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Spouse Perception of Speech Therapy for Individual's with Parkinson's Disease

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Abstract

The purpose of this study was to investigate the spousal perceptions of a partner with Parkinson's disease undergoing speech therapy versus a partner with Parkinson's disease (PD) without any form of therapy. A case study approach was used to complete this research project. Two couples with one spouse in each of the couples having a diagnosis of Parkinson's disease were sought through nomination as participants. The gender, age, and length of time since diagnosis were matched for the individual with PD. One of the couples will have been enrolled in speech therapy while the other couple will have not. A semi-structured interview about living with PD and therapy choices was separately conducted with each of the four individuals. The interviews were audio recorded for later transcription of content. The analysis consists of identifying themes for each of the two couples and will explore how these are similar and/or different.

### Spousal Perception of Speech Therapy for Individuals with Parkinson's Disease

A speech language pathologist works with a full variety of human communication and its disorders. The full-range spectrum includes evaluating and diagnosing speech, language, cognitive-communication and swallowing disorders and treating for these disorders in individuals of all ages, from infants to the elderly (ASHA, 2011). Parkinson's disease is a disorder of the central nervous system as a result of an alteration in the part of the brain that controls movements such as walking and balance. The symptoms consist of tremors, slothfulness of movement, muscle stiffness and difficulties with stability. Common speech complications experienced with Parkinson's patients consist of concentrated volume, condensed pitch range, and trouble with enunciation of sounds, also recognized as dysarthria. They find it challenging to convey emotion when speaking as well as finding it hard to form the words they are attempting to articulate (McNamara, 2010).

Both definitions stated above link together in numerous ways. As time goes on and symptoms progress, speech and communication worsen to the point where patients may avoid conversing with others. Speech language pathologists are here to assist in that dilemma through speech therapy. However, what is it that these men and women actually want to gain from there therapy? This is an important question because at times, the individual with PD versus the spouse may be looking for something completely different. The optimal way patients can be helped is if they have speech therapy to somewhat assist them in communication. But, because of the difference in expectations, couples may find this entire process challenging or even unacceptable to their lifestyle and personal goals. Therapy is a very stressful process and if the couple is not on the same page, additional stress can only be added.

The purpose of this study is examine perceptions and values that patients with PD and their spouses have about speech-language therapy.

### **Review of the Literature**

Parkinson's disease is a nervous system disorder common amongst both men and women over the age of 50. In the United States alone, approximately one million people are living with the disease today (A.D.A.M., 2013). This disease results from a deficiency and demise of nerve cells in the brain that create dopamine that results in difficulty with muscle control. In time, the disease and damage worsen until almost every part of the body is affected. Patients experience mild to severe tremors of the hands, arms, legs, jaw and face as well as stiffness of the upper and lower extremities. Bradykinesia, slowness of movement, and impaired balance and coordination are also in occurrence (A.D.A.M., 2013).

Parkinson's leads to a variety of common speech disorders that impact communication and may affect self-worth. Speech therapy is an option that can help maintain skills. Throughout the progression of speech therapy, it typically consists of a series of voice exercises given by a speech language pathologist. The exercises entail training in control of speech rate, stress and intonation of emotion, loudness, articulation and breathing. Some therapists have claimed that these routine therapies can be a great success (McNamara, 2012). Those with PD may also experience psychological upset due to their speech inadequacy. This includes and is not limited to forms of depression, psychosis, and anxiety.

### **Living with Parkinson's Disease**

As can be seen from the overview of PD, the quality of life for individuals can diminish because of a wide range of progressive and reoccurring symptoms. Each of these can have a tremendous impact on the spouse who is typically the caregiver, yet there are few studies that

explored this relationship. A closer look at research on the various complex issues that face individuals with PD and their spouses will now be reviewed.

### **Quality of Life**

Of those with Parkinson's disease, they seek out treatment predominantly directed towards refining motor function. The disease, conversely, is complicated by further difficulties. These comprise of numerous psychological concerns such as depression, anxiety, and psychosis. With the addition of further problems, an individual with Parkinson's quality of life is prominently changed. By definition, quality of life (QOL) is measured as a comprehensive multidimensional perception that comprises of subjective assessments of both positive and negative aspects of life (Centers for Disease Control and Prevention, 2011).

### **Psychological affects**

**Depression.** For those existing with Parkinson's, they are faced with the hardships and struggles from what their symptoms lead to, psychological concerns. A common issue found in, on average 60 percent of Parkinson's, is depression which can range from moderate to severe (Parkinson's Disease Foundation, 2013 a). Many areas of the brain are provoked by Parkinson's. New studies have proposed that the chemical imbalance in the brain is a key trigger in the problem. This includes a specific area where serotonin, a brain chemical associated with depression, is produced. In addition is the frontal lobe, which is imperative for mood regulation. The overwhelming stress caused by the disease also plays a vital role in the psychological disorder. Family members often take first notice of the gradual changes in the individual. Because depression affects Parkinson's patients inversely in relation to the broad-spectrum, the disorder is marked by feelings of cynicism due to their incapability of doing things they once could. Today, treatments for depression are growing in numbers. Cognitive behavioral therapy,

a form of psychotherapy, is very common amongst the treatment plans for PD. Antidepressants such as Selective serotonin reuptake inhibitor (SSRI) and Serotonin and norepinephrine reuptake inhibitor (SNRI) are also very commonly used (National Institute of Mental Health (2011)).

**Anxiety.** Anxiety is another common psychological disorder that many with PD suffer from. The reasons for this disorder to stem from Parkinson's are endless. For example, because anxiety is a feeling of fear, it is obvious to see that the individuals are at high risk for the disorder because of the many symptoms that are linked to Parkinson's. Anxiety typically fluctuates depending upon the situation which correlates to the symptoms of PD which also come and go. Fear, constant worry, and tension are shown present as well as physical symptoms such as dizziness, muscle pain, and nausea. These symptoms interlink with the symptoms of PD which is why certain psychological disorders turn up unnoticed. The usual treatments can be used such as counseling, participating in a support group, muscle relaxing therapies, and forms of anti-anxiety medication (Parkinson's UK, 2013).

**Psychosis.** Psychosis, according to the United States National Library of Medicine, is a loss of contact with reality and includes delusions and hallucinations (A.D.A.M., 2013). Most Parkinson's patients experience psychosis due to the side effects of their PD medications. This is because certain medications to improve motor controllability have an increase in dopamine levels which can unintentionally harvest this psychological disorder. Other common medications taken that have a lower level of acetylcholine and an alteration in levels of dopamine can also develop a derivation for the disorder. Dementia and delirium are furthermore known causes of psychosis. Due to the various origins of the disorder, ruling out a treatment plan can be challenging. The cause must first be identified before a strategy can be formed. In relation to PD medications, levels of dopamine need to be balanced in accordance to the psychosis. Other

medications may need to be reduced or adjusted as well (National Parkinson Foundation, 2013 a).

### **Speech Disorders and their Treatment**

**Speech production.** Utilization of the primary articulators which include the lips, tongue, vocal folds, jaw and oral cavity are all essential in the utilization of speech and swallowing. In the case of Parkinson's disease, it conflicts with the musculature of these structures as well as the nerves that coincide. Studies have shown that up to 90% of those with Parkinson's disease find themselves having difficulty with speech and some have severely limiting symptoms. This compromises of difficulty with speech as well as swallowing, chewing, and eating. They experience speech disorders such as dysarthria, difficulty speaking, and dysphagia, trouble swallowing. Speaking with lax or hoarse speech or having a monotone voice is very common among PD patients. Difficulty in pitch variation and speaking rate are included in this symptom, as well. The struggle of pronunciation and articulating properly is seen quite often due to emerging tremors in the voice. With the accumulation of these various disorders, people with Parkinson's tend to remove themselves from conversation. Their inadequate speech causes a sense of insecurity and therefore results in societal withdraw (Parkinson's Disease Foundation, 2013 b).

**Speech therapy.** Speech therapy is essential with PD patients, especially those with severe forms of speech disorders. The Lee Silverman Voice Technique (LSVT) has been proven to be the most effective form of speech therapy. Results have been presented to last up to two years post-therapy. This method of therapy compromises of a concentrated 4-week course that assists in the development of strength required for typical spoken volume. Positive outcomes have derived from this and indicate a substantive increase in intelligibility, swallowing, and

facial expressions. Several may refer to non-verbal forms of communication. They utilize residual speech which is the practice of making the most of their speaking capability, operative use of expressions and gestures, and alleviating the extent of stress (Cleveland Clinic, 2009).

**Evidence based practices using therapy.** The best therapy is that which is supported by research. Such research can assist therapists and families to make decisions about issues such as duration of treatment, frequency of treatment, and potential outcomes. Simberg, Rae, Kallvik, Salo, and Martikainen (2012), researchers and therapists at The Department of Psychology & Logopedics, assessed the effects of a two-part, 15-day rehabilitation course on speech and voice function in Parkinson's disease. The process they used consisted of regular speech therapy sessions in both individual and group sessions. Six participants with Parkinson's and their spouses partook in the study. Speech samples were logged and examined in means of perception and acoustics. Additionally, the participants completed the Voice Activity and Participation Profile. A version of the questionnaire was also specified to the spouses. They used this to assess their spouses' voice restrictions and activity and participation limitations. The results exhibited that the voice quality improved significantly both in the reading and speech samples. Acoustic analysis indicated that ordinary fundamental frequency and vocal range augmented in the measurements made three months post onset of treatment. Likewise, the outcomes from the VAPP revealed that the quality of life did in fact improve (Simberg, et al., 2012).

### **Effects on Spouse and Caregiver**

Parkinson's disease is the noticeable cause for countless psychological disorders. However, when viewing from an outside perspective, one might lose sight of the fact that the spouse of an individual with PD is also tremendously affected. Those men and women who tend to act as the caregiver are also at risk for certain psychological disorders or major implications

themselves. A study was conducted by O'Reilly, Finnan, Allwright, Smith and Ben-Shlomo (1996) to determine if caring for a partner with PD is connected with a deteriorating social, psychological and physical well-being versus a spouse and their partner who aren't suffering from the disease. The researchers randomly collected 154 spouses with partners with PD and 124 spouses with partners without PD. They were found in a previous national case study of early-onset PD. The average age of the spouse was 56.4 years old. The patients with Parkinson's were allowed in this study because they had two or more of the standard diagnostic criteria. Each individual was required to complete a self-administered questionnaire at home. Social function was assessed by inspecting social interaction, excursions and holidays. Psychological health was calculated by the 12-item general health questionnaire. Physical health was weighed by their health care utilization, medication and self-reported illness. The dependency of the PD patient was also assessed, centered on how much care they required. Other data was factored in such as socio-economic status, household income, and life changing events.

Outcomes of this research suggested that spouses of partners with Parkinson's disease were under a great strain. Various things contributed to this. The likelihood of leaving the house once a week was slim. Due to the high necessity for care, their contact with friends decreased contingent upon severity of the PD. In relation to the amount of care provided, psychiatric morbidity was almost 5 times greater than that of spouses of partners without Parkinson's disease. Medical outcomes were also less favorable among the spouses. In conclusion, social, psychological, and physical well-being were lower in those spouses dealing with a partner with PD. Of those spouses providing a more significant amount of care experienced even worse

health. However, the most severe cases of PD were excluded from this study so the affects may be an underestimate (O'Reilly, Finnan, Allwright, Smith, & Ben-Shlomo, 1996).

An additional study was completed on the caregiver burden in Parkinson's disease by Martínez-Martín, Forjaz, Frades-Payo, Rusiñol, Fernández-García, Benito-León, and Catalán (2007) and had similar findings from the previous study stated. The researchers measured caregiver burden (CB) by the realm of physical, mental, and socio-economic problems. The impact of PD on patients' and caregivers' quality of life and caregiver burden has developed attention amongst researchers. For this particular study, these two factors were examined in caregivers of PD. The connection between the relationship between quality of life and CB and socio-demographic, patient-care, functional, and emotional issues were also assessed. The researchers purposed that CB was linked to the level of patient care and that there was a correlation between CB and the caregivers' quality of life. They also believed that there was a substantial relationship between CB and quality of life with the severity of PD. In addition, they hypothesized that the depression of a PD patient would have an impact on a CB and their quality of life. To conduct this study, 80 patients with Parkinson's disease and their respective caregivers from four Spanish provinces were tested. A customary assessment completed by a neurologist qualified them for the research. Other examinations specific to the study were administered to determine the projected measures. Results revealed that caregiver burden was not linked to the caregivers' age and was consistently higher in females. Caregiver burden was directly interrelated with the amount of time dedicated to care and the level of exertion in that role. The severity of the disease, as well as disabilities it incorporates, were found to influence quality of life. The caregivers' depression was linked with higher CB and lower quality of life. Overall, the many factors that can effect CB are as followed: the psychological welfare of a

caregiver, severity of symptoms of disease, patient with PDs' temperament, and quality of life in both individuals (Martínez-Martín, Forjaz, Frades-Payo, Rusiñol, Fernández-García, Benito-León, & Catalán, 2007).

Pasetti, Ross Ferrario, Fornara, Picco, Foglia, and Galli (2003) performed a similar study to investigate the matters of those caring for patients with Parkinson's disease. Regardless of the stage and severity, they were determined to seek out the difficulties each caregiver professed. Twenty-five spouse-patient couples and 57 caregivers completed surveys. The sample group of 25 couples participated in individual interviews. They were asked to answer questions based on the areas that might be affected by the diagnosis and response to the disease. This included disease-induced deviations connected to work, ordinary activities, relationships with others, economic harms, drug management, and expectations. Of the 57 caregivers, majority of them were spouses. They were asked about their emotional instability, emotional distress, difficulties with social participation, comprehension of PD, the eminence of family structure, feelings on death, and their quality of life. Of those 25 couples questioned, the majority of patients with Parkinson's disease had parallel needs as to those of their spouses. In regards to the second sample of 57 caregivers, the need for further information was linked to greater emotional distress. Moreover, the outcomes suggested that optimistic family relationships were associated with one's quality of life and consequently led to greater willing to execute certain responsibilities. Subjects that scored higher on items inspecting emotional instability had additional concerns. This consisted of anxiety, depression, thoughts of death, and social isolation. In terms of gender, the researchers found that females had a greater emotional burden than male caregivers. Overall, the results of this study showed that patients with PD and their spouses need better understanding of the actual disease and roles as a caregiver. Part of this for

the caregiver is recognition of their everyday contributions. The variances discovered amongst male and female caregivers contradict other research completed on gender studies. Selected studies have found that male caregivers have greater emotional burden than their female counterparts. This needs to be more thoroughly scrutinized as well as factoring in the stage and severity of the disease (Pasetti, Rossi Ferrario, Fornara, Picco, Foglia, Galli, 2003).

Just over 1% of published papers on Parkinson's disease have included or specifically targeted spouse-related problems (Pasetti, Rossi Ferrario, Fornara, Picco, Foglia, & Galli, 2003). This is why further research needs to be completed to gain additional information on this topic. In regards to the previous studies discussed, it is obvious that caregivers undergo great emotional distress when dealing with a patient with Parkinson's disease. All of these studies have been geared towards the same issues; a caregiver's emotional and physical health.

### **Summary and Questions of the Study**

As can be seen from this review of the literature, a good deal is known about the medical course of Parkinson's disease, both the physical decline and the mental health issues that accompany this. There have also been a number of studies that have explored spousal issues. Research has not asked what the spouse actually wishes for their partner with Parkinson's disease in order to make that life better. More specifically, no studies have explored spousal responses to speech-language therapy over the course of the disease process. Therefore, the purpose of this study was to investigate spousal perspectives on such treatment. The specific questions of the study are as followed.

1. What are the everyday complications and concerns that spouses of individuals with Parkinson's disease experience as the disorder progresses?
2. Do spouses of individuals with Parkinson's disease recognize speech therapy as helpful?

3. Do spouses value therapeutic interventions differently as the disorder changes over time?
4. Are the expectations and satisfaction of spouses different if their partner received speech therapy versus those who did not?

## **Method**

### **Participants**

Two couples, one of whom has a diagnosis of Parkinson's disease were sought through nomination as participants in this study. One of the couples did not, nor ever, had been enrolled in speech therapy while the other couple had received therapy. The person with Parkinson's disease in each couple was matched for age within a five year span, duration of disease process, and gender. There was no preset control for age, duration of disease, gender of the person with Parkinson's or the spouse, or how long they have lived together.

### **Materials**

A series of questions was used to conduct the semi-structured interviews with spouses and the person with Parkinson's disease. This included questions that addressed (a) the diagnosis and history of the disease, (b) symptoms and complications of Parkinson's disease, (c) everyday activities, (d) medical interventions, (e) emotional and psychological stress, and (f) perceived value of speech therapy.

### **Procedures**

Individuals within the community, SLPs and Parkinson's support groups were contacted in order to see if they can nominate couples for the study. The researcher completed a follow-up on each nomination until two couples that fit the study design were located. The researcher then met with each couple individually to explain the purpose of the research and receive permission to include them in the study. An individual semi-structured interview was conducted in a

clinical or home setting, dependent upon the interviewee's request. The interview was audio recorded and transcribed.

### **Analysis**

The resulting data was analyzed for themes. Once this was completed, the participants were contacted for a second time to check over the data and the interpretation of this by the researcher. This was to ensure that no errors were made when transcribing the audio recording. After the member checking was completed, the results portion was completed followed by a discussion section.

## **Results**

### **Demographics**

Two couples were participants in this study and underwent an individual 30-minute interview at their location of choice (see Table 1). In each couple there was a spouse living with Parkinson's disease. One couple was undergoing speech therapy while the other was not. The first participating couple, Mr. and Mrs. Smith, reside in Arkansas. Mr. Smith is 75, retired, and has been living with PD for 8 years. He is currently undergoing speech therapy. Mr. Smith's major symptoms included complications with rigidity, balance, vocal strength, swallowing, and dementia. He is also recuperating from lung cancer, skin cancer, and prostate cancer. His wife was 68 years old and acts as the sole caregiver. She was also retired, acts as a mother and grandmother, and partakes in activities in her community. The second participating couple, Mr. and Mrs. Jones, are from Missouri. Mr. Jones, 76, has had Parkinson's disease for 6 years. He was not participating in any form of speech therapy. His major symptoms included difficulties with swallowing, breathing, vocal strength, and tremors. His spouse, at age 77, was the sole

caregiver. Mrs. Jones is retired, a mother and grandmother, and partakes in activities outside the home.

### **Question One**

The first question of this study asked what the everyday complications and concerns were that individual's with Parkinson's disease and their spouses experience as the disorder progresses. The regular complications of Parkinson's disease were divided into four categories. Items 1, 2 and 3 of the interview questions were used to assess each category. In regards to the first topic, voice and swallowing, Mr. Smith, who is undergoing speech therapy, delivered the highest number of responses (see Table 2.) When asked about the general symptoms of his Parkinson's, he replied with, "Of course I've had speech problems and swallowing problems (J. Smith, personal communication, April 11, 2014)."

Concerning the second class, mental complications, Mr. Smith also placed highest amongst the participants. When inquired on item 1 about the general symptoms, he replied with "the stopping and slowing down of mental processes" and "cognitive impairments (J. Smith)" immediately following the question. Mrs. Smith discussed the same issues concerning her husband and ranked second in frequency of response.

The third category, social isolation, was brought up most frequently in the couple undergoing no speech therapy, Mr. and Mrs. Jones. When asked what activities Mr. Jones wasn't able to participate in anymore, item 2, he replied with a number of things. This led to discussion on feelings of helplessness and avoiding public places due to physical symptoms. For example, he said, "I feel embarrassed from my speech problem. The shaking bothers me when I'm out in public (R. Jones, personal communication, January 3, 2015)". Mrs. Jones stated that

his speech and swallowing issues inhibited him from speaking around others which caused a shift in their social life.

For the last set, physical complications and limitations, Mr. Smith, responded the greatest amount of times on this matter. In response to item 1, he replied with a number of problems. For instance, he said, "I feel like I have tremors all over. You know a lot of rigidity. I have some balance problems (J. Smith)". In response to item 2 on limiting symptoms that had to be overcome, he also talked about the effects his PD has on walking, standing, and driving.

Overall, Mr. Smith, whom is partaking in speech therapy, had the highest number of responses on three out of the four categories regarding everyday complications and concerns. Mrs. Smith and Mrs. Jones each ranked second in 2 categories.

### **Question Two**

The second question of this study asked if spouses of individuals with Parkinson's disease recognize speech therapy as helpful. Items 4 and 5 of the interview questions provided information to answer this. Mrs. Smith, whose husband is undergoing speech therapy, said intervention was valuable for those with Parkinson's disease. In response to item 4, she stated that her husband has done very well in his therapy. The amount of times she requests that he speak louder and mask his speech complications has condensed dramatically. Mrs. Jones, whose husband is not undergoing any form of speech therapy, was asked alternative questions regarding intervention. When asked if she or her husband considered therapy, she replied with, "I really was not aware until recently that the speech therapy would be beneficial and I think that's an option he should really consider (J. Jones, personal communications, January 3, 2014)". She then went on to talk about the speech and swallowing issues that could improve with speech therapy. Both caregivers stated if vocal quality and swallowing improved, their quality of life

would improve as well. Therefore it was reported that speech intervention was beneficial for the partner afflicted with Parkinson's disease as well as the spouse.

### **Question Three**

The third question of this study asked if spouses value therapeutic interventions differently as the disorders change over time. Items 4, 5, and 6 of the interview were used to answer this question. In response to item 6, Mr. Smith stated, "I think also speech therapy is one of those double edged swords. On one end, yes, it helps and that's a very positive aspect. But at the same time, it's reminding you that you're needing speech therapy. You can't talk anymore so you're having to face a reality of decline at the same time that you're hoping for an improvement (J. Smith)". He stated that as his condition progresses, he will find that speech therapy is more of a remedial tool than a curable one. However, Mr. Smith said that receiving speech therapy over time would give his wife a peace of mind. When asked the question from item 5 in the alternate interview, Mr. Jones stated that he had not considered speech therapy at this point in time. He does not believe that his speech and swallowing are extreme enough to need such help. Nevertheless, when asked if he would consider it as the disease developed, he affirmed and indicated that his doctor has made this recommendation in the past.

The spouses without PD did not give as much information as the spouses with PD on this question. However, they provided insight to determine that as speech and swallowing degraded, they would put more emphasis on speech therapy. For example, in reply to item 4, Mrs. Smith indicated that she did put importance on speech therapy as her husband's speech and swallowing advanced. She stated that his vocal quality was enhanced which improved her daily life. Mrs. Jones delivered stated that if her husband's symptoms worsened, she too would see speech therapy as advantageous.

#### **Question Four**

The fourth question of study asked if the expectations and satisfaction of spouses are different if their partner received speech therapy versus if they did not. Items 5 and 6 from the interview questions provided information used to answer this question. The responses given by Mrs. Smith sketch a very positive image of speech therapy. She claimed that her spouse has benefited greatly from therapy. In response to item 6, she stated that she is able to hear her spouse more easily than she could prior to his speech therapy. Therefore, she is satisfied with the improvement Mr. Smith is making while undergoing speech therapy. In regards to her expectations, she stated she anticipates that he will continue to make use of his entire voice while conversing in social conversation. Mrs. Jones specifically provided information on what she could potentially see a benefit for her husband's speech and swallowing difficulties. As stated previously, she believed that in retrospect, if Mr. Jones was to enroll in therapy, his overall quality of life would improve which would correspondingly improve hers. She stated, "He would not be as ill at ease about eating with people. I think he would be more comfortable with people in general (J. Jones)". If therapy were to be utilized, she believes she would be satisfied with his speech. But, as of right now, she stated her main concern is with the problems caused by his Parkinson's disease. Therefore, she has no expectations of her husband seeking speech therapy. She does, conversely, expect there would be an improvement if he would undergo speech therapy.

#### **Discussion**

Over time, a number of studies have investigated the mental and physical deterioration caused by Parkinson's disease. In recent years, the impact of the disease on caregivers has been

studied (O'Reilly, F., Finnan, F., Allwright, S., Smith, G. D., & Ben-Shlomo, Y., 1996). This literature points out that caregivers undergo emotional stress which may lead to physical decline. However, very few studies have included the role of speech therapy or spousal concerns in response to speech-language therapy over the course of the disease development. For that reason, the purpose of this study was to explore the spousal perceptions of a partner with Parkinson's disease undergoing speech therapy versus a partner with Parkinson's disease without any form of therapy.

When analyzing the general symptoms and complications of Parkinson's disease, it seems that there is a relationship between enrolling in speech therapy and spousal perception of changes in functional speech production. When reviewing the results of the response frequencies regarding general symptoms, the couple undergoing speech therapy had more insight based on the classifications of the complications. The spouse with PD spoke more often of his voice, swallowing, mental and physical complications than each of the other four participants. Likewise, his spouse spoke more clearly about mental and physical complications. The couple undergoing no form of speech therapy was less perceptive about these matters. They did, however, provide more insight about the issue of social isolation than the couple undergoing speech therapy. These outcomes suggest that speech therapy can make living with PD more understandable. In the interview, even though the couple was receiving speech therapy, they talked repeatedly of the general symptoms of Parkinson's disease versus the second couple who spoke less of the subject matters. However, the couple undergoing no form of therapy reported higher responses in the category of social isolation. This suggests that better speech may reduce societal separation even if it highlights the disease process. This is consistent with the finding

that the accumulation of the many disorders stemming from Parkinson's disease can result in societal withdraw (Parkinson's Disease Foundation, 2013).

When looking at the spousal perceptions in relation to therapy, it can be concluded that speech therapy can be a valuable tool for spouses. The literature firmly supported that therapy can be a very positive intervention for individuals with Parkinson's disease. When looking at a study on the effects of a two part, 15-day rehabilitation course, results showed that voice quality significantly improved. Also, three months after the treatment, data illustrated that fundamental frequency and vocal range were augmented, and quality of life did in fact improve (Simberg, et al., 2012). This is consistent with the results of this study because the spouse of the husband undergoing speech therapy detected an improvement in his voice. Therefore she considered speech therapy to be particularly constructive. Similarly, when observing the second couple not undergoing speech therapy, the spouse without PD specified she thought it might help her husband.

The results of this study also seem to indicate that spouses might value therapeutic interventions differently as the disorder progresses. The husband with PD undergoing speech therapy was both positive and negative in his perceptions. He believed that while speech therapy acts as a representation of weakness, it also forces a sense of reality that patients may not be willing to face. This is illustrated by the participant with PD not undergoing speech therapy who wanted no involvement at the present time. Although, he did list a substantial amount of speech and swallowing problems, he was more concerned with the disease progress. The responses of the caregivers about speech therapy were very similar, both thinking better communication would help in everyday life.

There is a correlation between the progression of the disease and the overall worth of speech therapy reported in the literature. As speech and swallowing decline, a need for intervention surges. This can be due in part to the fact that as the disease becomes more debilitating, the amount of time dedicated to care and level of exertion increases. This is correlated to caregiver burden which has a direct influence on quality of life. Factors such as psychological welfare and severity of symptoms are just few of the many that can impact caregiver burden (Martínez-Martín, Forjaz, Frades-Payo, Rusiñol, Fernández-García, Benito-León, & Catalán, 2007). Thus, the results of this study align with these research findings.

Perhaps more importantly, it can be concluded from this study that the expectations of spouses do differ if their partner received speech therapy versus if their partner did not. However, their satisfaction did not contrast in any ways. The spouse of the husband undergoing speech therapy had higher expectations for her husband than did the spouse of the husband not enrolled in speech therapy. This could be because she was highly satisfied with the progress he was making in his speech and swallowing. Therefore, she would anticipate that he would continue to progress even though her husband believes that this is just a remedial tool, not a curable tool. The spouse of the husband with PD not receiving speech therapy had no expectations for her husband's speech changing. Moreover, she did not think it was an issue that needed professional assistance at the time of the study. Both caregivers did consider that their satisfaction was a vital influence on their quality of life. This can be supported by evidence concluding that social, psychological, and physical well-being are congruently lower if they are caring for a partner with Parkinson's disease (O'Reilly, Finnan, Allwright, Smith, & Ben-Shlomo, 1996). Overall, the caregiver's expectations were impacted by the progression of their

spouse's Parkinson's disease and whether or not they were enrolled in any form of speech therapy.

### **Limitations**

While this research did offer insight into the spousal perception of speech therapy, the limitations of the study did restrict the resulting data. The two couples had varying backgrounds and temperaments. Because of the unevenness in demeanor, this may have impacted the length of response given after each question. Furthermore, the four participants delivered revealing data but additional applicants would have provided an enhanced understanding of the spousal perception. More couples are needed to obtain further insight into the spousal perception of speech therapy. The nomination process was slow and made matching by age and gender difficult. Data could have been obtained using a variety of open-ended questions that could be distributed at support groups for PD. This would allow for more informative answers as well as ease the tension brought on by face-to-face interview.

### **Future Directions**

A future direction for this study is to collect data using focus groups at PD support meetings. This data will be used to then target different approaches to speech intervention as the PD process unfolds.

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## Appendix A

### Tables of the Study

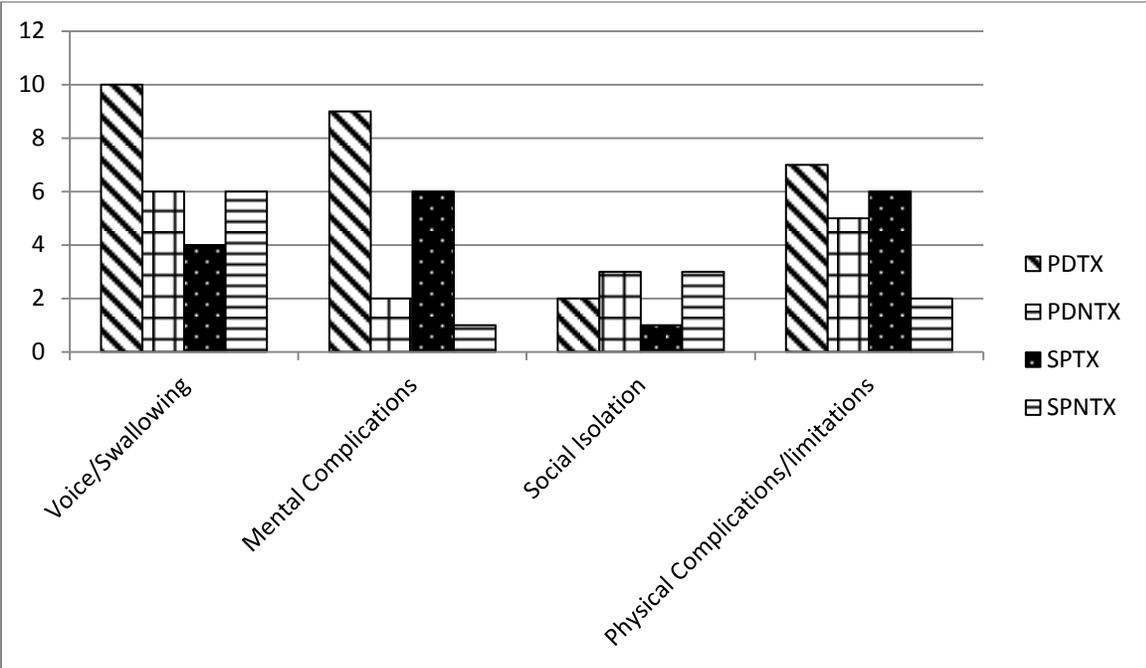
Table 1

#### *Demographics of Respondents*

	Mr. Smith	Mrs. Smith	Mr. Jones	Mrs. Jones
Caregiver/Parkinson's disease	PD	Caregiver	PD	Caregiver
Enrolled in speech therapy	Yes	No	No	No
Age	75	68	76	77
Number of years with PD	8	N/A	6	N/A
Employment	Retired	Retired	Retired	Retired
Residence	Arkansas	Arkansas	Missouri	Missouri
Major symptoms	Rigidity, balance, loudness of voice, swallowing, dementia	N/A	Tremors, swallowing, vocal intensity, breathing	N/A

Table 2

*Frequency of responses on the regular complications of Parkinson's disease*



*Note:* PDTX= PD patient undergoing therapy, PDNTX= PD patient with no speech therapy, SPTX= Spouse of patient with PD undergoing speech therapy, SPNTX= Spouse of patient with PD with no speech therapy

## **Appendix B**

### **Interview for Spouse with Parkinson's disease:**

1. At what age were you diagnosed with Parkinson's disease and what have been the general symptoms and complications you have been required to overcome?
2. What activities do you participate in on a daily basis? What activities are you limited from?
3. Is there anything that you have dynamically done to mask these symptoms and complications to maintain a façade?
4. In what ways have you felt differently after diagnosis of this disease and has that changed over time?
5. What do you believe is your overall goal you're attempting to achieve in speech therapy?
6. What do you believe is your spouse's overall goal you're attempting to achieve in speech therapy?
7. In regards to your family and friends, have they added any significant burden? Has the dynamic changed in any way?

### **Interview for Spouse without Parkinson's disease:**

1. What do you believe have been the biggest complications your spouse has been required to overcome in comparison to the biggest complications you have been forced to overcome?
2. In what ways have you felt differently after diagnosis of this disease and has that changed over time?

3. As a caregiver, do you believe that this is and will continue to disrupt your daily life as a healthy individual?
4. What do you believe your spouse should be accomplishing from their speech therapy?
5. How do you think this should benefit them in their daily lives? How do you think this should benefit you in your daily life?
6. In regards to your family and friends, have they added any significant burden? Has the dynamic changed in any way?

**Alternate Questions for Spouse with Parkinson's Undergoing No Speech Therapy**

5. Did you or your spouse consider speech therapy? Is so, why or why not?
6. Do you think in retrospect that it would have impacted/improved your daily life?

**Alternate Questions for Spouse of Person Undergoing No Speech Therapy**

4. Did you or your spouse consider speech therapy? If so why or why not?
5. Do you think in retrospect that it would have impacted/improved your daily life?

**Appendix C**

November 19, 2013

MEMORANDUM

TO: Emily McLain  
Fran Hagstrom

FROM: Ro Windwalker  
IRB Coordinator

RE: New Protocol Approval

IRB Protocol #: 13-10-216

Protocol Title: *Spousal Perception of Speech Therapy for Individuals with Parkinson's Disease*

Review Type:  EXEMPT  EXPEDITED  FULL IRB

Approved Project Period: Start Date: 11/18/2013 Expiration Date: 11/17/2014

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Your protocol has been approved by the IRB. Protocols are approved for a maximum period of one year. If you wish to continue the project past the approved project period (see above), you must submit a request, using the form *Continuing Review for IRB Approved Projects*, prior to the expiration date. This form is available from the IRB Coordinator or on the Research Compliance website (<http://vpred.uark.edu/210.php>). As a courtesy, you will be sent a reminder two months in advance of that date. However, failure to receive a reminder does not negate your obligation to make the request in sufficient time for review and approval. Federal regulations prohibit retroactive approval of continuation. Failure to receive approval to continue the project prior to the expiration date will result in Termination of the protocol approval. The IRB Coordinator can give you guidance on submission times.

**This protocol has been approved for 4 participants.** If you wish to make *any* modifications in the approved protocol, including enrolling more than this number, you must seek approval *prior* to implementing those changes. All modifications should be requested in writing (email is acceptable) and must provide sufficient detail to assess the impact of the change.

If you have questions or need any assistance from the IRB, please contact me at

210 Administration Building, 5-2208, or [irb@uark.edu](mailto:irb@uark.edu).