PERCEPTION OF SYMPTOMS, CURRENT NEEDS, AND BARRIERS OF SERVICE DELIVERY FOR INDIVIDUALS WITH PARKINSON DISEASE AND THEIR FAMILIES

By

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Bachelor of Science in Speech Pathology and Audiology

University of North Texas

Denton, TX

2019

Submitted to the Faculty of the
Graduate College of the
Oklahoma State University
in partial fulfillment of
the requirements for
the Degree of
MASTER OF SCIENCE
May 2021

PERCEPTION OF SYMPTOMS, CURRENT NEEDS, AND BARRIERS OF SERVICE DELIVERY FOR INDIVIDUALS WITH PARKINSON DISEASE AND THEIR FAMILIES

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ACKNOWLEDGEMENTS

First and foremost, I want to extend my profound gratitude to my advisor, Dr. Sabiha Parveen, for the innumerable ways she guided me throughout this process. The manner in which she directed me exceeded any expectation. Also, the encouragement and support received from my other committee members, Ms. Karen Copeland, and Dr. Tim Passmore, is greatly appreciated and was beyond what they could have done. I also want to express special thanks to those who completed surveys. Without such participation my work could not have been done as accurately and efficiently as required. Lastly, for my family and friends who helped me stay the course, words fail as I attempt to thank you. The endless support and covering in love will remain etched in my thoughts.

Name: Jaelan Moore

Date of Degree: MAY 2021

Title of Study: PERCEPTION OF SYMPTOMS, CURRENT NEEDS, AND BARRIERS TO SERVICE DELIVERY FOR INDIVIDUALS WITH PARKINSON DISEASE AND THEIR FAMILIES

Major Field: COMMUNICATION SCIENCES AND DISORDERS

Abstract: Parkinson disease (PD) is a progressive degenerative neurogenic disorder associated with a variety of symptoms and affecting multiple modalities of an individual's functioning. A systematic examination of current perception of symptoms, different met and unmet needs, and barriers of healthcare related services for people with PD and their families can allow healthcare professionals to design more effective education, awareness, and management programs for the PD community. Therefore, the current study focused on examining perceptions of different PD-related symptoms among individuals with PD and communication partners (including spouses and family members) living in the Midwest region of the United States. Additionally, the study examined the current met and unmet needs, as well as existing barriers to healthcare services for individuals with PD and their communication partners living in these regions. Findings indicated that both participants with PD and communication partners reported motor symptoms more frequently when compared to nonmotor and communication symptoms. Specific to unmet needs and barriers of service delivery, both groups reported need for specialized services and educational resources related to PD symptoms in their communities. Overall, findings from the study will help create more effective service delivery programs for individuals with PD and their families.

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CHAPTER I

INTRODUCTION

Overview of PD

Parkinson disease (PD) is a progressive motor disorder caused by the degeneration of neurons, located in the substantia nigra of the basal ganglia, responsible for producing dopamine (Freed, 2020). According to the American Parkinson Disease Association (APDA, 2020), a new individual is diagnosed with PD every nine minutes, and approximately six new cases of PD are diagnosed each hour within the United States. Onset of PD is typically later in life between the ages of 40 and 70 years old (Freed, 2020). Parkinson disease is a multimodality disorder characterized by motor, including physical and speech-related changes as well as nonmotor symptoms (Adubi et al., 1997; Miller et al., 2006). Some of the major motor symptoms related to PD are gait-related changes, presence of rest tremors, rigidity, and bradykinesia (or slowness of movements; Adubi et al., 1997). Parkinson Disease is typically characterized by hypokinetic dysarthria and includes different speech and voice deficits such as reduced respiratory support, reduced volume, imprecise consonants, limited loudness variability, variable rate of speech, and monopitch (Freed, 2020). Further, PD is associated with nonmotor symptoms, including REM (rapid eye movement) sleep disorder, loss of smell, cognitive changes, and constipation (Hatano et al., 2009).

Currently, there are three main avenues of treatment for PD. These treatments can be categorized as behavioral, surgical, or pharmaceutical in nature. The pharmaceutical treatment approaches target replacing the dopamine deficiency in the striatum by using medications such as Levodopa or using anticholinergic drugs to correct the neurotransmitter imbalance in the basal ganglia (Freed, 2020). There are two main options of surgical treatment for people with PD. These include ablation procedures, which consist of lesions made in certain parts of the basal ganglia, and deep brain stimulation or DBS (Freed, 2020). Further, PD is managed by different behavioral treatment options. These include physical therapy consisting of different exercise programs, occupational therapy, and speech therapy (Bogard, 2010). Speech therapy is primarily administered through traditional techniques and specific programs, including the Lee Silverman Voice Treatment (LSVT®; Ramig et al., 2018), and the SPEAK OUT! ® and LOUD Crowd® programs developed by Elandary and her colleagues (Levitt, 2014). Traditional speech therapy techniques for people with PD typically focus on components of speech, such as breathing techniques for respiration, different exercises aimed at natural prosody, phonatory exercises with increased loudness and ideal voice quality as main objectives (Pinto et. al, 2004). In conclusion, PD is a multimodality disorder that is currently managed by different avenues of pharmacological and behavioral interventions.

The present study examined the current level of knowledge, different met and unmet needs, and existing barriers of service delivery for people with PD and their primary communication partners. Communication partners can include spouses or live-in partners, adult children, or siblings who are in direct contact with individuals with PD and may often accompany them to medical appointments and different therapy services. The following sections summarize the existing literature about the existing perceptions including level of knowledge regarding different PD symptoms, current met and unmet needs, and barriers to healthcare services for individuals with PD and their families.

Quality of Life Perceptions of Participants with PD

Quality of life (QOL) is a multidimensional concept that includes the physical, psychosocial, and emotional functioning of a person. Researchers have used the terms QOL and well-being interchangeably (Theofilou, 2013). Over the years, researchers have reported that PD affects the QOL and well-being of individuals with PD. One of the existing studies discussed the perception of control and well-being among individuals with PD (Wallhagen & Brod, 1997). The study included 101 individuals with PD (with disease duration of 1 year or longer) and 45 spouses. Data were collected through initial interviews and questionnaires that assessed control, beliefs, and the perception of the well-being of the individuals with PD and their family members. Results indicated that the participants with PD who were better able to control their PD symptoms had significantly better scores of perceived well-being, and their spouses also reported better well-being of individuals with PD and their family members. However, there was no significant relationship between the well-being of participants with PD and the well-being of family members. Overall, the authors reported that an individual's situational beliefs regarding changes affecting daily living had a more impactful influence than their long-term beliefs regarding disease progression on their well-being. Situational beliefs represented symptoms that participants experienced daily, and long-term beliefs represented the progression of the disease. It was also concluded that there was no correlation between an individual's perceived control of their PD-related symptoms and the well-being of the person with PD or family.

In a different study, Caap-Ahlgren and her colleagues discussed the experiences of Swedish women living with PD-related symptoms who attended medical appointments in a local Swedish neurology outpatient clinic (Caap-Ahlgren, Lannerheim & Ove Dehlin, 2002). This is one of the few existing studies specifically looking at the QOL perceptions of women participants with PD. The purpose of this study was to explore the experiences of these women and how their symptoms affected their QOL. This study included eight women between the ages of 63 and 80 years who had been diagnosed with PD for 5 to 15 years. All women were in the moderately to severe stages of PD and demonstrated relatively intact cognitive functioning at the time of study participation. Data were collected through interviews focused on participants describing their conditions and opinions. Overall, the study reported that all the participants with PD reported the presence of hypokinesia as a major barrier, felt too tired to carry on social interactions with family and friends, and faced difficulties in managing the household chores due to their symptoms. The authors concluded that PD not only affected the QOL of these women participants but the lives of their families as well.

Specific to impact of PD on a person's QOL, Grosset and Grosset (2005) discussed patient-perceived involvement and levels of satisfaction due to therapy decisions as well as QOL of individuals with PD. In recent decades, there has been a gradual shift with more direct involvement of participants with PD in the planning of their care. A total of 116 participants with PD attending a neurology clinic in Glasgow participated in the study. The survey scored the perceived involvement of participants with PD in therapy decisions and the self-reported satisfaction of these participants. This study concluded that higher patient involvement was associated with higher self-reported satisfaction. In addition, the higher level of satisfaction with therapy decisions was found to be associated with relatively better QOL of participants with PD.

More recently, Leroi and his colleagues (2012) discussed the differences in the QOL, and the level of disability experienced by individuals with PD. The participants included 25 participants with PD dementia (PDD), 48 participants with PD mild cognitive impairment (PD-MCI), and 54 participants with PD and no co-existing cognitive impairments. In addition, the study included 102 participants who were either spouses or family members of participants with PD. All participants completed the Parkinson Disease Questionnaire (PDQ-8; Jenkinson et. al., 1997), the Unified Parkinson's Disease Rating Scale-Activities of Daily Living (ADL) subscale (Dubois et. al., 2007), and the Zarit Burden Interview (ZBI; Zarit et. al., 1985). The authors found that the cognitive deficits among participants with PD increased the level of disability in their functioning. However, the authors could not determine a clear progression between the different groups of PD and how that may have affected the specific QOL of participants with PD.

In a different study, Santos-Garcia and de la Fuente-Fernandez (2013) discussed the impact non-motor symptoms may have on health-related and perceived QOL of individuals with PD. This study involved 150 participants with PD based in Spain. Multiple linear regression methods were used to examine the possible relationships between different PD-related non-motor symptoms for these participants. These measures included the Non-Motor Symptoms Scale (NMSS; Chaudhuri et. al., 2007), the PD Quality of Life Questionnaire (PDQ-39; Jenkinson et. al., 1997), and a subjective assessment of the perceived quality of life (PQ-10; Santos-Garcia & de la Fuente-Fernandez, 2013). Results indicated that higher NMSS scores among participants with PD were associated with relatively poorer QOL. Overall, the authors concluded a direct negative impact of non-motor symptoms on health related and perceived QOL among participants with PD.

In a detailed systematic review and meta-ethnography by Soundy, Stubbs and Roskell (2014), several findings related to experiences and perceptions of individuals with PD were summarized. The authors included 37 articles published between 1991 and 2014. The authors found that social identity was a key factor in the well-being of individuals with PD. The ability to develop, maintain, or retain their social identity was crucial in providing hope and upkeeping of the well-being of these individuals. In addition, the review discussed the importance and the need to develop more patient-centered care models for participants with PD (Soundy, Stubbs, & Roskell, 2014).

Most recently, Anzaldi and Shifren (2019) examined optimism, pessimism, coping strategies, and depression in individuals with PD. A total of 70 participants (including 35 males and 35 females) with PD ranging in age from 26 to 79 years old participated in the study recruited from the Michael J. Fox Foundation Parkinson's disease website. The participants were surveyed using the Brief COPE scale (Carver, 1997), Life Orientation Test-Revised (Sheier et al., 1994), and the Center for Epidemiological Studies Depression Scale (Radloff, 1977). The authors examined PD-related coping strategies in three main categories: problem-focused, emotion-focused, and avoidance behaviors. Problem-focused strategies referred to behaviors used to manage stressors while emotion-focused strategies involved the regulation of emotions to deal with stressors. The study concluded that participants with PD used similar amounts of problem-focused and emotion-focused coping strategies. In addition, it was reported that females indicated more problem-focused coping strategies (mean score of 17.46) when compared to corresponding scores of male participants with PD (mean score of 15.15). Overall, the participants with PD in this study reported a higher level of optimism and relatively lower levels of pessimism secondary to their PD-related symptoms. The authors concluded that the feeling of optimism among participants with PD helped them to mediate the relationship between their strategies and depressive symptoms.

In conclusion, the above-mentioned studies affirmed concerns related to factors affecting the QOL of individuals with PD. Many of the studies indicated that people with PD often self-reported lower QOL due to PD-related symptoms. Both participants with PD and their family members reported increased burden, increased levels of disability, and possible changes in self-identity, all leading to substantial effects on the QOL of both individuals with PD and family members.

PD-Related Education Programs

Patient-related education programs can be a great avenue to increase awareness about PD-related symptoms as well as provide information about effective assessment and management resources to participants with PD and their families. Among the existing studies, a study by Montgomery and his colleagues (1994) examined the value of effective patient education and health promotion among participants with PD. The Health Promotion Program (PROPATH) was developed to improve health confidence, provide education, and support, and create opportunities to collaborate with physicians to optimize treatment among participants with PD. A total of 322 participants with PD were initially recruited for the study based throughout the United States. Out of these, 155 participants were randomly assigned to the experimental group, and the remaining 167 participants were assigned to the control group. At the end of the 6 months, the experimental group included 140 participants, while the control group included 150 participants, all of whom completed the full program. The experimental group received a 6-month trial of the PROPATH program, while the control group only received questionnaires.

Although data analysis did not reveal significant differences between the experimental and control group, there were other findings worth consideration. The experimental group experienced few medication side-effects, reported completing relatively greater number of exercise regimes, and reportedly had overall lower scores on the PD-related measures. In addition, the experimental group experienced fewer sick days, fewer hospital days, and a smaller number of doctor visits. In contrast, the control group participants experienced an increase in levodopa dosage. Overall, the authors suggested a relatively better performance for activities of daily living in the experimental group when compared to the control group. They also concluded that patient education programs can be useful to improve the long-term outcomes of individuals with PD (Montgomery, Lieberman, Singh, & Fries, 1994).

In a different study, Macht et al. (2007) examined the possible benefits of a PD-related education program among newly diagnosed participants with PD. The study included 151 participants with PD based in Spain, Finland, Italy, Netherlands, United Kingdom, Estonia, and Germany. All participants were required to attend eight group-based educational in-person or online sessions that lasted for 90 minutes each. A standardized questionnaire was used to measure the participants' level of PD based knowledge before and at the end of the program. By session seven of the program, 68 participants said their expectations of the program had been fulfilled, 83 participants discussed their positive experiences about techniques that helped them to deal with emotional and social problems, and 43 participants reported improved understanding about PD when compared to the beginning of the study. In addition, results from the standardized tests at the end of the study showed a decrease in disease-related psychosocial problems, better QOL, and reduced symptoms of depression among these participants. In conclusion, the authors reported that PD-related education programs are a feasible and effective resource for existing and newly diagnosed individuals with PD. In addition, such programs can aid in reducing the social burden and negative societal attitudes associated with PD.

In summary, the above-mentioned articles confirmed the efficacy of PD-related education programs and the need for additional programs for individuals with PD and their family members. Existing studies confirm that both PD participants and their family members reported positive impacts when attending such programs, including a better understanding of PD-related symptoms, and having access to resources and techniques to better handle different problems associated with PD.

PD-Related Symptoms Knowledge

Specific to knowledge of different PD symptoms, a study by Abudi, Bar-Tal, Ziv, and Fish (1997) discussed the perceptions of symptoms by individuals with PD compared to current literature and healthcare professionals' perceptions. The study involved 39 individuals with PD (including 29 males and 10 females) based in central Israel. The participants with PD completed a survey for different PD-related symptoms, including motor disability, emotional impact on life and well-being, psychosocial issues, and other non-specific problems. The authors concluded that there was agreement about the severity of PD-symptoms among the participants with PD and the healthcare professionals. Both groups agreed on the frequency and severity of motor symptoms associated with PD. However, some of the symptoms were ranked differently by the two rater groups. Symptoms such as morning stiffness, deficits in cognitive sequencing, and dressing self were categorized as less severe by the PD participants. In contrast, psychosocial symptoms such as depression and anxiety were categorized as more frequent and severe among individuals with PD when compared to ratings provided by the healthcare professionals. In conclusion, the authors reported agreement between participants with PD and healthcare professionals for major symptoms. However, the authors cautioned that sometimes it might be helpful to confirm actual symptoms from a communication partner or the attending health-care professionals due to possible underlying self-bias among some individuals with PD regarding their self-awareness of symptoms.

In a separate study, Miller, Noble, Jones, and Burns (2006) examined the communication changes presented in individuals with PD and how these changes affected their daily life. The authors specifically examined self-perception of speech changes, how the PD-related changes affected their daily communication, and the coping mechanisms used by these participants with PD. The study included 23 men and 14 women with PD with different disease severities. The survey results indicated that most participants were aware of their PD-related symptoms. In addition, the study reported that individuals with PD felt a shift in interactions with others, conversational issues, and problems with speech intelligibility with disease progression. Specific to the use of coping mechanisms, participants with PD reported using physical strategies (slowing down, concentrating, persevering), conversation management, personal monitoring, and adjustment, and helping others to understand.

Specific to awareness of nonmotor symptoms of PD, Cheon, Ha, Park, and Kim (2008) examined the prevalence and awareness regarding these symptoms among individuals with PD and their families. This study included 74 participants with PD and 54 family members. Data were collected through a translated version of the Non-Motor Symptoms Questionnaire (NMSQuest study) completed by each participant (Chaudhuri et al., 2006). The most frequent non-motor symptom was nocturia (frequent nighttime urination) reported by 67.6% of participants with PD. In addition, loss of saliva was reported as the non-motor symptom that most participants were aware of (i.e., 31.9% of the participants with PD). Further, approximately

37.8% of individuals with PD were found to be unaware of PD-related non-motor symptoms. Overall, the authors concluded that nonmotor symptoms associated with PD should be routinely assessed, and both individuals with PD and family members should be educated about possible ways to effectively manage these PD-related symptoms.

In recent years, Dobkin and her colleagues (2013) discussed the barriers to the utilization of mental health care for individuals with PD based within the United States. The purpose of this study was to identify and describe the existing barriers for people with PD. The study included 769 participants with PD (including 380 males and 375 females), within the age ranges of 53.38-74.28 years. All participants completed a short survey with questions related to their demographic, medical, and psychiatric backgrounds. The results indicated that 93% of the participants with PD believed treatment for mental health issues would be beneficial. However, 60% of participants were unaware of possible local services available to them. The top barriers reported by these participants were the mentality of "anyone in my situation would be struggling", professionals not being sensitive to PD-related issues, and the high financial expenses associated with PD-related treatment care and management. Further, the study concluded multiple variables to be linked to the related healthcare barriers faced by individuals with PD and suggested the possible benefits of teletherapy services to help eliminate some of these barriers.

In conclusion, the current literature attests to the need for increased awareness and knowledge of different PD symptoms among people with PD as well as their family members. There were discrepancies reported between individuals with PD and healthcare professionals regarding the severity and frequency of some symptoms. More specifically, existing studies suggest a lack of awareness regarding non-motor symptoms among individuals with PD and their families. Thus, additional studies examining the current level of knowledge regarding PD-related symptoms would be beneficial to determine the current knowledge gaps and needs and subsequently develop patient-centered intervention programs for both people with PD and their families.

Caregiver Related Perceptions and Experiences

In addition to impact of PD on a person's QOL, different researchers have examined the effect of PD on the QOL and levels of functioning of caregivers and family members of individuals with PD. In one of the studies, Berry and Murphy (1995) examined the correlation between PD participants' level of functioning and their families' overall well-being. Participants for this study included a convenience sample of 30 spouses of individuals with PD based in a large metropolitan city in the United States. While the well-being of individuals with PD was dependent on the staging of their disease, the main factors influencing the well-being of the family members included their own physical and social functioning. Data were collected through structured interviews by the researchers. Overall, the study concluded that there is a negative correlation between the progression of the disease and the decline in family member's well-being. In other words, increased disease progression of individuals with PD was associated with relatively poorer well-being of the spouses of individuals with PD. The authors suggested that spouses of individuals with PD should be included in the planning of care for their loved ones with PD as their well-being and functioning are also influenced by the functioning of the individuals with PD (Berry & Murphy, 1995).

In a different study, Martinez-Martin, and his colleagues (2008) discussed the perceived burden and other psychosocial aspects of PD among family members of people with PD. The study consisted of 286 individuals with PD and their family members based in Spain. This was a nationwide observational study that used neurological measures to get an understanding of the caregivers' characteristics. The participants were assessed using the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983), EuroQol (EQ; The EuroQOL Group, 1990), and the Zarit Caregiver Burden Inventory (ZCBI; Zarit, Reever, & Bach-Peterson, 1980). The results indicated that 21.7% of family members of people with PD experienced anxiety, 9.1% experienced depression, and only 4.7% of family members perceived no burden. In conclusion, family members of individuals with PD reported the presence of anxiety and depression more frequently than would be expected in their age groups. Further, the study indicated that as the disease severity of the person with PD increased, the caregiver burden and depression status of family members also worsened.

Similar concerns and burdens were also reported for family members of people in advanced stages of PD by Goy and his colleagues (2008). The authors examined how prepared families were for caring their loved ones with PD during their end-of-life stages. The study included 54 family members of deceased individuals with PD recruited through the Oregon Health & Science University Movement Disorders Clinic. The participants completed in-person interviews and surveys. Some of the factors that were examined in the study included the amount of assistance provided, settings of care, type of care, and the caregiver's role. The family members discussed their experiences regarding different aspects of caregiving for their family member with PD. The results from the study indicated that the caregiver participants felt unprepared to cope with the different circumstances during the end-of-life stages of their family member with PD and emphasized the need for better communication with the health professionals.

The authors acknowledged their study results needed to be interpreted with caution as the surveys were completed by participants from only two hospital systems (Goy, Carter, & Ganzini, 2008). In conclusion, the authors suggested that the sample size may not have truly represented all the possible experiences of individuals with PD and their families. The authors suggested that additional studies with a larger sample size of family members can further shed light on the different aspects of caregiving associated with individuals with PD during different stages, including end-of-life care.

In a different study, Bogard (2010) examined the cognitive, affective, and psychomotor capabilities, and attributes associated with informal caregiving for those with PD. This study involved an in-depth investigation into the lives of 13 participants, based in the Midwest region of states from both rural and urban areas, who perceived to be in a caring relationship with an individual diagnosed with PD. The study included two open-ended interviews in which the family members were asked about the participant's caring experiences. The results of the study indicated three main themes: the family members felt as though they are living with the disease as well, caregiving was a completely unplanned journey, and the family members of individuals with PD felt their relationships with the person they cared for and others had shifted from what it was before the PD diagnosis of their family member. The findings of the study indicated a need for change within the clinical practice, such as providing formal guidance and educational opportunities for family members throughout the disease progression and viewing individuals with PD and their family members from a holistic perspective.

Around the same time, McLaughlin et al. (2010) reported perceptions of family members of individuals with PD based in Northern Ireland. The purpose of this study was to identify the roles and experiences of family members caring for people with PD. The study included 26 participants, including 17 female participants and 9 male participants. All participants were spouses who helped with many aspects of caregiving for their loved ones with PD. Participants were interviewed in a semi-structured format. The study reported a widespread burden on the emotional and physical health of the caregiver participants. In addition, the authors discussed the presence of a financial burden resulting in difficulty accessing benefits and a lack of integration regarding their loved ones' care from the perspective of the caregivers.

Similar findings of increased family burden among family members of people with PD was also reported by Lageman, Mickens, and Cash (2015). The study assessed the caregiver perceptions of their own medical and supportive service needs and those of individuals with PD. The study included a total of 66 participants who were family members caring for individuals with PD as well as their family members. The survey included questions about PD symptoms, the impact on the health status, and the QOL of the family members. The article concluded the presence of an overall positive QOL for family members, although levels of stress were reported by more than half of the participants. Specifically, the family member participants mentioned the need for specific services related to symptom management and better coping strategies to help them get adjusted with the changes in caregiving. Lastly, the study concluded lack of insurance and limited-service availability in their communities as some of the major barriers experienced by the individuals with PD.

In a similar study, Habermann (2017) discussed the perspective of spouses of individuals with PD. The study aimed to explore the challenges experienced by the spouses of individuals with PD. The study recruited participants through convenience sampling based in the Midwest region of the United States. A total of eight spouses (including five wives and three husbands), between the ages of 44 and 58 years old, participated in the study. All spouses were interviewed for about 1.5 to 2 hours in a semi-structured setting. The questions throughout the interview were centered around understanding a typical day and the changes pre and post disease or how they dealt with challenges of caregiving for someone with PD. The article concluded that the most significant challenges faced by these spouses were watching their loved one's struggle and become frustrated. Further, the study concluded that the spouses tried to maintain their own lives, encouraged their partners to stay engaged, and self-reported some of the possible coping mechanisms they used to help them with their daily functioning. Overall, family members of people with PD in the above-mentioned studies expressed unpreparedness and lack of adequate knowledge related to PD during their period of helping the individual with PD. In conclusion, the current literature indicated the importance of additional studies that aided in a clear and better understanding of the current met and unmet needs of both people with PD as well as their families.

Unmet Needs of PD

Parkinson disease affects a person's functioning in multiple ways including possible loss of social, physical, emotional, and financial resources. It is therefore important to understand the unmet needs and ways to educate and provide the necessary and relevant resources to people with PD and their families. Specific to unmet needs, a study by Buetow, Giddings, Williams, & Nayar (2008) discussed the perceived unmet needs of individuals with PD living in New Zealand. The purpose of this study was to assess how individuals with PD perceived their own health needs. A total of 500 interviews were conducted with individuals who self-identified as having PD. Questions during the interviews gathered information about PD-related issues, changes over the year, depression, and cognitive changes. The results reported that most participants had seen a healthcare professional with a specialization in PD, however approximately 1 in 5 of those participants wanted to have increased access to those specialists in the future. In contrast, about 1.8% of the participants reported not ever seeing a specialist despite wanting to because of not being offered so due to their regular general practitioner's lack of knowledge regarding PD. The authors concluded that people with PD may not always have access to PD-specific healthcare professionals in their area and this in turn can be considered as a major unmet need for the PD community.

A year later, Hatano and his colleagues (2009) discussed the unmet needs of individuals with PD based in Tokyo, Japan. A total of 132 participants in stages I-III of PD and 51 family members of individuals in stages IV-V of PD participated in the study. Data were collected through a 20-item questionnaire-based interview. The unmet needs of the individuals with PD in this study fell into three main categories: better treatment for motor symptoms, new treatments for non-motor symptoms, and improved communication. Some of the common themes reported by participants with PD included a lack of understanding about patient's feelings by the physician. In addition, the participants expressed the need for an adequate healthcare system involving all professionals necessary to help treat their diagnosis, and more access to PD-related specialist or a prominent physician. In this study, the family members reported some of their unmet needs including limited information regarding new drugs and latest available treatments and possible measures for handling any adverse situations. In summary, the study concluded several unmet needs specific to treatment and standard of care reported by participants with PD and family members.

More recently, van der Eijk et al. (2015) discussed some of the unmet needs of participants with PD based within the United States and Canada. The study included participants from 20 Parkinson Centers of Excellence located in these two countries. Each center included 50 participants with PD completing the questionnaire. It has been proven that knowing participants' perspectives is essential and critical to providing adequate care assessments. Data were collected using the Patient Centeredness Questionnaire for PD (PCQ-PD; Eremenco, Cella, & Arnold, 2005). The study concluded that individuals with PD experienced a lack of collaboration with the healthcare professionals and were often under-informed about their critical care needs.

About PD-related unmet needs, researchers Jost and Bausch (2017) discussed the current patient perspective on treatment options for PD. The authors have discussed that there is limited data regarding the PD-related treatments. To determine the perceptions of people with PD regarding available treatments and levels of satisfaction about these treatments, the author created a patient-centered survey consisting of 22 questions. A total of 4,485 participants with PD based different within regions of Germany participated in the questionnaire. The authors reported lack of information among participants with PD regarding different PD-related symptoms. Overall, people with PD desired to gain more information on how to effectively identify and manage side-effects of their medications.

Most recently, Lee et. al. (2018) reported the unmet needs of 172 participants with PD based in South Korea. The authors discussed the different unmet needs of these participants as well as suggested possible ways to facilitate more effective treatment interventions for people with PD. The article included important guidelines such as providing community support and resources, providing tailored care in different settings, and easier access to other healthcare professionals that can be helpful for healthcare professionals to keep in mind as they work with people with PD and their families. In summary, the above-mentioned studies clearly indicated several existing unmet needs including management of medications and possible side-effects, lack of collaboration between healthcare professionals, and unmet needs regarding standard of care that in turn may adversely impact the daily functioning of people with PD and their primary caregivers or family members.

Conclusion

Overall, prior studies have discussed the impact of PD on QOL of both individuals with PD and their family members. To the best of our knowledge, no studies currently exist that have examined the current level of knowledge and unmet needs of the PD community in mid-west regions of the United States including Oklahoma and Texas. Therefore, based on the current World Health Organization's objective of patient-centered care, we aimed to examine the current perceptions regarding PD-related symptoms among individuals with PD living and their primary communication partners (including spouses or other family members) within the Midwest region including Oklahoma, Texas, Arkansas, and Kansas (*Health Systems Strengthening Glossary* 2011). In addition, we examined the different met and unmet needs of the PD community as reported by these groups, including individuals with PD and the communication partners (including spouses, family members).

Therefore, two main research questions are as follows:

1. Determine the current perceptions regarding the PD-related symptoms among individuals with PD and communication partners (including spouses and family members) living in Midwest regions of the United States (including Oklahoma, Texas, Arkansas, and Kansas).
2. Determine the current met and unmet needs and barriers to healthcare service delivery reported by people with PD and their family members.

CHAPTER II

METHODS

Time Frame of Collection

Approval for the study was obtained from the Institutional Review Board at Oklahoma State University (Protocol ID# IRB-20-280) prior to data collection. After approval, data were collected from June to September 2020. A total of 39 participants including 27 people with PD and 12 communication partners (including spouses or other adult relatives) based in Oklahoma, Texas, and Kansas completed the surveys.

Participants

The current study included two primary groups- individuals with PD and communication partners. All participants with PD had a self-reported diagnosis of PD and self-reported visual and reading abilities adequate to qualify for participation in an online survey. Communication partners included spouses, adult children, or relatives of individuals with PD. They also self-reported visual and reading abilities adequate to complete in an online survey.

The age of participants with PD ranged from 58 to 87 years old. Among the 27 participants with PD, 13 were female, 13 other participants were males, and one participant did not disclose their gender. Specific to the educational background of participants with PD, 6 reported high school level education, 3 reported vocational training/ associate degree, 10 reported an undergraduate degree, 5 reported a graduate degree, and 3 reported a doctoral degree. Next regarding working status, about 81% (*n*=22) of the participants reported to be retired. Two additional participants reported to be on disability, and the remaining three participants reported to be working part-time, volunteering, or unemployed at the time of study participation. Majority of participants indicated a presence of at least one or more health condition in addition to PD.

The participants with PD also completed a mental health and depression screening (Pomeroy, Clark, & Philp, 2001). Due to the nature of PD, it was essential to gather information about their mental states as that could impact their perceptions of their symptoms, needs, and barriers to services. Twenty-six participants with PD completed the survey with 74% of participants (*n*=20) indicating a score of 2 or more on the depression scale thereby indicating possible presence of depression.

The study included a total of 12 communication partners (Males= 2; Females= 10) ranging in age between 55-91 years. Half of the communication partners reported to be spouses of people with PD. The remaining half were either family members or did not indicate their specific relationship with the person with PD. Regarding the educational status of the communication partners, 3 reported vocational degree/ associate degree, 1 reported an undergraduate degree, 6 reported a graduate degree, and 2 reported a doctoral degree. Specific to work status, 6 of the communication partners reported to be retired. Three additional participants were working part-time, and one was working full-time at the time of study participation. Specific to medical history of communication partners, most of them self-reported presence of anxiety, type 2 diabetes, and prior history for surgeries.

Similarly, to the PD participant group, communication partners also completed a mental health and depression screening. Due to the amount of time and involvement communication partners provide to their loved ones with PD, it was important to also gain knowledge about their mental states as it could impact their views as well. Twelve of the 13 communication partners completed the mental health screening and 69% (*n*= 9) of these participants scored a 2 or greater on the screening thereby indicating possible depression.

Study Survey Measures

The current study included modifications of existing surveys (Adubi et al., 1997; Cheon et al., 2008; Freed, 2020; Miller, 2012) that were related to knowledge and perceptions of PD symptoms, knowledge of PD symptoms, current met and unmet needs, and barriers to healthcare services specific to people with PD.

Collection Sites and Modes of Surveys

The original plan was to conduct data collection through a combination of both in-person and online recruitment methods and both paper-based and online surveys. However, due to COVID-19 related social distancing guidelines and health recommendations, the study was transitioned to a completely online format in May 2020. Participants who were members of different PD support groups based in Oklahoma, Arkansas, Texas, and Kansas were sent emails with the study flyers. In addition, the author personally contacted different PD support groups, speech-language pathologists, and healthcare professionals working with individuals with PD via emails and phone calls to share details of the study. Interested participants with PD first completed the online informed consent. Next, all participants completed a brief demographic questionnaire and a short depression and mental health screening.

The participants with PD were scheduled to complete four different surveys- PD knowledge check, checklist to indicate their own PD symptoms, met and unmet needs specific to PD, and current barriers to healthcare service delivery. The communication partners were also expected to complete four surveys- PD knowledge check, perception of PD symptoms noted in their family member with PD, met and unmet needs specific to PD, and current barriers to healthcare service delivery. The study survey was made available through a Qualtrics link. For unknown technical reasons, the PD knowledge survey was not presented to any of the participants with PD and the communication partners participants. As a result, no data were obtained specific to this survey from the two groups. This was a technical error that was discovered only after the data collection was completed. As a result, the study analyzed findings from only three surveys- current perceptions of PD symptoms, met and unmet needs, and barriers of service delivery completed by both participant groups (people with PD and Communication Partners).

Statistical Analyses

The surveys were analyzed descriptively, and percentages, means, and raw scores were determined for the different questionnaires and measures. In addition, relationships between self-reported depression scores, self-reported mental health scores, disease severity scores, the educational and occupational background of participants were completed with non-parametric tests including Spearman correlations and Chi-square tests. The alpha value was considered to be significant at $p < .05$.

CHAPTER III

RESULTS

Self-Reported Symptoms of Parkinson Disease

The current study aimed to examine the self-awareness of different symptoms associated with PD among people with PD. Results indicated that most commonly self-reported symptoms were changes in handwriting (*n*=25; 93%), followed by rest tremors (*n*=22; 81%), and motor symptoms such as changes in physical gait and reduced arm swing (each with *n*=19; or 70%). Among the three major domains of symptoms (motor, non-motor, and speech and communication), participants self-reported a relatively greater number of motor symptoms when compared to non-motor, speech, and cognitive symptoms. Table 1 below includes the summary of the self-report by participants with PD in percentages.

Table 1: Self-Reported PD-Related Symptom Perception

PD-Related Symptom Perceptions Self-Report		
Symptoms	**Number of Participants (*n*)**	**Percentage of Responses**
Changes in handwriting	25	93%
Rest tremors (shaking of hands, fingers, legs)	22	81%
Changes in physical gait (reduced steps, shuffling, freezing)	19	70%
Reduced arm swing	19	70%
Constipation	19	70%
Fine movements (buttoning, tying shoelaces)	17	63%
Quiet voice (reduced loudness)	16	59%
Changing positions in bed	16	59%
Daytime sleepiness	16	59%
Lack of dexterity (holding tools such as a brush or pen with hands)	15	55%
Voice getting quieter	15	55%
Difficulty concentrating	14	52%
Intense, vivid dreams	14	52%
Dribbling of saliva	14	52%
Change in smell	14	52%
Walking outside home (walking on pavements/walking surfaces outside home)	13	48%
Mumbling	13	48%
Feeling anxious	13	48%
Morning stiffness	12	44%
Urinary urgency	12	44%
Changes in swallowing	12	44%
Muscles cramps	12	44%
Changing positions (e.g., from sitting to standing, from lying to sitting)	11	41%
More effort to maintain intelligible speech	11	41%
Ability to clip one's own nails using a clipper	11	41%
Muscles aches	11	41%
Restless legs	11	41%

Symptoms	**Number of Participants (*n*)**	**Percentage of Responses**
Slowness of speech	10	37%
Memory changes	9	33%
Loss of interest	9	33%
Nocturia (or excessive nighttime urination)	9	33%
Sleep talking and walking	9	33%
Loss of clarity	8	30%
Voice getting husky	8	30%
Getting in/out of bed	8	30%
Sexual dysfunction	7	26%
Change in sexual interest	7	26%
Swelling of legs	7	26%
Feeling sad	6	22%
Dressing self	6	22%
Constant throat clearing	6	22%
Shallow breathing	6	22%
Double vision	6	22%
Imprecise consonants	5	19%
Insomnia	5	19%
Dyskinesias (out-of-control movements of hands and legs)	5	19%
Voice tremors	5	19%
Toileting/ Difficulty toileting	5	19%
Eating problems	5	19%
Bowel incontinence	5	19%
Hallucinations (experience something that really does not exist such as seeing a person, animal, or an object)	4	15%
Change in taste	4	15%
Monopitch (same pitch across all sentences)	4	15%
Other symptoms not mentioned in the list	4	15%
Unexplained pain	3	11%
Tight mouth	3	11%
Voice getting deeper	3	11%

Symptoms	**Number of Participants (*n*)**	**Percentage of Responses**
Reduced control of exhalation	3	11%
Orthostatic dizziness or hypotension (sudden drop in blood pressure when standing up from sitting or lying down	2	7%
Incomplete bowel emptying	2	7%
Reduced breath support	2	7%
Excessive sweating	2	7%
Delusions (false beliefs)	2	7%
Palilalia (repetition of words)	2	7%
Vomiting	1	4%
Nausea	1	4%
Mild changes in nasality (extra air coming out)	1	4%
Unexplained weight loss	0	0%

Access to Service Delivery Reported by Participants with PD

In addition to the survey of PD-related symptoms, all participants with PD completed a survey about the current healthcare services that they either have accessed in the past or may have access to at the time of study participation. The survey included a list of different healthcare and community services including physical therapy, neurological care, speech therapy, and counseling. This survey listed common services that are related to the treatment and management of PD. Based on the survey results, the top three services that participants accessed were pharmacy (n=9; 70%), neurological care (n=17; 63%), and physical therapy (n=15; 56%). Less than 45% of the survey respondents had access to a Movement Disorder Specialist in their current locations. In addition, only 8 out of 27 participants (about 30%) with PD reported access to either online or in-person support groups. Further, none of the participants self-reported working with an occupational therapist, sleep specialist, or other counseling support services.

Table 2 below summarizes the survey responses of current healthcare and community services accessed by participants with PD.

Table 2: Self-Reported Access to PD-Related Services

Self-Reported Access to PD-Related Services		
Services	**Number of Participants *(n)***	**Percentage of Responses**
Pharmacy	19	70%
Neurology	17	63%
Physical Therapy/ Exercise Groups (boxing, Tai Chi, regular exercise)	15	56%
Speech therapy/ SPEAK OUT! ® / LOUD Crowd® / LSVT Groups	14	52%
Movement Disorder Specialist	11	41%
Online/ Video/ In-person support groups	8	30%
Swallowing Specialist	3	11%
Home-Health Related Services	3	11%
Other services not mentioned in the list	2	7%
Clinical Trials/ Research Studies	2	7%
Psychology/ Counseling	1	4%
Occupational Therapy	0	0%
Sleep Specialist	0	0%
Neuropsychology/ Psychiatry	0	0%
Nutrition	0	0%
Social Work	0	0%
Palliative/ End-of-life Care	0	0%

Unmet Needs Reported by Participants with PD

Following the survey about access to PD-related services, all participants with PD completed a survey about their current unmet needs. These PD-related needs addressed symptom management, lifestyle changes and planning for the future, wellness strategies, cognitive and psychosocial changes, and coping with PD diagnosis and patient education about PD diagnosis. A few of the needs listed in the survey were issues with swallowing, safety at home, nutritional changes, and maintaining a social life. Based on the survey results, participants with PD reported that vacationing and travel tips (n=10; 37%) was the common most unmet need followed by implementation of an exercise regime or adapting a regime to fit personal needs (n=9; 33%). Additionally, 4% (n=1) of participants with PD reported attention, visual hallucinations, spiritual support, parenting-related issues, balancing familial/ medical/ health responsibilities with work duties, transitioning from full-time to part-time work, advocating form accommodations, and patient education about PD diagnosis as some of the other unmet needs. Below, Table 3 outlines the responses of self-reported PD symptoms by participants with PD.

Table 3: Self-Reported Unmet Needs by Participants with PD

Self-Reported Unmet PD-Related Needs		
Needs Related to PD	**Number of Participants (*n*)**	**Percentage of Responses**
Vacationing and travel tips	10	37%
Beginning an exercise regime or adapting one to fit personal needs	9	33%
Fall prevention	8	30%
Long-term planning for the future	8	30%
Resource identification and accessing resources for future	8	30%
Experiencing fatigue	7	26%
Tremor/gait/balance problems	7	26%
Driving	7	26%
Safety in the home	7	26%
Experiencing anxiety	6	22%
Stress management	6	22%

Needs Related to PD	**Number of Participants (*n*)**	**Percentage of Responses**
Maintaining a social life	6	22%
Disclosing your PD diagnosis; how to and if you should	6	22%
Nutritional changes and healthy eating strategies	6	22%
Incontinence	5	19%
Vision changes/ issues	4	15%
Common medication side effects	4	15%
Experiencing apathy	4	15%
Expressing self	4	15%
Legal issues	3	11%
Role changes	3	11%
Speech/ voice/ communication	3	11%
Issues with swallowing	3	11%
Changes in personal relationships post diagnosis	3	11%
Caregiver/ Communication partner/ Family stress	3	11%
Experiencing depression	3	11%
Communicating with treating doctors/nurses	3	11%
Financial concerns	3	11%
Identifying emotional support systems	3	11%
Other areas not mentioned in the list	3	11%
Memory	2	7%
Problem solving	2	7%
Major family decision-making and planning	2	7%
Sexual problems	2	7%
Inappropriate behaviors	2	7%
Aggression	2	7%
Analyzing transferable skills and new/different job possibilities following the PD diagnosis	2	7%
Adjust to PD diagnosis	2	7%

Needs Related to PD	**Number of Participants (*n*)**	**Percentage of Responses**
Attention	1	4%
Visual hallucinations	1	4%
Spiritual support	1	4%
Parenting-related issues	1	4%
Balancing family, medical and health responsibilities with work duties	1	4%
Transitioning from full-time to part-time work	1	4%
Advocating for accommodations	1	4%
Patient education about PD diagnosis	1	4%
Early onset of PD diagnosis	0	0%

Quality of Life Rating Reported by Participants with PD

The current study examined QOL of participants with PD. All participants with PD completed the PDQ-8 questionnaire (Jenkinson et al., 1997) which includes statements related to their mobility, activities of daily living, emotional well-being, social support, and cognitive and communicative functioning. Higher scores on the PDQ-8 are associated with poorer QOL. The average PDQ-8 score was 7.9, standard deviation (S.D.) was 5.07, and the range was (0-19). There were 3 missing responses and only 1 out of the total 27 participants reported no negative impact of PD on their functioning. Following this paragraph, Table 4 (on next page) summarizes the QOL reported by people with PD.

Table 4: Participants with PD Quality of Life Questionnaire

Participants with PD Quality of Life Questionnaire									
Participant ID	**Q1**	**Q2**	**Q3**	**Q4**	**Q5**	**Q6**	**Q7**	**Q8**	**Total**
PD1	0	0	0	0	1	0	1	0	2
PD2	0	1	3	1	1	1	1	4	12
PD3	4	1	2	0	3	2	0	4	16
PD4	0	0	0	0	3	2	0	4	9
PD5	0	1	1	0	0	0	0	1	3
PD6	2	0	0	0	0	1	1	0	4
PD7	3	3	3	2	2	2	2	2	19
PD8	4	1	2	0	3	3	2	2	17
PD9	1	1	0	0	1	2	1	2	8
PD10	0	1	0	0	1	1	0	0	3
PD11	1	1	1	0	1	1	0	1	6
PD12	2	0	0	1	1	1	1	2	8
PD13	0	0	1	1	0	1	0	0	3
PD14	NR	NR	NR	NR	NR	NR	NR	NR	
PD15	1	1	0	0	0	1	1	0	4
PD16	1	1	1	1	1	1	1	1	8
PD17	NR	NR	NR	NR	NR	NR	NR	NR	
PD18	0	0	0	0	0	0	0	0	0
PD19	1	3	1	2	2	1	2	0	12
PD20	0	0	2	2	2	2	1	2	11
PD21	0	0	0	0	1	0	0	0	1
PD22	2	1	1	0	1	2	0	0	7
PD23	1	0	1	2	2	2	1	2	11
PD24	NR	NR	NR	NR	NR	NR	NR	NR	
PD25	0	0	1	0	2	0	1	0	4
PD26	0	0	3	1	1	2	1	0	8
PD27	0	0	1	2	0	1	2	2	8

Symptoms Related to PD Observed by Family Members

Similar to participants with PD, all communication partners of people with PD completed a survey about the symptoms they noticed in their loved ones with PD. The most observed symptoms by family members and communication partners were rest tremors and changes in physical gait (*n*=7; 58%) followed by difficulties in performing fine movements (such as buttoning), changes in handwriting, loss of clarity, and hallucinations (each with 6 responses; 50%). In contrast to participants with PD, the family members reported a relatively smaller number of motor and nonmotor symptoms among their loved ones with PD. Specifically, only 42% of participants reported presence of non-motor symptoms such as memory changes, orthostatic hypotension, and emotions of sadness in their family member with PD. Table 5 below includes a summary of PD symptoms reported by family members of people with PD.

Table 5: Presence of PD-Related Symptoms Reported by Family Members

Presence of PD-Related Symptoms Reported by Family Members		
Symptoms	**Number of Participants (*n*)**	**Percentage of Responses**
Rest tremors (shaking of hands, fingers, legs)	7	58%
Changes in physical gait (reduced steps, shuffling, freezing)	7	58%
Fine movements (buttoning, tying shoelaces)	6	50%
Changes in handwriting	6	50%
Loss of clarity	6	50%
Hallucinations (experience something that really does not exist such as seeing a person, animal, or an object)	6	50%
Reduced arm swing	5	42%
Changing positions (e.g., from sitting to standing, from lying to sitting)	5	42%
Walking outside home (walking on pavements/walking surfaces outside home)	5	42%
Morning stiffness	5	42%
Lack of dexterity (holding tools such as a brush or pen with hands)	5	42%
Quiet voice (reduced loudness)	5	42%
Imprecise consonants	5	42%
Unexplained weight loss	5	42%
Memory changes	5	42%
Feeling sad	5	42%
Orthostatic dizziness or hypotension (sudden drop in blood pressure when standing up from sitting or lying down	5	42%
Dyskinesias (out-of-control movements of hands and legs)	4	33%
Ability to clip one's own nails using a clipper	4	33%
Mumbling	4	33%
Slowness of speech	4	33%
More effort to maintain intelligible speech	4	33%

Symptoms	**Number of Participants (*n*)**	**Percentage of Responses**
Change in taste	4	33%
Incomplete bowel emptying	4	33%
Urinary urgency	4	33%
Insomnia	4	33%
Muscles aches	3	25%
Changing positions in bed	3	25%
Dressing self	3	25%
Toileting/ Difficulty toileting	3	25%
Eating problems	3	25%
Changes in swallowing	3	25%
Monopitch (same pitch across all sentences)	3	25%
Voice getting husky	3	25%
Voice getting quieter	3	25%
Voice tremors	3	25%
Loss of interest	3	25%
Difficulty concentrating	3	25%
Muscles cramps	2	17%
Getting in/out of bed	2	17%
Constant throat clearing	2	17%
Tight mouth	2	17%
Reduced breath support	2	17%
Nocturia (or excessive nighttime urination)	2	17%
Unexplained pain	2	17%
Feeling anxious	2	17%
Sexual dysfunction	2	17%
Excessive sweating	2	17%
Delusions (false beliefs)	2	17%
Other symptoms not mentioned in the list	2	17%
Change in sexual interest	2	15%
Voice getting deeper	1	8%
Reduced control of exhalation	1	8%
Shallow breathing	1	8%
Dribbling of saliva	1	8%
Daytime sleepiness	1	8%
Intense, vivid dreams	1	8%
Sleep talking and walking	1	8%
Double vision	1	8%
Mild changes in nasality (extra air coming out)	0	0%
Nausea	0	0%
Palilalia (repetition of words)	0	0%
Change in smell	0	0%
Vomiting	0	0%

Symptoms	**Number of Participants (*n*)**	**Percentage of Responses**
Constipation	0	0%
Bowel incontinence	0	0%
Restless legs	0	0%
Swelling of legs	0	0%

Access to PD-Related Service Delivery Reported by Family Member Participants

In addition to reporting different PD symptoms in their loved ones, all family members completed a survey about different healthcare and community services accessed by their family members with PD. The survey completed by family members listed the same PD-related healthcare and community services. The three most common services family members reported having access to were neurology (*n*=7; 58%), followed by pharmacy (*n*=6; 50%), and physical therapy/ exercise groups and speech therapy (*n*=4; 33%). In comparison to participants with PD, none of the family members reported access to a sleep specialist, counseling, psychiatric services, nutrition, social work, or palliative care specific to needs of their loved one with PD. Table 6 (on next page) provides a summary of different healthcare services that family members reported for their loved ones with PD.

Relationships between Participants' Variables and QOL Scores

Based on the completed surveys, non-parametric Spearman correlations were completed to determine any relationships between the age of participants, gender of participants, self-reported depression scores, self-reported QOL scores, and self-reported PD severity for the PD participants alone. Specific to the PD group, significant positive correlations were observed between self-reported depression and QOL scores (r= 0.504; p= .012) and between gender and depression scores (r= 0.463; p= .017). In other words, PD participants with depression reported poorer QOL. The study included equal number of male and female PD participants, 13 each. So, no one gender group reported depression symptoms more frequently than the other.

Table 6: Access to PD-Related Services Reported by Family Members

Access to PD-Related Services Reported by Family Members		
Services	**Number of Participants (*n*)**	**Percentage of Responses**
Neurology	7	58%
Pharmacy	6	50%
Physical therapy/ Exercise Groups (boxing, Tai Chi, regular exercise)	4	33%
Speech therapy/ SPEAK OUT!®/LOUD Crowd®/LSVT® Groups	4	33%
Movement Disorder Specialist	3	25%
Online/Video/ In-person Support Groups	3	25%
Swallowing Specialist	2	17%
Home-Health Related Services	2	17%
Occupational Therapy	1	8%
Other areas (not listed above) please list if applicable	1	8%
Sleep Specialist	0	0%
Psychology/Counseling	0	0%
Neuropsychology	0	0%
Nutrition	0	0%
Clinical Trials/ Research Studies	0	0%
Social Work	0	0%
Palliative/ End-of-life Care	0	0%

Unmet Needs Reported by Family Member Participants

Due to the extensive symptoms of PD and the amount of time family members spend with their loved ones with PD, the current study included reports of communication partner participants about their unmet needs specific to their loved ones with PD. Based on the survey results, the most unmet need reported by family members of people with PD was vision changes/issues (*n*= 4; 33%). In comparison to the participants with PD, about 25% (*n*= *3*) of communication partners reported each of the areas namely common medication side effects, legal issues, memory, problem solving, role changes, and services to address apathy secondary to PD to be currently unmet. In contrast, some of the areas such as nutritional changes, work transition, and advocacy issues were not selected to be missing or unmet by any of the communication partners. It is possible either these did not apply to their specific needs or they were not aware of these areas to be directly related to PD. Table 7 below summarizes the responses of family members regarding unmet needs of PD-related services.

Table 7: PD-Related Unmet Needs Reported by Family Members

PD-Related Unmet Needs Reported by Family Members		
Symptoms	**Number of Participants (*n*)**	**Percentage of Responses**
Vision changes/ issues	4	33%
Common medication side effects	3	25%
Legal issues	3	25%
Memory	3	25%
Problem solving	3	25%
Role changes	3	25%
Experiencing apathy	3	25%
Speech/voice/communication problems	2	17%
Issues with swallowing	2	17%
Communicating with treating doctors/nurses	2	17%
Fall prevention	2	17%
Long-term planning	2	17%
Resource identification and accessing resources	2	17%
Expressing self	2	17%
Attention	2	17%
Changes in personal relationships post diagnosis	2	17%
Major family decision-making and planning	2	17%
Caregiver/ Communication partner/ Family Stress	2	17%
Experiencing anxiety	2	17%
Experiencing depression	2	17%
Experiencing fatigue	2	17%
Visual hallucinations	2	17%
Tremor/gait/balance problems	1	8%
Incontinence	1	8%
Sexual problems	1	8%
Driving	1	8%

Symptoms	**Number of Participants (*n*)**	**Percentage of Responses**
Vacationing and travel tips	1	8%
Safety in the home	1	8%
Financial concerns	1	8%
Beginning an exercise regime or adapting one to fit personal needs	1	8%
Stress Management	1	8%
Spirituality	1	8%
Maintaining a social life	1	8%
Identifying emotional support systems	1	8%
Parenting-related issues	1	8%
Disclosing your PD diagnosis; how to and if you should	1	8%
Inappropriate behaviors	1	8%
Aggression	1	8%
Nutritional changes and healthy eating strategies	0	0%
Balancing family, medical and health responsibilities with work duties	0	0%
Transitioning from full-time to part-time work	0	0%
Analyzing transferable skills and new/different job possibilities following the PD diagnosis	0	0%
Advocating for accommodations	0	0%
Patient education about PD diagnosis	0	0%
Adjustment to PD diagnosis	0	0%
Early Onset of PD diagnosis	0	0%
Any other areas that may not have been included above (please use the space below to discuss more):	0	0%

Quality of Life Reported by Family Member Participants

The current study examined the QOL of communication partners. All participants completed the PDQ-Carer questionnaire (Jenkinson et al., 2011) that addressed the mental implications of caring for an individual with PD. Higher scores on the PDQ-Carer are associated with poorer QOL. The average PDQ-Carer score was 24.6, standard deviation (S.D.) was 16.5, and the range was (4-38). Of the twelve participants, five did not complete the questionnaire. Table 8 (on Page 40) summarizes the complete data from the questionnaire.

Similar to the PD group, when relationships were examined for different variables related to the communication partner group, no specific relationships were noted for the age, gender, self-reported depression, and QOL scores of these participants. It is important to note that the communication partner group only had 11 participants with only seven who completed the PDQ-Carer questionnaire. It is possible that the small sample size may have attributed to lack of any significant relationship between the different scores and participants' demographic variables.

Table 8: Communication Partners Quality of Life Questionnaire

	Q1	**Q2**	**Q3**	**Q4**	**Q5**	**Q6**	**Q7**	**Q8**	**Q9**	**Q10**	**Q11**	**Q12**	**Q13**	**Q14**	**Q15**	**Q16**	**Q17**	**Q18**	**Q19**	**Q20**	**Q21**	**Q22**	**Q23**	**Q24**	**Q25**	**Q26**	**Q27**	**Q28**	**Q29**	**Total**
CP 1	0	0	0	0	0	2	0	0	0	2	0	2	1	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	8
CP 2	1	2	2	0	0	1	2	2	2	1	1	2	1	1	0	1	0	0	4	1	1	0	2	2	4	2	0	1	2	38
CP 3	1	0	1	2	2	0	1	1	2	1	1	2	1	1	1	2	2	2	4	2	1	0	2	2	2	0	2	4	2	44
CP 4	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
CP 5	1	0	1	1	2	0	0	0	1	1	1	2	0	0	1	1	2	2	1	2	4	0	1	1	2	0	4	4	2	37
CP 6	4	0	1	2	1	1	0	1	2	1	2	1	0	0	1	0	2	1	1	1	1	0	2	1	1	0	2	0	1	30
CP 7	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
CP 8	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
CP 9	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
CP 10	2					1				2	2					2								2						11
CP 11	2	0	0	0	0	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	4
CP 12	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR

Barriers to Service Delivery Reported by Participants

The last survey of the study asked all participants to indicate five of their greatest barriers to service delivery and ranking them in ascending order. The survey included different services related to assessment, care, and management of people with PD. A majority of participants reported specialized services such as Movement Disorders Specialist and Physical Therapy as most of the most important areas of need. The overall summary of all responses related to this survey are included in Table 9 (on next page).

Table 9: Barriers to Service Delivery Reported by Participants

	Ranked 1	**Ranked 2**	**Ranked 3**	**Ranked 4**	**Ranked 5**
Most Frequently Reported	Movement Disorder Specialist- 5	Physical Therapy- 4	Physical Therapy- 4	Psychology/ Counseling- 3	Pharmacy- 3
	Neurology- 3	Movement Disorder Specialist- 2	Sleep Specialist- 2	Physical Therapy- 2	Speech Therapy- 3
↑	Physical Therapy- 3	Online/ Video/ In-Person Support Groups- 2	Psychology/ Counseling- 2	Speech Therapy- 2	Swallowing Specialist- 3
	Nutrition- 1	Neurology- 1	Nutrition- 2	Neurology- 1	Movement Disorder Specialist- 1
	Clinical Trials- 1	Pharmacy- 1	Clinical Trials- 2	Movement Disorder Specialist- 1	Sleep Specialist- 1
↓	Home Health related services- 1	Speech Therapy- 1	Speech Therapy- 1	Pharmacy- 1	Neuropsychology/ Psychiatry- 1
		Nutrition- 1	Palliative Care- 1	Occupational Therapy- 1	Online/ Video/ In-Person Support Groups- 1
		Occupational Therapy- 1		Clinical Trials- 1	Home Health related services- 1
Least Frequently Reported				Online/ Video/ In-Person Support Groups- 1	
				Home Health related services- 1	

Note. The number next to the services refers to number of people who ranked each of the services.

CHAPTER IV

DISCUSSION

The aim of the present study was to examine the current perceptions specific to PD-related symptoms experienced by people living with PD and their primary communication partners within the Midwest region of the United States (Oklahoma, Kansas, and Texas). In addition, the study examined the current met and unmet needs as well as barriers of service delivery for people with PD and their families. The following sections discuss the key findings and observations from the surveys completed by the participants with PD as well as their communication partners.

Symptoms Experienced

Based on the current understanding of PD-related symptoms, the current study included a PD-related symptom checklist that included possible motor, non-motor, and communication changes. The symptom checklist was based on previous studies' identification of symptoms (Adubi et al., 1996; Cheon et al., 2008; Garcia & de la Fuente-Fernandez, 2013; Hatano et al., 2009). Specific to the PD symptom checklist, most participants with PD and communication partner participants checked most of the motor symptoms included in the survey. In contrast, nonmotor and communication changes were not reported as frequently by the survey respondents including participants with PD and communication partners.

It is possible that sometimes family members or communication partners may not be aware of some of the changes experienced by people with PD or may not associate these changes specifically to PD. Some of the nonmotor changes associated with PD include memory changes, daytime sleepiness, double vision, and unexplained weight loss. Communication changes associated with PD may include reduced breath support, imprecise consonants, monopitch, and slowness of speech. It is important to note that only 25-42% of communication partners indicated these changes. In other words, more than half of the communication partners did not report any nonmotor or communication changes in their loved ones with PD which can suggest either these changes were not experienced by their loved ones with PD, or the communication partners were not aware of these changes to be directly linked with PD.

The relatively lower reports of presence of nonmotor symptoms by communication partners is in agreement with some of the prior studies that have examined perception of PD-related nonmotor symptoms by family members. For example, Cheon et al. (2008) examined awareness regarding different symptoms in people with PD and their family members. While 67.6% of family members reported nocturia as a possible non-motor symptom of PD, only 17% of our study participants reported nocturia as a symptom. Two other non-motor symptoms, constipation and restless syndrome, were each reported by more than two-thirds of the participants in the Cheon study (2008) while none of the communication partner reported either of these symptoms in the current study. Additionally, constipation was reported by 65.8% of family member participants as a prevalent nonmotor symptom in Cheon et al. study. However, none of family members, in the current study, reported constipation as a nonmotor symptom. Lastly, restless legs syndrome was reported as one of the more prevalent nonmotor symptoms by

66.7% of family member participants in the Cheon study (2008). This was in stark contrast to the current study where none of the communication partners reported the symptom.

There were some methodological differences between the two studies which could explain some of the different findings. Cheon et al. completed the study in South Korea while the current study was based in Midwest regions of the United States. Cheon et al. included 54 family members while the current study included only 11 family members. Also, the current study and the Cheon study included different questionnaires so there were some subjective differences in the wording and ordering of the symptoms. Further, the mean ages of the PD and partner groups were different for the prior study and the current study. In conclusion, some of these methodological differences may have contributed to the different survey responses for the two studies.

Access to Services

In addition to PD-related symptoms, all participants completed a survey to report access to PD specific healthcare services. The PD-related services targeted physical, psychosocial, disease progression, and environmental adaptations. Results suggested that communication partners and people with PD had similar reports of healthcare services that they currently had access to specific to PD. Participants with PD reported pharmacy, neurology, and physical therapy to be the most frequently accessed services. Similarly, communication partners reported neurology, pharmacy, and physical therapy as the most commonly accessed PD-related services. Surveys indicated that there were several services available to target some of the more external and physical symptoms (gait, balance, voice) through physical therapy and voice therapy programs. The current study findings are in agreement with prior studies. For example, Lageman and her colleagues (2015) reported neurology (63.6%), pharmacy (43.9%), and physical therapy

(30.3%) as the most utilized PD-related services in Virginia. In contrast, there were other services the participants did not have access similar to the current study. In summary, physical and communication related services were more readily available while sleep, psychiatric, a sleep specialist, nutrition services, counseling, and end-of-life care related services were lacking for many PD participants in the prior study by Lageman et al. and the current study.

Unmet Needs

Other than surveys about PD symptoms and access to PD-related healthcare services, the current study analyzed unmet needs related to PD. The multitude of needs were categorized by varied daily and long-term effects of PD including symptom management, lifestyle changes, emotional changes, and other related changes. Approximately 30% of PD participants expressed a need for support regarding planning for the future, wellness strategies, and lifestyle changes. It is important to note that 40% of participants were based in Texas, 35% of participants were based in Oklahoma, 5% of participants were based in Kansas, and 20% of participants' location was unknown at the time of data collection. Although a majority of participants reported resources related to early onset of PD diagnosis to be met, a large percentage of participants with PD as well as communication partners reported symptom management, planning for the future, resources aimed at emotional and cognitive changes to be some of their commonly unmet areas of need. Based on the available results, it can be concluded that family members of people with PD expressed more concern with activities affecting daily functioning. Specifically, 25-33% of communication partners reported unmet needs specific to vision, medication side effects, legal issues, memory, problem solving, role changes, and experiencing apathy.

Although prior studies have reported about unmet needs and barriers to service delivery in regions such as South Korea, New Zealand, Japan, Canada, and Germany, little to no research has been conducted to compare the unmet needs of people with PD and their family members in rural communities such as Oklahoma, Arkansas, and Texas. To the best of our knowledge, the current study adds to the understanding of current perceptions and experiences of participants with PD and their family members based in rural areas such as Oklahoma and Texas. There were some overlapping themes between the current study based in some of the rural communities of the United States and a prior study by Hatano et al. (2009) related to participants in Tokyo. While the participants in the prior study by Hatano et al. (2008) reported measures for adverse situations and pharmaceutical treatments to be some of the unmet needs, the current study indicated that communication partners would also like to have more information and resources centering emotional and familial changes, future planning, and symptom management. Overall, the current study provided a snapshot of some of the unmet needs in these communities. Further studies with greater sample sizes and representation of different PD severities can be helpful to better understand the current experience of people with PD and their communication partners.

Some of the services that were reported to be lacking more than a decade ago are becoming more available in the current times. For example, Buetow et al. reported in 2008 that 16.8% of participants had never seen a physiotherapist, 13.9% of participants had never seen a dietician, and 13.4% had never seen an occupational therapist. In contrast, such services are more readily available now as more than half of the PD participants and more than 30% of communication partners in the current study reported having access to or currently participating in physical therapy or exercise groups. This indicates that availability and access to some of the therapy services have increased in recent years in rural communities such as Oklahoma and Texas. However, other services are still lacking as a majority of participants with PD reported unmet needs related to services to help adjust one's lifestyle secondary to PD and helpful resources to plan for the future.

Although PD is known to affect multiple modalities, there is presently a strong unmet need for services pertaining to non-motor symptoms. Specifically, communication partners reported not having access to sleep specialists, psychology/counseling, neuropsychology, nutrition, clinical trials/research studies, social work, and palliative care to address needs of their family member with PD. Some of these concerns were also reported by participants with PD. Overall, the current study clearly indicated the need for more specialized services for symptoms related to nonmotor changes of PD. These findings are in agreement with prior studies that were completed during the last 13 years. Both studies by Dobkin et al. (2013) and Hatano et al. (2009) reported need for mental health services among their participants with PD. Thus, it is important that healthcare professionals collaborate with other stakeholders including support groups, community organizations, and social workers and help create programs related to these areas for people with PD and their families.

Barriers to Service Delivery

Similar to findings discussed by Lagemen and her colleagues (2015), the present study reported barriers to services aimed at mental health changes within the PD community of the Midwest region. Specific to the previous study, 10.6% of the participants reported a desire for counseling and psychiatric services in Virginia. Additionally, 24.2% of the participants reported the lack of specialists and services in their local area. Similarly, the participants of the current study reported counseling and psychiatric services among the top five greatest barriers in the Midwest region. The unmet needs and barriers can be minimized with healthcare professional education and collaboration, community outreach, and flexible resources. Resources such as online programs, short-term camps, and education programs would aid in improving the unmet needs experienced by the PD community in the Midwest region.

The information gained from this survey aids in understanding the current barriers in healthcare services for individuals with PD based in the Midwest region of the U.S. To the best of our knowledge, previous studies have not examined the self-awareness of PD participants based in different rural regions as well as current met and unmet needs specific to PD in these communities. The survey results suggested movement specialists, neurological services, physical therapist, nutritional services, clinical trials information, and home-health related services were some of the most frequently needed services for the study participants.

Quality of Life

In addition to examining the current perceptions and unmet needs related to PD, the current study asked participants with PD about the impact of PD on their life QOL. As PD is a multimodality disorder, understanding how it impacts the QOL of the PD community is important. The scores for PDQ-8 ranges from 0 to 32 with higher scores indicating poorer QOL. All 27 participants with PD indicated at least some level of impact of PD symptoms on their QOL. In addition, the current study indicated positive relationship between depression and QOL scores. People who self-reported depression also had poorer QOL. These are in agreement with prior studies by Dobkin et al. (2013) and Marsh (2013). In conclusion, the current study adds to the existing literature about possible impact of depression on QOL of people with PD.

CHAPTER V

CONCLUSION

The aim of the present study was to determine the perceptions related to different PD-related symptoms experienced, understand the met and unmet needs of the PD community, and identify possible barriers to PD-related services within the Midwest region of the United States. Based on the current findings, several future directions and areas of improvement were identified within the PD community of the Midwest region. Knowledge about PD and access of PD-related services can be addressed through providing information to newly and those with an existing diagnosis with PD patients during routine medical appointments, community-based education programs, distribution of factsheets and brochures about PD in different PD support groups.

Study Limitations

The present study endured many unforeseen limitations. Throughout the time frame of data collection, a global pandemic limited participant recruitment to a large extent. Due to the Center of Disease Control guidelines, only online outreach and participation were accessible. The online only format led to limited participant responses as compared to if the surveys were administered both on paper and online formats. People in the PD community without internet access and proficiency were unable to participate in the survey. The study surveys were shared with participants as a Qualtrics link. At the end of data collection, it was observed that some of the questions did not appear on the participants' end leading to missing responses for some questions.

Future studies with larger sample sizes, involving people with different severities of PD and disease durations can be helpful in understanding the current perceptions and barriers experienced by people with PD and their families. Additionally, due to formatting of the survey, participants were not required to select their state of residence. Instead, their locations were reported via IEP addresses at the time of survey participation. Future studies can include questions specific to their primary residential region and current location to minimize any discrepancies in geographical location of the participants.

Clinical Implications

The present study provided an amplitude of information regarding symptoms, met and unmet needs, and barriers experienced by the PD community in the Midwest region of the United States. Based on the survey results, several conclusions can be drawn to help improve the experiences of both individuals with PD and communication partners. Specific to the symptoms experienced, more treatments need to be provided to manage mental and nonmotor symptoms. Increasing the availability of resources that improve and address mental health concerns such as depression and anxiety should be a focus in the Midwest regions of the United States. Also, with as many nonmotor symptoms associated with PD, it is important than an emphasis is put towards better awareness and education about these symptoms during medical visits and as part of different healthcare services and resources. Furthermore, the barriers to PD-related specialists need to be addressed. Increased information and access to specialists that help with all modalities affected by PD can be very beneficial for the PD communities. Finally, providing the education about available resources and their benefits to both people with PD and their families can address many of the barriers to service experienced.

REFERENCES

Abudi, S., Bar-Tal, Y., Ziv, L., & Fish, M. (1997). Parkinson's disease symptoms— ‘Patients’ perceptions. *Journal of Advanced Nursing*, *25*(1), 54-59.

Anzaldi, K., & Shifren, K. (2019). Optimism, pessimism, coping, and depression: A study on individuals with Parkinson’s disease. *The International Journal of Aging and Human Development*, *88*(3), 231-249.

Berry, R. A., & Murphy, J. F. (1995). Well-being of caregivers of spouses with Parkinson's disease. *Clinical Nursing Research*, *4*(4), 373-386.

Bogard, C. L. (2010). *The experience of care-giving for a person with Parkinson’s Disease*. University of Minnesota.

Buetow, S., Giddings, L. S., Williams, L., & Nayar, S. (2008). Perceived unmet needs for health care among Parkinson's Society of New Zealand members with Parkinson's disease. *Parkinsonism & Related Disorders*, *14*(6), 495-500.

Caap-Ahlgren, M., Lannerheim, L., & Ove Dehlin, M. D. (2002). Older Swedish women's experiences of living with symptoms related to Parkinson's disease. *Journal of Advanced Nursing*, *39*(1), 87-95.

Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of Behavioral Medicine*, 4(1), 92100. doi:10.1207/s15327558ijbm0401_6

Chaudhuri, K.R., Martinez-Martin, P., Brown, R.G., Sethi, K., Stocchi, F., Odin, P., …, and Schapira, A.H. (2007), The metric properties of a novel non-motor symptoms scale for Parkinson's disease: Results from an international pilot study. *Movement Disorders, 22,* 1901-1911.

Chaudhuri, K.R., Martinez-Martin, P., Schapira, A.H., Stocchi, F., Sethi, K., Odin, P., …, and Olanow, C.W. (2006). International multicenter pilot study of the first comprehensive self-completed nonmotor symptoms questionnaire for Parkinson's disease: The NMSQuest study. *Movement Disord*ers, 21: 916-923.

Cheon, S. M., Ha, M. S., Park, M. J., & Kim, J. W. (2008). Nonmotor symptoms of Parkinson's disease: prevalence and awareness of patients and families. *Parkinsonism & Related Disorders*, *14*(4), 286-290.

Dobkin, R. D., Rubino, J. T., Friedman, J., Allen, L. A., Gara, M. A., & Menza, M. (2013). Barriers to mental health care utilization in Parkinson's disease. *Journal of Geriatric Psychiatry and Neurology*, *26*(2), 105-116.

Dubois, B., Burn, D., Goetz, C., Aarsland, D., Brown, R.G., Broe, G.A., …, and Emre, M. (2007), Diagnostic procedures for Parkinson's disease dementia: Recommendations from the movement disorder society task force. *Movement Disorders.,* 22: 2314-2324.

Eremenco, S. L., Cella, D., & Arnold, B. J. (2005). A comprehensive method for the translation and cross-cultural validation of health status questionnaires. *Evaluation & the health professions*, *28*(2), 212-232.

Freed, D. B. (2020). *Motor Speech Disorders: Diagnosis and Treatment*. San Diego, CA: Plural Publishing.

Goy, E. R., Carter, J. H., & Ganzini, L. (2008). Needs and experiences of caregivers for family members dying with Parkinson disease. *Journal of Palliative Care*, *24*(2), 69-75.

Grosset, K. A., & Grosset, D. G. (2005). Patient-perceived involvement and satisfaction in Parkinson's disease: effect on therapy decisions and quality of life. *Movement Disorders, 20*(5), 616-619.

Group, T. E. (1990). EuroQol-a new facility for the measurement of health-related quality of life. *Health Policy*, *16*(3), 199-208.

Habermann, B. (2000). Spousal perspective of Parkinson's disease in middle life. *Journal of Advanced Nursing*, *31*(6), 1409-1415.

Hatano, T., Kubo, S. I., Shimo, Y., Nishioka, K., & Hattori, N. (2009). Unmet needs of patients with Parkinson's disease: interview survey of patients and caregivers. *Journal of International Medical Research*, *37*(3), 717-726.

Health Systems Strengthening Glossary. (2011, March 23). Retrieved June 27, 2020, from https://www.who.int/healthsystems/hss_glossary/en/index8.html

Jenkinson, C., Fitzpatrick, R. A. Y., Peto, V. I. V., Greenhall, R., & Hyman, N. (1997). The Parkinson's Disease Questionnaire (PDQ-39): development and validation of a Parkinson's disease summary index score. *Age and ageing*, *26*(5), 353-357.

Jenkinson, C., Fitzpatrick, R., Peto, V., Greenhall, R., & Hyman, N. (1997). The PDQ-8: development and validation of a short-form Parkinson's disease questionnaire. *Psychology and Health*, *12*(6), 805-814.

Jenkinson, C., Dummett, S., Kelly, L., Peters, M., Dawson, J., Morley, D., & Fitzpatrick, R. (2012). The development and validation of a quality of life measure for the carers of people with Parkinson’s disease (the PDQ-Carer). *Parkinsonism & Related Disorders*, *18*(5), 483-487.

Jost, W. H., & Bausch, J. (2017). Patients’ perspective on current treatment options for Parkinson’s Disease. *Basal Ganglia*, *9*, 7-11.

Kent, R. D., Kent, J. F., Weismer, G., & Duffy, J. R. (2000). What dysarthrias can tell us about the neural control of speech. *Journal of Phonetics*, *28*(3), 273-302.

Lageman, S. K., Mickens, M. N., & Cash, T. V. (2015). Caregiver-identified needs and barriers to care in Parkinson's disease. *Geriatric Nursing*, *36*(3), 197-201.

Lee, J., Kim, Y., Kim, S., Kim, Y., Lee, Y. J., & Sohn, Y. H. (2019). Unmet needs of people with Parkinson’s disease: A cross-sectional study. *Journal of Advanced Nursing*, *75*(12), 3504-3514.

Leroi, I., McDonald, K., Pantula, H., & Harbishettar, V. (2012). Cognitive impairment in Parkinson disease: impact on quality of life, disability, and caregiver burden. *Journal of Geriatric Psychiatry and Neurology*, *25*(4), 208-214.

Macht, M., Gerlich, C., Ellgring, H., Schradi, M., Rusiñol, À. B., Crespo, M., ... & Candini, L. (2007). Patient education in Parkinson's disease: formative evaluation of a standardized programme in seven European countries. *Patient Education and Counseling*, *65*(2), 245-252.

Marsh, L. (2013). Depression and Parkinson’s disease: Current knowledge. *Current Neurology and Neuroscience Reports, 13*(12), 409.

Martinez-Martin, P., Arroyo, S., Rojo-Abuin, J. M., Rodriguez-Blazquez, C., Frades, B., & de Pedro Cuesta, J. (2008). Burden, perceived health status, and mood among caregivers of Parkinson's disease patients. *Movement Disorders*, *23*(12), 1673-1680.

McLaughlin, D., Hasson, F., Kernohan, W. G., Waldron, M., McLaughlin, M., Cochrane, B., & Chambers, H. (2011). Living and coping with Parkinson’s disease: perceptions of informal carers. *Palliative Medicine*, *25*(2), 177-182.

Miller, N., Noble, E., Jones, D., & Burn, D. (2006). Life with communication changes in Parkinson’s disease. *Age and Ageing*, *35*(3), 235-239.

Montgomery Jr, E. B., Lieberman, A., Singh, G., & Fries, J. F. (1994). Patient education and health promotion can be effective in Parkinson's disease: a randomized controlled trial. *The American Journal of Medicine*, *97*(5), 429-435.

Parkinson’s Foundation. (2021). Retrieved on May 23, 2020 from https://www.parkinson.org/Understanding-Parkinsons/Statistics?_ga=2.72066199.580164167.1554047767-1543185907.1554047767

Pinto, S., Ozsancak, C., Tripoliti, E., Thobois, S., Limousin-Dowsey, P., & Auzou, P. (2004). Treatments for dysarthria in Parkinson's disease. *The Lancet Neurology*, *3*(9), 547-556.

Pomeroy, I.M., Clark, C.R. and Philp, I. (2001). The effectiveness of very short scales for depression screening in elderly medical patients. *International Journal of Geriatric Psychiatry, 16*, 321-326.

Radloff, L. S. (1977). The CES-D: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1(3), 385–401. doi:10.1177/ 014662167700100306

Santos-García, D., & de la Fuente-Fernández, R. (2013). Impact of non-motor symptoms on health-related and perceived quality of life in Parkinson's disease. *Journal of the Neurological Sciences*, *332*(1-2), 136-140.

Scheier, M. F., Carver, C. S., & Bridges, M. W. (1994). Distinguishing optimism from neuroticism (and trait anxiety, self-mastery, and self-esteem): A reevaluation of the life orientation test. *Journal of Personality and Social Psychology*, 67(6), 1063–1078. doi:10.1037/0022-3514.67.6.1063

Soundy, A., Stubbs, B., & Roskell, C. (2014). The experience of Parkinson’s disease: A systematic review and meta-ethnography. *The Scientific World Journal*, *2014*.

Theofilou, P. (2013). Quality of life: Definition and measurement. *Europe’s Journal of Psychology, 9*(1), 150-162.

van der Eijk, M., Faber, M. J., Post, B., Okun, M. S., Schmidt, P., Munneke, M., & Bloem, B. R. (2015). Capturing patients' experiences to change Parkinson's disease care delivery: a multicenter study. *Journal of Neurology*, *262*(11), 2528-2538.

Wallhagen, M. I., & Brod, M., (1997). Perceived control and well-being in Parkinson's disease. *Western Journal of Nursing Research*, *19*(1), 11-31.

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *The Gerontologist*, *20*(6), 649-655.

Zarit, S., Orr, N. K., & Zarit, J. M. (1985). The hidden victims of Alzheimer's disease: Families under stress. *NYU press*.

Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, *67*(6), 361-370.

APPENDICES

Appendix A: Demographic Questionnaire

Participant Groups: Individuals with PD and Family Members of People with PD

1. Age: _____________

2. Gender: ☐ Male ☐ Female ☐ Prefer not to indicate

3. Are you: ☐ Person with PD ☐ Spouse (or live-in partner) of an individual with PD ☐ Other family member of individual with PD (Adult child/ Grandchild/ Sibling/ Cousin/ Parent)

4. Race/ Ethnicity (check all the boxes that apply to you):

☐ African American ☐ Asian ☐ Hispanic/Latino ☐ Native American

☐ Pacific Islander ☐ White/ Caucasian ☐ Other (_____________________________)

☐ Prefer not to indicate

5. Highest Level of Education Obtained:

☐ Elementary level ☐ High School ☐ Vocational training/ Associate's Degree

☐ Bachelor's Degree ☐ Master's Degree ☐ Professional/ Doctoral Degree

6. Employment Status:

☐ Retired ☐ Working Full-time ☐ Working Part-time ☐ Volunteer ☐ On disability

☐ Unemployed, but not retired or on disability

PD-related questions for participants with PD

7. Medical History (list all of the conditions that you may have including Parkinson disease if applicable): ____

8. Do you have any self-identified or diagnosed changes in cognition (including attention, memory, reasoning, problem-solving, executive functioning)? ☐ Yes ☐ Maybe ☐ No

9. Do you currently take any dopaminergic medications? ☐ Yes ☐ Maybe ☐ No

10. Have you had any neurosurgery to control your PD-symptoms including deep brain stimulation? ☐ Yes ☐ No

11. How would you self-rate your PD severity?

☐ Very mild ☐ Mild ☐ Moderate ☐ Moderate-severe ☐ Severe

12. What stage of PD would you consider yourself to be at this time?

☐ Stable ☐ Progressive ☐ Rapidly progressive ☐ Other ☐ Do not know

Family-member questions

12. Your medical history: ____

13. Do you have any self-identified or diagnosed changes in cognition (including attention, memory, reasoning, problem-solving)? ☐ Yes ☐ Maybe ☐ No

14. Your occupation (prior and/or current): ____

Demographic Questionnaire

Participant Group: Healthcare Professionals

1. Age: _____________

2. Gender: ☐ Male ☐ Female ☐ Prefer not to indicate

3. Race/ Ethnicity (check all the boxes that apply to you):

☐ African American ☐ Asian ☐ Hispanic/Latino ☐ Native American

☐ Pacific Islander ☐ White/ Caucasian ☐ Other (______________________________)

☐ Prefer not to indicate

4. Highest Level of Education Obtained:

☐ Elementary level ☐ High School ☐ Vocational training/ Associate's Degree

☐ Bachelor's Degree ☐ Master's Degree ☐ Professional/ Doctoral Degree

5. List your specific profession: __________________________________

6. List your specific work setting: Nursing home/ Acute care/ Hospital/ Outpatient/ Private Practice/ Others (_____________________________________)

7. State of practice: ☐ Arkansas ☐ Colorado ☐ Kansas ☐ New Mexico ☐ Oklahoma ☐ Texas ☐ Other region (____)

8. Employment Status:

☐ Working Full-time ☐ Working Part-time ☐ Volunteer ☐ Retired ☐ On disability

☐ Unemployed, but not retired or on disability

9. How often do you work with patients with PD as part of your regular caseload?

☐ All the time (76-10% of the caseload) ☐ Some of the time (26-75% of the caseload) ☐ Rarely (1-25% of the caseload) ☐ Not at all

10. Do you have any self-identified or diagnosed changes in cognition (including attention, memory, reasoning, problem-solving)? ☐ Yes ☐ Maybe ☐ No

11. Do you have a family member/ friend (current/ past) with a diagnosis of Parkinson disease?

☐ Yes ☐ No

Demographic Questionnaire

Participant Group: Adults 18 years or older

1. Age: ____________

2. Gender: ☐ Male ☐ Female ☐ Prefer not to indicate

3. Race/ Ethnicity (check all the boxes that apply to you):

☐ African American ☐ Asian ☐ Hispanic/Latino ☐ Native American

☐ Pacific Islander ☐ White/ Caucasian ☐ Other (____________________________)

☐ Prefer not to indicate

4. Highest Level of Education Obtained:

☐ Elementary level ☐ High School ☐ Vocational training/ Associate's Degree

☐ Bachelor's Degree ☐ Master's Degree ☐ Professional/ Doctoral Degree

5. List your current occupation (if applicable): ________________________________

6. Do you have a family member/ friend (current/ past) with a diagnosis of Parkinson disease?

☐ Yes ☐ No

Appendix B: Self-reported Depression Questionnaire and Mental Health Inventory

Source: Pomeroy, I.M., Clark, C.R. and Philp, I. (2001). The effectiveness of very short scales for depression screening in elderly medical patients. *International Journal of Geriatric Psychiatry, 16*, 321-326.

Geriatric Depression Scale: 4- item version

1. Are you basically satisfied with your life? ☐ Yes ☐ NO
2. Do you feel your life is empty? ☐ YES ☐ No
3. Are you afraid that something bad is going to happen to you? ☐ YES ☐ No
4. Do you feel happy most of the time? ☐ Yes ☐ NO

Note: Score 1 for each answer in CAPITALS. A score of 1 or more indicates possible depression.

Mental Health Inventory: 1- item version

How much of the time over the past month have you felt downhearted and sad?

All of the time	6
Most of the time	5
A good bit of the time	4
Some of the time	3
A little of the time	2
None of the time	1

Note: A score of 3 or more indicates possible depression.

Appendix C: PD Knowledge Survey

Sources: The following checklist was developed based on findings reported by the following sources.

Abudi, S., Bar-Tal, Y., Ziv, L., & Fish, M. (1997). Parkinson's disease symptoms- Patients' perceptions. *Journal of Advanced Nursing, 25*, 54-59.

Cheon, S-M., Ha, M-S., Park, M.J., & Kim, J. W. (2008). Nonmotor symptoms of Parkinson's disease: Prevalence and awareness of patients and families. *Parkinsonism and Related Disorders, 14*, 286-290.

Freed, D.B. (2020). *Motor Speech Disorders: Diagnosis and Treatment.* San Diego, CA: Plural Publishing.

Miller, N. (2012). Speech, voice and language in Parkinson's disease: Changes and interventions. *Neurodegenerative Disease Management, 2*(3), 279-289.

<u>Instructions:</u> Below is a checklist of different symptoms related to Parkinson disease (PD). Please check ALL of the symptoms that you think may be related to Parkinson disease (PD).

Check all the boxes that you think are related to Parkinson Disease	*Possible Changes*
	I. Motor Changes
	i. Rest tremors (shaking of hands, fingers, legs)
	ii. Dyskinesias (out-of-control movements of hands and legs)
	iii. Changes in physical gait (reduced steps, shuffling, freezing)
	iv. Reduced arm swing
	v. Changing positions (e.g., from sitting to standing, from lying to sitting)
	vi. Walking outside home (walking on pavements/walking surfaces outside home)
	vii. Muscle ache
	viii. Muscle cramps
	ix. Fine movements (buttoning, tying shoelaces)
	x. Changing position in bed
	xi. Ability to clip one's own nails using a clipper

	xii. Dressing self
	xiii. Getting in/out of bed
	xiv. Toileting/ Difficulty toileting
	xv. Morning stiffness
	xvi. Eating problems
	xvii. Changes in swallowing
	xviii. Changes in handwriting
	xix. Lack of dexterity (holding tools such as brush, pen with hands)
	II. Communication Changes
	i. Quiet voice (reduced loudness)
	ii. Monopitch (same pitch across all sentences)
	iii. Voice getting husky
	iv. Voice getting deeper
	v. Voice getting quieter
	vi. Voice tremors
	vii. Constant throat clearing
	viii. Mumbling
	ix. Imprecise consonants
	x. Tight mouth
	xi. Slowness of speech
	xii. Loss of clarity
	xiii. More effort to maintain intelligible speech
	xiv. Palilalia (repetition of words)
	xv. Reduced breath support
	xvi. Reduced control of exhalation
	xvii. Shallow breathing
	xviii. Mild changes in nasality (extra air coming out)

	III. Non-motor Changes
	i. Dribbling of saliva
	ii. Change in taste
	iii. Change in smell
	iv. Vomiting
	v. Nausea
	vi. Constipation
	vii. Bowel incontinence
	viii. Incomplete bowel emptying
	ix. Urinary urgency
	x. Nocturia (or excessive nighttime urination)
	xi. Unexplained pain
	xii. Unexplained weight loss
	xiii. Memory changes
	xiv. Loss of interest
	xv. Hallucinations (experience something that really does not exist such as seeing a person, animal, or an object)
	xvi. Difficulty in concentrating
	xvii. Feeling sad
	xviii. Feeling anxious
	xix. Change in sexual interest
	xx. Sexual dysfunction
	xxi. Orthostatic dizziness or hypotension (sudden drop in blood pressure when standing up from sitting or lying down)
	xxii. Daytime sleepiness
	xxiii. Insomnia
	xxiv. Intense, vivid dreams
	xxv. Sleep talking and moving

	xxvi. Restless legs
	xxvii. Swelling of legs
	xxviii. Excessive sweating
	xxix. Double vision
	xxx. Delusions (false beliefs)

Appendix D: PD Symptom Checklist

Sources: The following checklist was developed based on findings reported by the following sources.

Abudi, S., Bar-Tal, Y., Ziv, L., & Fish, M. (1997). Parkinson's disease symptoms- Patients' perceptions. *Journal of Advanced Nursing, 25*, 54-59.

Cheon, S-M., Ha, M-S., Park, M.J., & Kim, J. W. (2008). Nonmotor symptoms of Parkinson's disease: Prevalence and awareness of patients and families. *Parkinsonism and Related Disorders, 14*, 286-290.

Freed, D.B. (2020). *Motor Speech Disorders: Diagnosis and Treatment.* San Diego, CA: Plural Publishing.

Miller, N. (2012). Speech, voice and language in Parkinson's disease: Changes and interventions. *Neurodegenerative Disease Management, 2*(3), 279-289.

Check all the boxes that you or your loved one with Parkinson disease experiences	*Possible Changes*
	IV. Motor Changes
	xx. Rest tremors (shaking of hands, fingers, legs)
	xxi. Dyskinesias (out-of-control movements of hands and legs)
	xxii. Changes in physical gait (reduced steps, shuffling, freezing)
	xxiii. Reduced arm swing
	xxiv. Changing positions (e.g., from sitting to standing, from lying to sitting)
	xxv. Walking outside home (walking on pavements/walking surfaces outside home)
	xxvi. Muscle ache
	xxvii. Muscle cramps
	xxviii. Fine movements (buttoning, tying shoelaces)
	xxix. Changing position in bed
	xxx. Ability to clip one's own nails using a clipper
	xxxi. Dressing self

	xxxii. Getting in/out of bed
	xxxiii. Toileting/ Difficulty toileting
	xxxiv. Morning stiffness
	xxxv. Eating problems
	xxxvi. Changes in swallowing
	xxxvii. Changes in handwriting
	xxxviii. Lack of dexterity (holding tools such as brush, pen with hands)
	V. Communication Changes
	xix. Quiet voice (reduced loudness)
	xx. Monotonous voice (lack of loudness and pitch variation)
	xxi. Voice getting husky
	xxii. Voice getting deeper
	xxiii. Voice getting quieter
	xxiv. Voice tremors (shakiness of voice)
	xxv. Constant throat clearing
	xxvi. Mumbling
	xxvii. Imprecise consonants
	xxviii. Tight mouth
	xxix. Slowness of speech
	xxx. Loss of clarity
	xxxi. More effort to maintain intelligible speech
	xxxii. Palilalia (repetition of words)
	xxxiii. Reduced breath support
	xxxiv. Reduced control of exhalation
	xxxv. Shallow breathing
	xxxvi. Mild changes in nasality (extra air coming out)
	VI. Non-motor Changes

	xxxi. Dribbling of saliva
	xxxii. Change in taste
	xxxiii. Change in smell
	xxxiv. Vomiting
	xxxv. Nausea
	xxxvi. Constipation
	xxxvii. Bowel incontinence
	xxxviii. Incomplete bowel emptying
	xxxix. Urinary urgency
	xl. Nocturia (or excessive nighttime urination)
	xli. Unexplained pain
	xlii. Unexplained weight loss
	xliii. Memory changes
	xliv. Loss of interest
	xlv. Hallucinations (experience something that really does not exist such as seeing a person, animal, or an object)
	xlvi. Difficulty in concentrating
	xlvii. Feeling sad
	xlviii. Feeling anxious
	xlix. Change in sexual interest
	l. Sexual dysfunction
	li. Orthostatic dizziness or hypotension (sudden drop in blood pressure when standing up from sitting or lying down)
	lii. Daytime sleepiness
	liii. Insomnia
	liv. Intense, vivid dreams
	lv. Sleep talking and moving
	lvi. Restless legs

	lvii. Swelling of legs
	lviii. Excessive sweating
	lix. Double vision
	lx. Delusions (false beliefs)

Appendix E: Unmet Needs and Barriers for Service Delivery of People with PD

Adapted from: Lageman, S.K., Cash, T.V., & Mickens, M.N. (2014). Patient-reported needs, non-motor symptoms, and quality of life in essential tremor and Parkinson's disease. *Tremor and Other Hyperkinetic Movements, 4. doi: 10.7916/D8RF5S4J*

Section I: Current Unmet Needs for People with PD

Check ALL the boxes to indicate things you need help with	*Service Areas*
	1. Symptom management
	i. Tremor/gait/balance problems
	ii. Speech/voice/communication problems
	iii. Common medication side effects
	iv. Issues with swallowing
	v. Incontinence
	vi. Sexual problems
	vii. Vision changes/ issues
	viii. Communicating with treating doctors/nurses
	2. Lifestyle changes and Planning for the future
	i. Driving
	ii. Vacationing and travel tips
	iii. Fall prevention
	iv. Safety in the home
	v. Long-term planning for the future
	vi. Financial concerns
	vii. Resource identification and accessing resources for future
	viii. Legal issues
	3. Wellness strategies
	i. Beginning an exercise regime or adapting one to fit personal needs

	ii. Nutritional changes and healthy eating strategies
	iii. Stress management
	iv. Spiritual support
	4. Thinking changes
	i. Expressing self
	ii. Memory
	iii. Attention
	iv. Problem solving
	5. Relationship changes
	i. Maintaining a social life
	ii. Changes in personal relationships post diagnosis
	iii. Identifying emotional support systems
	iv. Role changes
	v. Parenting-related issues
	vi. Major family decision-making and planning
	vii. Caregiver/ Communication partner/ Family stress
	6. Emotional changes
	i. Experiencing anxiety
	ii. Experiencing depression
	iii. Experiencing fatigue
	iv. Experiencing apathy
	7. Work-related or social expectations
	i. Disclosing your PD diagnosis; how to and if you should
	ii. Balancing family, medical and health responsibilities with work duties
	iii. Transitioning from full-time to part-time work

	iv. Analyzing transferable skills and new/different job possibilities following the PD diagnosis
	v. Advocating for accommodations
	8. Personality/ behavioral changes
	i. Visual hallucinations
	ii. Inappropriate behaviors
	iii. Aggression
	9. Coping with PD diagnosis Patient education about PD diagnosis
	i. Patient education about PD diagnosis
	ii. Adjustment to PD diagnosis
	iii. Early onset of PD diagnosis
	10. Any other areas that may not have been included above (please use the space below to discuss more):

<u>Section B: Access to Services Related to Assessment, Care, and Management of People with PD</u>

Service Areas	*Check ALL the services that you with a diagnosis of PD are receiving or your loved one with PD is currently receiving*
Neurology	
Movement Disorder Specialist	
Pharmacy	
Physical Therapy/ Exercise Groups (boxing, Tai Chi, regular exercise)	
Speech therapy/ SPEAK OUT! ®/ LOUD Crowd®/ LSVT® Groups	
Swallowing Specialist	
Sleep Specialist	
Psychology/ Counseling	
Neuropsychology/ Psychiatry	
Nutrition	
Occupational Therapy	
Clinical Trials/ Research Studies	
Online/Video/ In-person Support Groups	
Social Work	
Home-Health Related Services	
Palliative/ End-of-life Care	

Other areas (not listed above) please list if applicable	

Section C: Barriers to Effective Assessment, Care, and Management of People with PD

Service Areas	*Rank the top five areas in order of "Greatest Need" (1- greatest or most important area of need or priority; 5- fifth most important area of need or priority)*
Neurology	
Movement Disorder Specialist	
Pharmacy	
Physical Therapy/ Exercise Groups (boxing, Tai Chi, regular exercise)	
Speech therapy/ SPEAK OUT! ®/ LOUD Crowd®/ LSVT® Groups	
Swallowing Specialist	
Sleep Specialist	
Psychology/ Counseling	
Neuropsychology/ Psychiatry	
Nutrition	
Occupational Therapy	
Clinical Trials/ Research Studies	
Online/Video/ In-person Support Groups	
Social Work	
Home-Health Related Services	
Palliative/ End-of-life Care	
Other areas (not listed above) please list if applicable	

Appendix F: Parkinson’s Disease Quality of Life Questionnaire (PDQ-8)

Source: Jenkinson, C., Fitzpatrick, R., & Peto, V. (1998). *Oxford University Innovation Limited.*

Parkinson’s Disease Quality of Life Questionnaire (PDQ-8)

Due to having Parkinson’s disease, **how often <u>during the last month</u> have you…**

Please **check one box** for each question

		Never	**Occasionally**	**Sometimes**	**Often**	**Always or cannot do at all**
1.	Had difficulty getting around in public places?	☐	☐	☐	☐	☐
2.	Had difficulty dressing?	☐	☐	☐	☐	☐
3.	Felt depressed?	☐	☐	☐	☐	☐
4.	Had problems with your close personal relationships?	☐	☐	☐	☐	☐
5.	Had problems with your concentration, for example, when reading or watching TV?	☐	☐	☐	☐	☐
6.	Felt unable to communicate effectively?	☐	☐	☐	☐	☐
7.	Had painful muscle cramps or spasms?	☐	☐	☐	☐	☐

8.	Felt embarrassed in public due to having Parkinson’s disease?	☐	☐	☐	☐	☐

Please verify that you have ***checked one box for each question***.

Thank you for completing the questionnaire.

Final English (US) PDQ-8 1996.

Appendix G: Parkinson's Disease Carer Questionnaire

Due to being a carer,
how often during the last 4 weeks have you…

*Please **check one box** for each question*

		Never	**Occasionally**	**Sometimes**	**Often**	**Always**
1.	Found you could not sleep through the night?	☐	☐	☐	☐	☐
2.	Found it difficult to get out to do the grocery shopping?	☐	☐	☐	☐	☐
3.	Found the demands of caring physically difficult?	☐	☐	☐	☐	☐
4.	Felt anxious because of the responsibility of caring?	☐	☐	☐	☐	☐
5.	Been prevented from pursuing hobbies and other interests?	☐	☐	☐	☐	☐
6.	Felt worried about your own physical health?	☐	☐	☐	☐	☐
7.	Thought that your caring role was taken for granted by others?	☐	☐	☐	☐	☐

Please verify that you have *<u>checked one box for each question</u>*
before going on to the next page.

Due to being a carer,
how often <u>during the last 4 weeks</u> have you…

Please ***check one box*** *for each question*

		Never	Occasionally	Sometimes	Often	Always
8.	Felt that relationships with friends have been affected?	☐	☐	☐	☐	☐
9.	Felt impatient with the person you care for?	☐	☐	☐	☐	☐
10.	Felt exhausted?	☐	☐	☐	☐	☐
11.	Felt worried about the future?	☐	☐	☐	☐	☐
12.	Felt you lacked the energy and motivation to do the things you enjoy?	☐	☐	☐	☐	☐
13.	Taken less care with your diet?	☐	☐	☐	☐	☐
14.	Felt more withdrawn because of your caring role?	☐	☐	☐	☐	☐

15.	Felt depressed?	☐	☐	☐	☐	☐

Please verify that you have <u>checked one box for each question</u>
before going on to the next page.

Due to being a carer,
how often <u>during the last 4 weeks</u> have you…

Please ***check one box*** *for each question*

		Never	**Occasionally**	**Sometimes**	**Often**	**Always**
16.	Felt less in control of your temper than before you became a carer?	☐	☐	☐	☐	☐
17.	Felt worried about what would happen if you were unwell?	☐	☐	☐	☐	☐
18.	Been limited in what you can do socially?	☐	☐	☐	☐	☐
19.	Felt that your workload around the house has increased significantly?	☐	☐	☐	☐	☐
20.	Found it difficult to see friends and family in person?	☐	☐	☐	☐	☐

21.	Found it difficult to leave the person you care for alone for more than one hour?	☐	☐	☐	☐	☐
22.	Felt that your physical health has been affected by your caring role?	☐	☐	☐	☐	☐
23.	Felt that you are responsible for everything at home?	☐	☐	☐	☐	☐

Please verify that you have checked one box for each question ***before going on to the next page.***

Due to being a carer,
how often during the last 4 weeks have you…

Please ***check one box*** *for each question*

		Never	Occasionally	Sometimes	Often	Always
24.	Felt that you cannot do things on the spur of the moment?	☐	☐	☐	☐	☐
25.	Found it difficult to be involved in activities which require commitment (for example volunteering work or regularly meeting friends)?	☐	☐	☐	☐	☐
26.	Paid less attention to your own health (for example put off visiting a doctor, ignored symptoms etc.)?	☐	☐	☐	☐	☐

27.	Felt unable to go on holiday or take short breaks?	☐	☐	☐	☐	☐
28.	Felt responsible for Parkinson's disease medication being available and/or taken at appropriate times?	☐	☐	☐	☐	☐
29.	Had to limit outings because you worry that the person you care for won't be able to cope?	☐	☐	☐	☐	☐

Please verify that you have checked one box for each question**.**

Thank you for completing this questionnaire.

Appendix H: IRB Approval Page

Oklahoma State University Institutional Review Board

Application Number:	IRB-20-280
Proposal Title:	Current Knowledge, Unmet Needs, and Barriers of Service Delivery forIndividuals with Parkinson Disease And Their Families

Principal Investigator: SABIHA PARVEEN
Co-Investigator(s):
Faculty Adviser:
Project Coordinator:
Research Assistant(s): Jaelan Moore

Status Recommended by Reviewer(s): Approved

Study Review Level: Exempt Modification
Approval Date: 08/20/2020

The modification of the IRB application referenced above has been approved. It is the judgment of the reviewers that the rights and welfare of individuals who may be asked to participate in this study will be respected, and that the research will be conducted in a manner consistent with the IRB requirements asoutlined in section 45 CFR 46. The original expiration date of the protocol has not changed.

Modifications Approved:
Modifications Approved: revise recruitment flyer

The final versions of any recruitment, consent and assent documents bearing the IRB approval stamp areavailable for download from IRBManager. These are the versions that must be used during the study.

As Principal Investigator, it is your responsibility to do the following:

1. Conduct this study exactly as it has been approved.
2. Submit a status report to the IRB when requested
3. Promptly report to the IRB any harm experienced by a participant that is both unanticipated andrelated per IRB policy.
4. Maintain accurate and complete study records for evaluation by the OSU IRB and,

if applicable,inspection by regulatory agencies and/or the study sponsor.

5. Notify the IRB office when your research project is complete or when you are no longer affiliatedwith Oklahoma State University.

Sincerely,

Oklahoma State University IRB
223 Scott Hall, Stillwater,
OK 74078Website:
https://irb.okstate.edu/
Ph: 405-744-3377 | Fax: 405-744-4335| irb@okstate.edu

VITA

Jaelan Moore

Candidate for the Degree of

Master of Science

Thesis: SYMPTOM PERCEPTION, UNMET NEEDS, AND BARRIERS OF SERVICE DELIVERY FOR INDIVIDUALS WITH PARKINSON DISEASE AND THEIR FAMILIES

Major Field: Communication Sciences and Disorders

Biographical:

Education:

Completed the requirements for the Master of Science in Communication Sciences and Disorders at Oklahoma State University, Stillwater, Oklahoma in May, 2021.

Completed the requirements for the Bachelor of Science in Speech Language Pathology and Audiology at the University of North Texas, Denton, Texas in 2019.

Experience: Student Intern at Total Health, Student Intern at Highland Park elementary school, Graduate Clinician at Oklahoma State University Speech-Language & Hearing Clinic.

Professional Membership: National Student Speech-Language Hearing Association, National Black Association for Speech-Language and Hearing, Sisters in Speech Therapy and Audiology