess I'm feeling as if I need to fill up my life but not neglect him. So we are really running on two tracks. Which in many ways is hard, but I think if I don't do it, I would have regrets that I'm not living my life either."

Perception of persons with PD's feelings. The participants provided several responses that described how they think the person with PD feels at times.

Negative emotions. The participant who was a daughter described how her dad seemed **anxious** at times. *"He has anxiety and that kind of takes over. He has outburst when he gets anxious so it's best to just leave him in his room by himself."* One participant discussed how her husband became **irritated** because he was so often asked to repeat something he said. Two other participants reported the person with PD appeared **frustrated** due to the same reason. *"It's frustrating to him sometimes that I ask him to repeat,"* Another participant described how her husband seemed **discouraged** because of his difficulties and as a result, caused him to withdraw. *"I think it's hard because he has a hard time getting the words out when he starts to say something and he feels bad about that so he just doesn't want to talk at all."* Another wife described something similar because her husband felt **self-conscious** and as a result, attempted to joke in order to hide his deficits.

"When he was aware that he had some cognitive decline when we'd leave the couple, he'd say, "Did I say anything embarrassing or stupid?" So he had enough recognition to know, but it wasn't. It was just that everything was a joke. There was never a serious discussion with anybody."

Positive emotions. Some participants described how some feelings of the person with PD made going through this experience a little easier. Some of the participants described how being around family can be more comfortable. *"He's not very good about communicating when there are strangers around. But family, he is very relaxed. He's not nervous about what he is saying"* One participant described her spouse as having, *"...such a good attitude"* and that he will laugh

at his own mistakes. Another participant said about her spouse, *“He doesn't get mad at me, he probably should, but he doesn't.”*

One wife described how a group therapy setting had a positive impact on her husband's emotions.

“I know that C likes to go to these different speech classes. I think he feels that it has helped him...I think it's encouraging to him. I think the other thing that he really enjoys about those things is just being with people that are accepting of the situation. Not only are the therapists accepting of him, but also the other people in the group are dealing with the same thing so it's a safe place. It is comforting to know that there are other people in the same spot and you don't have to be a certain way. They all have something in common that they are working through.”

Common emotions experienced. Some of the response reflected how PD has impacted the communication partner and the person with PD in the same way. Two participants reported feeling **frustrated** and **tired** of the deficits in communication.

“It's a constant reminder. I get tired of that, he gets tired of that, always being reminded. The hard part is, it's just a fine line. You don't know how many times you can keep reminding without causing some frustration. So, that's probably the hardest part about communication with us.”

One wife described how both she and her husband felt the changes in their relationships with others.

“You [her and her husband] don't have the same friends anymore. Because the friends you had before, don't really understand Parkinson's. So we have a whole new set of friends that know what we're going through and can relate to the things we go through.”

One wife told how even through the frustrations, having each other and maintaining that relationship as a couple was important to their psychosocial well-being. *“It's just every day, we have to figure out ways to tell each other we love you and be able to have a relationship yet as a couple.”*

Conclusion

Of the seven interviews performed, eight major themes emerged after a long table analysis approach. Recurring messages and commonality in responses from the participants provided multiple subthemes within the major themes. The major themes and subthemes outlined in the results will help SLPs to educate communication partners and individuals with PD. The information will also help communication partners and people with PD to understand how PD affects communication.

Chapter 5

Discussion

The study was able to answer the research question, “What are the experiences of communication partners of persons with Parkinson’s disease?” as the information shared by the participants resulted in rich experiences for analysis.

Deficits in Communication

One overarching theme identified in the interviews was that all seven participants reported deficits in communication between them and the person with PD. Most participants described incidences that resulted in an overall decrease in the amount of communication. Reasons for this ranged from frustration for one person, or both, difficulty to communicate because of a certain setting or situation, and some described severe cognitive deficits that almost eliminated verbal communication. The areas of deficits ranged between impairments associated with motor speech and cognitive declines, but changes in communication were evident across all of the experiences described.

Experiences with deficits in communication revealed connections between cognition and motor speech, which is consistent with published literature (Bayles & Tomoeda, 2014; Murray, 2008; Troche & Altmann, 2012). For instance, participants described how the person with PD did not seem to realize his/her voice was lower in volume than normal and therefore was unable to maintain positive communicative interactions. Persons with PD that experience cognitive communication impairments most commonly have difficulties in the areas of executive functioning and memory (Bayles & Tomoeda, 2014). Participants described daily executive

functioning tasks that involved memory, such as reading and following calendar events, were particularly difficult for some of the people with PD.

Another subtheme that was evident among several participants was the progressive nature of PD and the communication difficulties that accompanied the disease. All seven of the participants described a progressive decline in some area affecting communication or participation, whether it was motor speech, cognition or changes in mobility that had an impact on participation. Some participants described a decline in a certain area more than another, and some described a decline across all areas. This subtheme was consistent with the literature that reported PD as a progressive disease, along with the symptoms related to the disease process. (Yorkston, Miller, & Strand, 2004).

Emphasis on non-verbal communication.

Participants identified times when multiple modes of communication were used to facilitate communication. Another study that involved participants with PD and aphasia discovered the participants used other modes of communication as a way to repair breakdowns in communication (Carlsson, et al. 2014). Participants in the present study described using non-verbal communication to better communicate and even used them to help organization (e.g., using notes, pictures, written calendars). Participants also often described how the person with PD used non-verbal communication to better communicate with them (e.g., smiling, waving, and pointing). Emphasis was placed on how much more important it was to use gestures as a communication strategy, but training and reminding to use these strategies was also imperative to better communication.

Communication Partner Education

Participants shared about any experiences with training or therapy for improved communication skills. A few participants reported they had participated in a training or therapy, but not specifically for communication, and more for the general education of PD. Two participants commented that they wished they could have participated in some type of communication partner training to facilitate communication with people with PD. This finding was unique from the published literature reviewed.

Intervention a Common Experience

Therapy, training, and intervention was a theme discussed by many participants. They described the person with PD attending multiple therapies but most commonly, the persons with PD attended an LSVT LOUD training or, Think LOUD, or a similar intervention. It was noted that many participants reported the person with PD completed these trainings multiple times. Often the training was revisited when the person with PD displayed negative progression, specific to communication. This is consistent with a recent study that found the skills attained by the persons with PD during the LSVT LOUD program were maintained for about a year (Sapir et al., 2014). It is important to note that the people with PD discussed in the present study had the diagnosis of PD anywhere from 4-20 years, so some were more likely to have repeated the therapy.

Few participants described specific improvements noted after going through trainings but commented more on how they thought it was a way to "maintain" current skills. It should also be noted that the participants that described no improvements after attending therapy, reported how the person with PD was not consistent in practicing outside of therapy (specifically talking about

LSVT LOUD or Think LOUD). Recent literature on the practice of LSVT LOUD therapy emphasized the importance of intensive practice that was most beneficial if performed on a daily basis as well as continuing exercises beyond person-clinician practice (Fox et al., 2006).

Support Groups Proved Beneficial

An unexpected theme that emerged from this study was the importance of support groups. Several participants described how attending support groups provided the most benefits for their journey with a person who had PD. Participants described how beneficial it was to not only learn about strategies and tips from others but also to just have the opportunity to talk with others who were going through the same thoughts and feelings as they were. Some participants also described how the person with PD attended support groups. There was a strong theme of how support groups affected psychosocial well-being for the person with PD as well as his/her communication partner.

Psychosocial Responses

Psychosocial aspects was one of the most frequently described themes and was derived across all questions. Between all seven participants, approximately 40 responses were recorded that described the thoughts and feelings of the communication partners and the perception of how the person with PD felt. There were many commonalities between the participants' experiences. There were negative and positive feelings, but the responses provided an idea of how PD affected the person with PD and his/her communication partners. A similar study involved researchers interviewing people with PD and their feelings related to changes only in motor speech (Yorkston, et al., 2016.) The researchers reported participants felt multiple negative emotions related to communicating with others (Yorkston, et al., 2016.). The present

study expanded on this finding as psychosocial responses also related to cognitive decline and changes in participation in activities.

Difficulty adjusting to changes in communication and cognition.

After describing all the changes in communication and cognition, many participants commented how often they were frustrated with the changes, and how it equated to a feeling of their overall relationship changing. Several participants admitted to reducing communication because of these frustrations. Participants described how the person with PD felt the same way and reduced communication as a result. Because of all these changes, participants found it difficult to maintain their quality of life and the level of activities before the diagnosis, as well as feeling distance from friends and family. This was consistent with published literature that reported interviews with persons with PD and persons with aphasia where participants reported feeling isolated from their community and changes in relationships with family and friends (Brady, et al., 2011; Yorkston, et al., 2016.) Participants described how because of this, therapy and support groups were not only an activity for them but also a place where they felt comfortable. Both communication partners and the persons with PD found comfort in these activities because the other people at the activities were going through the same experiences, as well as interaction with the therapists and leaders that provided support and understanding. Because of difficulties with communication, both the person with PD and the communication partners felt their social life and events had either been reduced or changed from how they participated prior to the diagnosis. Communication partners found it important to try to continue activities the person with PD enjoyed.

Increased sense of responsibility.

Several participants shared how physical and cognitive limitations of the person with PD resulted in a reduced ability to perform tasks he/she used to complete. Because of this, participants felt an increased sense of responsibility and the stress that accompanied that. Participants reported they were "tired," or felt the responsibility to be "wearing," or even that it negatively affected their own social life.

Strengths of Research Design

The study contained integrity of data as the interviews were recorded word-for-word with opportunities for expansion and/or clarification. Participants were recruited until saturation of themes was noted. The data was thoroughly analyzed by two researchers and committee members were consulted with questions. The qualitative research design was effective in exploring and reflecting on the "real-life" experiences of the participants in order to understand their thoughts, feelings, and attitudes towards PD. Through interviews containing credibility and confirmability, and analysis of data containing triangulation and recurrent patterning, the qualitative research process is strengthened (Krueger & Casey, 2015; Maxwell & Satake, 2006).

Limitations

One possible limitation for this study was that all of the participants interviewed were from the upper Midwestern part of the country, including participants from North Dakota and Minnesota. Fairly broad inclusion criteria was utilized, so the severity of the PD varied across participants. All participants were asked to rate the level of independence of the person with PD and ratings ranged from 10% to 60% level of independence. The varied level of severities

provided a general view of experiences, rather than a more focused view of more similar experiences at one particular severity level.

Another possible limitation of this study was that although it was not an exclusion criterion, there were three participants and one person with PD that reported a self-diagnosed hearing impairment. Hearing impairments could have an effect on communication, however, that factor would have eliminated several participants from the study. The researchers made the decision to leave mild hearing impairments out of the exclusion criteria due to the high probability of occurrence in the population being studied.

Recommendations

This study provided rich information about the experiences of communication partners of people with PD. However, more research in this area would be beneficial due to the large population of people with PD. Each person with PD and his/her communication partners have their own expectations when referring to communication abilities. Further research in this area with a more diverse population would provide even more insight into how speech-language pathologists and other professionals can facilitate communication between people with PD and their communication partners. A future qualitative study on the same topic might focus on a particular severity level in order to gather more specific information. In addition, a similar study interviewing the person with PD instead of or in addition to the communication partner might also provide useful information alongside this study. It would also be beneficial to further explore a training program specifically designed for communication partners of people with PD, similar to the SPARC study (Forsgren, et al., 2013). Furthermore, with the unique information presented in this study about the significance of support groups and the connection to

psychosocial well-being, a future study aimed at discovering more on this topic might be beneficial for the communication partners of persons with PD.

Conclusion

This study shared the experiences and challenges people with PD and their communication partners encountered throughout their journey with PD. The information outlined in this study gives other communication partners of people with PD an insight into how the disease impacts communication, social life, and psychosocial well-being of all individuals involved.

It can be concluded from this study that changes in communication and cognition pose a real challenge for communication partners and people with PD. Some participants received information about the challenges they would face and some did not, but all participants shared the communication strategies they found to be helpful in their own lives.

In addition to sharing communication strategies that worked, the participants also shared their own thoughts and feelings. The study displayed the testimonies of how PD affects the psychosocial well-being of the communication partners. Among the important ideas shared by the participants, their responses included all the challenges in their lives due to the disease, and also the small strategies used to create joy.

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Appendix A



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Informed Consent Form for Research

Please read this consent agreement carefully before agreeing to participate in this study.

You are invited to participate in a research interview regarding your experiences as a primary communication partner of someone with Parkinson's disease. I hope to gain insight about the communication changes that have occurred since a diagnosis of Parkinson's disease has been made.

The interviews would be conducted one-on-one and will last approximately thirty minutes or less. Information will be audio taped for future analysis. The audio material would be kept in a locked place along with consent for this study. Any identifying information would remain confidential and would not be disclosed in any manner. In the write-up of the findings, your name will be changed, or you will be referred to in a general way that would not identify you in order to maintain as much confidentiality as possible.

If you choose to participate in this study, there will be no cost to you. There are no more than minimal risks associated with participating in this study. If you decide to participate, you are able to discontinue your participation at any time, with no penalty or prejudice from or to MSUM, or the SLP Department. If you participate in the study you will receive a copy of this form for your personal records.

Please feel free to ask questions at any time during the study. Should you have any questions, or wish to receive a synopsis of the results, please call me (Jackie Ellefson) at (701) 680-0665 or email me using the address ellefsojac@mnstate.edu or contact Dr. Nancy Paul, Professor, Speech Language Hearing Sciences, at (218) 477-4642 or paulnan@mnstate.edu. If you have questions about your rights, feel free to contact Lisa Karch, Ph.D., Chair of MSUM Institutional Review Board at lisa.karch@mnstate.edu.

The purpose and nature of this research have been explained and my signature indicates that I agree to participate in this study. I understand that I am free to withdraw at any time without any penalty.

Thank you for your participation.
Sincerely,

Jackie Ellefson, B.S.
Graduate Student, MSUM

Signature

Date

Name (Print)

Appendix B

Interview questions.

1. Tell me about any communication difficulties you encounter while communicating with (Person with PD).
2. Describe any changes over time in (Insert CP's name)'s communication abilities.
3. Share with me any strategies you use to better communicate with (Insert name).
4. Can you tell me about any strategies (Insert name) uses to better communicate with you?
5. Have you had any training or therapy on communication strategies?
 - A. Probe: If yes, please describe, and share how effective they have been.
6. Has (Insert name) had any training or therapy for communication strategies?
 - A. Probe: If so, could you describe anything they learned or any changes noted in communication afterwards?
7. Do you notice any changes in areas like memory, thinking, or attention for (insert name)? If so, can you share if/how this has affected communication?
8. Share how your own characteristics or interaction style have impacted communication with (Insert name).
9. Have difficulties in communication limited participation in events or activities you enjoy?
 - A. Probe: If yes, has that changed over time? Please explain.
10. Is there anything else you would like to share with me about communication with (Person with PD) that I have not asked about?

Additional questions about Swallowing and cognition for future analysis:

1. Have you noticed any changes in swallowing or eating? If so, can you share the swallowing problems (insert name) has experienced, and the effect this has had on you as (his/her) communication partner.

Appendix C

VI. Schwab and England Activities of Daily Living Scale

100% = Completely independent. Able to do all chores without slowness, difficulty or impairment. Essentially normal. Unaware of any difficulty.

90% = Completely independent. Able to do all chores with some degree of slowness, difficulty and impairment. Might take twice as long. Beginning to be aware of difficulty.

80% = Completely independent in most chores. Takes twice as long. Conscious of difficulty and slowness.

70% = Not completely independent. More difficulty with some chores. Three to four times as long in some. Must spend a large part of the day with chores.

60% = Some dependency. Can do most chores, but exceedingly slowly and with much effort. Errors; some impossible.

50% = More dependent. Help with half, slower, etc. Difficulty with everything.

40% = Very dependent. Can assist with all chores, but few alone.

30% = With effort, now and then does a few chores alone or begins alone. Much help needed.

20% = Nothing alone. Can be a slight help with some chores. Severe invalid.

10% = Totally dependent, helpless. Complete invalid.

0% = Vegetative functions such as swallowing, bladder and bowel functions are not functioning. Bedridden.

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