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Doctoral Capstone Experience with a Neurological Population

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Abstract

Through the completion of a doctoral capstone experience, an entry-level occupational therapy doctoral student is able to further develop advanced skills. The doctoral capstone experience is during the student's last semester in the program and is 16 weeks long. The doctoral capstone experience consists of both a culminating project and the experience itself. The capstone project is "comprised of a literature review, needs assessment, goals/objectives, and an evaluation plan based on specific focus areas" (ACOTE, 2020). The Nova Southeastern University Entry-Level Doctor of Occupational Therapy Doctoral Capstone Manual states that "the goal of the doctoral capstone project and experience is to develop an occupational therapist with skills that are more advanced or those beyond the level of a generalist" (NSU OTD Program, 2020, p. 41). The areas of focus for my capstone project were advanced clinical practice skills and program development. I worked with my mentor at an outpatient neurorehabilitation clinic that was a part of a larger hospital system, Christiana Care. At that clinic I was able to treat a full caseload of individuals with various neurological diagnoses. In addition to advancing my clinical skills, I developed a community resource list for individuals with Parkinson's disease which encompassed the state of Delaware and parts of surrounding states. I was also able to participate in various other learning opportunities such as shadowing a neurologist who specializes in movement disorders, attending the Parkinson's Symposium for the healthcare system, shadowing in the acute care and inpatient rehab settings, and completing continuing education courses.

Introduction to Capstone Project

The areas of focus for my capstone project were clinical practice skills and program development. My capstone project was completed at Christiana Care Health Services in Newark, Delaware at one of their outpatient rehabilitation locations. To further my clinical practice skills, I worked in an outpatient neurorehabilitation site and was able to treat individuals with various neurological conditions. For program development I worked with both my mentor and a neurologist who specialized in movement disorders to assist with the implementation of town halls for individuals with Parkinson's disease (PD) and their families as well as healthcare professionals who treat PD. I also created a cumulative community resource list (See Appendix A) for distribution to individuals with PD, their families, and other healthcare professionals in the area. This list encompassed the state of Delaware, Eastern Maryland, Southeastern Pennsylvania, Southern New Jersey, and national resources. The community resource list included various locations for Lee Silverman Voice Therapy (LSVT BIG and LOUD) programs, exercise resources, support groups, adaptive equipment, accessibility resources, research opportunities, and podcasts. LSVT BIG and LOUD are programs that are designed for individuals with PD to speak at a more "normal" volume and to move at a more "normal" amplitude. Clinicians can be trained in these programs and they are both backed by research to help individuals with PD "recalibrate" their movements (LSVT Global, 2021).

My capstone site specifically was Springside Rehabilitation which is an outpatient rehabilitation location within Christiana Care Health services. This location serves primarily individuals who have neurological diagnoses including cerebrovascular accidents (CVA), PD, spinal cord injury, traumatic brain injury, cerebral palsy, and essential tremor. My primary mentor, Julia Santini, is an occupational therapist (OT) at this site and has been practicing for 20 years. There are three OTs on staff at this site and I was able to work closely with all of them. One of the other OTs served as my mentor for working with the neurologist and program development. I treated a full caseload of clients each week in addition to working on my project development. My mentor has been working with this population for the last 15 years and the other OTs on staff also have 10 plus years of experience each with this population. I worked with Dr. Martello, the sole neurologist who specializes in movement disorders in the state of Delaware. Dr. Martello provides education on PD within the community and one of his current projects is the implementation of town halls for individuals with PD and their families. During my capstone project, he also hosted a Parkinson's Symposium for the community that provided education on various topics including medication, rehabilitation, psychological symptoms of PD, hospitalization considerations, and information for caregivers. I was able to attend this symposium and the resource list I developed was distributed at this event.

Literature Review of Capstone Topic

PD is a neurodegenerative disorder affecting more than 10 million individuals worldwide and about one million individuals in the United States (Elkouzi, 2020). PD affects the dopamineproducing neurons in the substantia nigra area of the brain. Individuals with PD may experience both motor and non-motor symptoms including tremors, bradykinesia, limb rigidity, gait and balance problems, cognitive impairment, depression, and sleep disorders (Elkouzi, 2020). The cause for PD remains unknown and it has a slow progression which varies from person to person and there is currently no cure (Elkouzi, 2020). Specialists often use the modified Hoehn and Yahr scale to gauge progression of the disease from stages zero to five with five being advanced PD (Elkouzi, 2020). As PD is a lifelong disease, individuals need medical support from professionals but also emotional and physical support from those in their lives. In addition to education and support about the disease itself, individuals with PD and their caregivers need information on the progression and maintenance of the disease. Research has been conducted regarding various types of programs and education that highlight the benefit for both individuals with PD and their caregivers. This research has primarily been focused on the benefit of exercise programs for individuals (Horne et al., 2019). While exercise is a critical aspect of PD management, individuals with PD also need education and psychological support. Difficulty accessing health information as a result of the COVID-19 pandemic highlights the need for a different format of providing information to older adults who may not have access otherwise. This literature review will highlight various themes that were identified in research including client and caregiver support, community resources, disease maintenance, psychosocial factors, and the impact of COVID-19 on individuals with PD.

Client and Caregiver Support

Individuals with PD require regular visits with their primary care doctor and/or neurologist to review medications and any new symptoms. Aside from those visits, monitoring symptoms and everyday care falls on the individual and their caregivers. Individuals with PD and their caregivers require education and support to ensure all parties are supported (Hellqvist et al., 2020).

A qualitative observational study conducted by Hellqvist et al. (2020) looked at the effects of self-management for individuals with PD and their care partners. This study was conducted in Sweden following the clinical practice implementation of a self-management program called the Sweden National Parkinson School, which used self-management and self-monitoring as central concepts. Self-management was defined as "a person's ability to collaborate with family, society, and healthcare providers to handle the symptoms, treatments,

lifestyle changes, psychosocial strain, and other consequences of the disease". Self-monitoring was defined as "the cognitive processes (including observation and assessment) of symptoms or activities of daily living leading to self-awareness" (Hellqvist et al., 2020, p. 742). The researchers sought to determine whether persons with Parkinson's disease (PwPD) and care partners implemented the management and monitoring strategies that were introduced in the Sweden National Parkinson School and if these strategies were used in clinical encounters with healthcare providers. Participants included ten PwPD in various stages of disease progression, and three of their care partners. The majority (five) of PwPD were categorized as a Hoehn and Yahr stage III. Data was collected from 3-15 months after program implementation by researchers and qualitative interviews were conducted with a physician. Researchers identified three main categories from the data "self-observation in everyday life," "self-care activities to promote health," and "managing the emotional impact of PD". They also identified a corecategory "awareness of own abilities strengthens mutual understanding and communication in the health care encounter" which was a blending of the others. Awareness of abilities and struggles of PwPD and their care partners was key to self-management of PD in everyday life. This awareness transfers over to the encounters between health care provider and PwPD and their care partners. Being listened to and being able to communicate with their physician about how they experience life with PD was identified as highly important to individuals. Selfobservation of both motor and non-motor symptoms in everyday life by PwPD and care partners was important to be able to report back to physicians regarding disease progression, medication side effects, and the impact of daily activities on symptoms (i.e., time of day). Education for PwPD and care partners surrounding the importance of this concept is critical for disease maintenance. Self-care activities were identified as a critical component of daily routines for

PwPD, helping to promote well-being and happiness. Activities included medication management (i.e., timing of medications to not interfere with food intake), energy conservation, and engaging in leisure activities. Managing the emotional impact of the disease was also identified as critical to PwPD and their care partners. Having anxiety surrounding disease progression, depression, and disease management were all identified during the interviews (Hellqvist et al., 2020). The themes identified in this study highlight the importance of educational and emotional support for PwPD and their care partners.

Another study about caregivers and individuals with PD conducted by Cholewa et al. (2016) looked specifically at the quality of life (QOL) of caregivers for patients with PD. There were 50 caregivers who participated in the study and they were given a survey that consisted of two parts (basic demographic information and a level of life satisfaction survey). It was found that the majority of the participants were caregivers to their spouses (56%) and the majority were female (66%). The stage of the disease of the patients was defined by the Hoehn-Yahr scale and all were classified as stage III. Participants were then split into two groups based on whether the patients were in rehabilitation (group A, 26 patients) or not (group B, 24 patients). Analysis of the results showed significance (p=0.001) between the group participating in rehabilitation (A) and less time spent caring for patients of PD by caregivers, indicating the benefit of rehabilitation. In group A, 54% of the individuals said they cared for less than 6 hours a day and only 2% declared more than 12 hours. With group B, only 22% spent less than 6 hours daily and 25% stated they cared for more than 12 hours a day. The activities that the individuals had to assist with also varied between the two groups. Group A required less assistance with their daily activities (i.e., cleaning, and household/financial management). Between groups A and B, there was also a difference in disease progression (as rated by the caregivers). In group A, only 19%

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declared a clear worsening and in group B as many as 62% declared a worsening of condition. Fatigue was also examined and participants in group A showed less rates of fatigue. The Satisfaction with Life Scale was administered to participants and consisted of 5 statements that were rated "agree" or "disagree". The majority of group A answers were "disagree" and for group B the most frequent answers were "neither agree, nor disagree" (Cholewa et al., 2016).

Researchers identified that long-term care of individuals may lead to a decrease in QOL for caregivers. An important finding of this study is the differences between the two groups (A and B) and the importance of exercise for not only the patient but also the caregiver. When patients are involved in rehabilitation it leads to an improved QOL for both the patient and caregiver. This finding highlights the potential opportunity of providing education to patients and caregivers on the benefits of rehabilitation.

Care for an individual with Parkinson's may fall on the individual's spouse. A pilot study titled "Benefits of a self-management program for the couple living with Parkinson's disease: A pilot study", implemented a self-management workshop that was community-based and the goal was to explore the health benefits for both the individual with PD and their spouse. Researchers pointed out that most research surrounding the impact of PD is focused either on the individual with PD or their spouse individually, not as a dyad or family unit. The focus of this research was shifted to include the experience of the couple as a unit and not just the individual's experiences (Lyons et al., 2020). Couples in this study participated in a workshop titled *Strive to Thrive* and followed the curriculum for Chronic Disease Self-Management Program (CDSMP). Researchers sought to determine if participation in this program would lead to better health, self-management behaviors, and illness communication. Researchers used a quasi-experimental two-wave design with measurements taken at baseline and at a seven-week follow up to examine the effects of the

program compared to a control group. There were 39 couples (19 with PD and 20 control), who participated in the seven week workshop that took place in Oregon. The curriculum for CDSMP reviews important aspects of chronic conditions including depression, sleep problems, and exercise. The curriculum also teaches self-management skills such as monitoring, taking action, problem-solving, decision-making, and evaluating results. Various measures were used to look at health variables, depressive symptoms, care strain, self-management behaviors, and illness communication.

There were 19 couples who participated in the *Strive to Thrive* program and there were 20 couples in a wait-list control group (Lyons et al., 2020). They categorized results into various groups including health outcomes, self-management outcomes, and illness communication. Adults with PD in the intervention group had greater declines in their physical health and their spouses in the intervention had greater declines in depressive symptoms than the control group. It was pointed out that spouses who participated in the program seemed to have greater health benefits than those with PD. Spouses who participated in the program demonstrated increased engagement in mental relaxation techniques, strength-based activities, and self-efficacy to support the individual with PD than the control group. The individuals with PD in the intervention group demonstrated an increase for aerobic activity and mental relaxation compared to the control group but had declines in self-efficacy to manage their PD. It was noted that spouses in the intervention group perceived less protective buffering (hiding their worries) than those in the control group. Researchers called for moving towards a dyadic approach with management of illness, i.e. to treat couples as a unit rather than one ill person and one healthy person. Findings from this article highlight the benefit for spouses participating in communitybased educational programs and allow for greater support of the individual with PD.

Psychosocial Factors and Mental Health

Mood disorders are the most common non-motor symptoms of PD and are often overlooked (Khedr et al., 2013). Depression and anxiety are among the most distressing symptoms of PD and present a further burden on patients and caregivers alike. Khedr et al. (2020), sought to determine various risk factors and frequency of anxiety and depression and the impact it has on quality of life for individuals with PD. For their cross-sectional study researchers recruited 64 patients who were diagnosed with PD according to the Unified Parkinson's Disease Rating Scale (UPDRS) to a group of 50 sex-and-age matched healthy control subjects and both groups were evaluated for depression and anxiety. For both groups, scores on the Mini-Mental State Examination (MMSE) were used to exclude individuals with moderate to severe dementia. A structured clinical interview was conducted based on the Diagnostic and Statistical Manual of Mental Disorders (5th edition) criteria to diagnose anxiety and depression, as well as eliminate any clinical comorbidities in both patients and controls. The Hamilton rating scales for both anxiety and depression were used to rank severity and the World Health Organization (WHO) Quality of Life: Brief version was used to assess QOL for all participants.

Results showed that individuals with PD had significantly higher rates of both depression (p = 0.032) and anxiety (p < 0.001) than those of the control group. Generalized Anxiety Disorder was the most common anxiety disorder and the overlap between depression and anxiety was 23.4%. Researchers identified that PD with depression was significantly more common with females (p = 0.004), low socioeconomic status (p = 0.004), and those with a past history of depression (p < 0.001). It was also identified that PD patients with depression had more advanced disease stage and more severe motor symptoms (p = 0.0014 and p < 0.001). There was

a correlation between age of onset for PD and anxiety, where a younger onset of PD was positively correlated with higher rates of anxiety (p < 0.001) (Khedr et al., 2020). There were higher rates of cognitive impairment for patients who were depressed. Overall QOL was also significantly worse in individuals with PD with depression and anxiety compared to those without depression in the physical and psychological domains. The findings of this study highlight the importance of individuals with PD receiving not only physical support but also emotional support. It is important for caregivers and health professionals to be aware of these cooccurring psychological disorders.

The importance of QOL was highlighted in another study "Quality of life in people with Parkinson's disease: the relevance of social relationships and communication" (Takahashi et al., 2016). The WHO defines QOL as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (World Health Organization, 2012). Researchers in Japan administered the Schedule for the Evaluation of Individual Quality of Life-Direct Weighting (SEIQoL-DW), a semi-structured interview tool with a manual to follow that yields a score of 0-100, and the Parkinson's Disease Questionnaire (PDQ-39) to 15 participants. Information was also gathered on disease severity and motor function using the UPDRS Part III and individuals' level of independence with activities of daily living using the Barthel Index. The correlation researchers identified between the PDQ-39 and the SEIQoL-DW index was for "communication" but not on any other dimensions. The PDQ-39 total score was strongly correlated with UPDRS-III (severity of PD) and the Barthel Index (independence). This finding indicates that QOL is directly impacted by severity of symptoms and an individual's independence level. Researchers highlighted the importance of social relationships for

individual's with PD and that a lack thereof may lower overall QOL. As speech and amplitude of movement are motor symptoms that may be present with PD, it was found that individuals in the study identified being "able to communicate" as important to maintaining social relationships with family and friends. Lack of social support has been correlated with higher rates of depression. Researchers highlighted the importance of health professionals providing education on the value of social relationships and communication for individuals with PD (Takahashi et al., 2016).

The role that social support plays for individuals with PD was further explored in another study titled "The role of social support in anxiety and depression among Parkinson's disease patients" (Saeedian et al., 2014). Researchers recruited 124 individuals with PD obtained sociodemographic information and medical history through an initial questionnaire. Participants then met with both a psychologist, to assess for anxiety and depression, and a neurologist who specialized in movement disorders who assessed each participants' severity and confirmed diagnosis using the UPDRS. Cognitive status was also assessed using the Mini Mental State Examination (MMSE) and exclusion criteria was a score <24. Perceived adequacy of social support was measured using the Multidimensional Scale of Perceived Social Support, which provides scores in three sections family, friends, and significant others. Anxiety and depression were measured using the Hospital Anxiety and Depression Scale, which is self-administered. The mean age of participants was 68.1 years old and researchers then identified two subgroups (older and younger) (Saeedian et al., 2014). The older subgroup consisted of individuals who were at least 69 years old and the younger subgroup who were individuals younger than 69 years old.

Results identified differences between the two subgroups and the occurrences of anxiety and depression (younger group: 28% were anxious and 7% were depressed, older group: 20% anxious and 12% were depressed). Researchers found that the "association of social support with anxiety and depression differs between younger and older PD patients" (Saeedian et al., 2014, p. 5). Another key finding from this article is that for the younger group, duration of the disease is a key factor regarding anxiety and for the older group, poor social support from friends specifically is associated with higher rates of depression. The findings of this research reinforces the importance of social support and providing individuals with education on the disease itself to help lower rates of depression and anxiety in individuals with PD.

Community Resources

Awareness of resources available within communities is critical to support individuals with PD and their families and educational programs are critical aspects that promote a strong social support system. In the article titled "Parkinson disease bootcamp: An education program for individuals with Parkinson disease and their families", Parveen (2020) from Oklahoma State University sought out to implement a three-day program for individuals with PD and their families to assess the potential benefits. The program was a multidisciplinary educational program with presentations and activities aimed at increasing knowledge of those with PD and their families and provide available resources within their communities. There were 52 individuals who attended the educational program which included individuals with PD, family members and friends, and health care professionals within the community (Parveen, 2020). The various topics included in the three-day bootcamp were psychological changes associated with PD, benefits of effective communication (speech, voice, and swallowing), role of diet and nutrition in PD, family issues related to PD, role of physical therapy in PD, and information on the Parkinson's Foundation of Oklahoma. Attendees were provided with a survey at the completion of each day to provide written feedback regarding the relevance and impact of the

various presentations. Overall participants provided positive feedback related to all of the offered presentations and the vast majority indicated "strongly agree" or "agree" to statements. Specifically, over 50% of individuals who attended stated "strongly agree" or "agree" to the statements "resources provided at this event are relevant to you" and "you are likely to use these resources in the future" (Parveen, 2020, p. 3). The positive feedback from this three-day event highlight the area of opportunity for other communities to provide this type of education and resources to those with PD, their families, and other healthcare professionals (Parveen, 2020).

Another aspect of community resources that individuals with PD need to be informed of is knowledge of and access to medical care. Pretzer-Aboff and Prettyman (2015) from the University of Delaware sought to determine the impact of implementing a multidisciplinary healthcare model to better serve individuals with PD and their families within the state of Delaware. This research was conducted in 2015 and followed the implementation of a PD clinic that consisted of a movement disorders specialist, psychologists, nurse practitioners, researchers, physical and speech therapists, exercise physiologists, nutritionists, and graduate students. The PD clinic was "based on a collaborative framework that uses synchronous videoconferencing telehealth technology to bring together out-of-state clinicians and scientists with expertise in PD to help deliver specialized care" (Pretzer-Aboff & Prettyman, 2015, p. 146). At the time of the study there was no movement disorder specialist within the Delmarva peninsula (made up of Delaware, eastern Maryland, and part of Virginia). Because of this, researchers utilized telehealth to bring in that specialist as part of their PD clinic. The PD clinic was based on a hybrid model allowing for the multidisciplinary team to see individuals and their families both face-to-face and via telehealth. Initially, each patient in the clinic had a first visit with all members of the team to allow for a comprehensive look at the patient's motor and nonmotor

symptoms. Researchers identified four key benefits of this model for the patients which were access to the movement disorders specialist, accurate diagnosis of PD and appropriate treatment of symptoms, decreased wait time to see the specialist, and providing individuals and their families with local access to a multidisciplinary healthcare team. Specific outcomes were assessed by utilizing various validated tools including the Montreal Cognitive Assessment, the Geriatric Depression Scale, the PDQ, and UPDRS. In the first six months of the clinic opening, 36 individuals with PD were evaluated and were able to receive medical advice such as altering medications, referrals to occupational, speech, or physical therapies, and psychological referrals as needed. Individuals were also provided with various educational resources on medication and exercise. Multiple benefits for individuals with PD and their families were increasing access to this type of care, wait times to be seen were reduced to less than three months and travel time to receive care reduced by as much as 80 miles each way (Pretzer-Aboff, & Prettyman, 2015). Potential benefits of this study highlight the gap in access to healthcare for individuals and how beneficial it is for disease maintenance when patients have access to a multidisciplinary team who can provide them with resources within their communities.

Disease Maintenance & Education

Once diagnosed, individuals and their caregivers need education regarding disease progression and maintenance. Exercise and educational support have been proven to help slow down disease progression and promote maintenance as highlighted in a study conducted by Horne et al. (2019) titled "Functional outcomes of an integrated Parkinson's disease wellbeing program". Researchers sought to determine if a five-week PD specific program would result in sustained physical and psychosocial benefits. There were 135 participants with mild to moderate PD who participated in the program. Gait, mobility, and psychosocial measures were taken at baseline, at 6 weeks post completion of the program, and at 12 months post completion. The program included an exercise program that consisted of 20 minutes of a cardiovascular warm-up, eight exercise stations for five minutes each, and ten minutes of stretching and cool down. Following the exercise portion, patients received education on ten topics including the importance of exercise, motivation and PD, nutrition and medication, communication, speech and swallowing, sleep and fatigue, stress management, falls, and freezing and posture. Researchers found that six weeks post there were both physical and psychosocial improvements. However, at 12 months post only physical measures showed benefits. Patients with more than one fall reduced from 66% to 33%. The findings of this study highlight the importance of providing patient education and the long-term benefits of exercise for individuals with PD. There were no long-term psychosocial benefits which may indicate that attending ongoing support groups and provision of PD specific programming are needed for long term psychological benefits.

Impact of COVID -19

The COVID-19 pandemic has altered the daily routines of most individuals in the world, including those with PD. The pandemic has altered an individual's ability to attend routine medical appointments, to see loved ones, and has introduced new health risks among many other things. A recent study conducted by Feeney et al. (2021), sought to determine the impact of COVID-19 and social distancing on those with PD. Researchers sent out a survey to individuals with PD and their caregivers and they obtained about 1,300 responses. This survey was an anonymous knowledge, attitude, and practice survey that looked at the impact of COVID-19. From this survey, researchers obtained information regarding onset of PD, medications, employment, PD symptoms, socioeconomic status, and age. Results found that nearly half of all

respondents noticed some negative change in their PD symptoms during the pandemic. These negative changes may be attributed to not receiving routine medical care as frequently, specifically rehabilitation therapies. Researchers also identified significant limitations with telehealth services and access to them for underserved populations. At the time of the survey in July 2020, the majority of individuals were only using telehealth for appointments with their primary care physician or neurologists, not therapy. The researchers called for increasing support of telehealth to allow for expansion to physical therapy, OT, speech therapy services, and psychology as well as expanding access to underserved populations (Feeney et al., 2021).

Conclusion

The themes discussed in this literature review highlight the importance of individuals with PD and their caregivers receiving education on critical factors regarding disease progression and maintenance. It is critical for individuals with PD to take an active role in self-management and self-maintenance of the disease to empower both the individual and their care partner (Hellqvist et al., 2020). Self-management of PD includes practice of a regular exercise regimen which has been found to reduce caregiver burden and lead to an overall improvement in QOL (Cholewa et al., 2016). Treatment of the couple with PD as a unit, rather than one healthy and one not, will allow for greater collaboration and opportunities for education for the individual with PD (Lyons et al., 2020). The COVID-19 pandemic has shifted the ways in which everyone is receiving medical care and especially for the individual with PD. It is known that individuals with PD are at a higher risk for developing non-motor symptoms of depression and anxiety and the pandemic has exacerbated these symptoms (Feeney et al., 2021). Promoting knowledge and awareness of non-motor symptoms, integrating the caregiver into receiving education, and

acknowledgment of the impact of the pandemic for individuals with PD will allow for improved quality of life and self-awareness regarding disease progression and maintenance.

Needs Assessment

The purpose of this needs assessment is to identify the gap within the community to highlight the opportunity for a series of educational town halls for both individuals with PD and their caregivers taking place through Christiana Care Health Services as well as compiling a comprehensive resource list for the state of Delaware (See Appendix A). Christiana Care is based in Wilmington, Delaware and is one of the largest health care providers in the mid-Atlantic, providing services to the state of Delaware, and the neighboring states of Pennsylvania, Maryland, and New Jersey. PD is a progressive nervous system disorder that affects an individual's movement. Symptoms of PD are caused by a loss of neurons that produce dopamine, leading to abnormal brain activity. There are both motor and non-motor symptoms associated with PD including tremor, bradykinesia, speech and cognitive changes, impaired posture and balance, and rigid muscles (Elkouzi, 2020). Approximately 60,000 individuals are diagnosed with PD each year in the United States (Marras et al., 2018). The OTD student is working with health professionals at an outpatient rehabilitation site and a neurologist specializing in movement disorders to assist in the development and implementation of town halls and a community resource list (See Appendix A) for individuals with PD and their caregivers.

It is widely recognized that individuals with Parkinson's require appropriate and frequent medical follow-up regarding their diagnosis to monitor symptoms and medication (Hellqvist et al., 2020). However, support in addition to a neurologist and their care team is also a critical aspect to monitoring PD (Pretzer-Aboff, & Prettyman, 2015). Once diagnosed, the lives of both the individual diagnosed and their caregivers will ultimately change. Everyday life may now

consist of monitoring symptoms, medical appointments, and medications on top of other everyday activities. The majority of individuals who are diagnosed and their families may have little to no previous knowledge on PD and enter a new world upon diagnosis. For some, this can be another overwhelming aspect to this disease possibly leading to isolation or other difficulties with mental health (Takahashi et al., 2020).

A review of literature conducted on the topic of supporting the individual with PD identified five topics that were pertinent client and caregiver support, community resources, disease maintenance, psychosocial factors, and the impact of the COVID-19 pandemic. This literature laid out the potential benefit of a virtual educational series for individuals and their caregivers. The importance of daily routine for individuals with PD is widely known and the COVID-19 pandemic has shifted that for so many (Feeney et al., 2021). Regular disease maintenance support that individuals received pre-pandemic may have included physical, occupational, and speech therapy services and receiving such services has been impacted by the pandemic for most individuals (Feeney et al., 2020). This impact on daily routine has affected individuals mental and physical health. Literature identified that when PwPD and their caregivers are supported, QOL for both parties increases (Takahashi et al., 2020).

The factors mentioned above identify the need for a virtual town hall and a comprehensive resource list (See Appendix A) for PwPD and their caregivers. The town halls will give individuals a chance to connect virtually with others in similar situations to their own, growing their network of support. Individuals will have the opportunity to connect with healthcare providers that they may not be in contact with currently due to the pandemic. Individuals will gain information from not only healthcare providers but also from others with PD experience. Participation in the town halls will provide individuals with a sense of

empowerment and coping strategies for not only PD but also navigating PD during the pandemic. Providing individuals with a network of support has been seen to increase QOL. Being heard is an essential component to gaining a network of support, the aim of the town halls is to provide individuals with that support (Takahashi et al., 2020).

Providing PwPD and their caregivers with a comprehensive resource list for the state of Delaware will be beneficial for many of the same reasons previously mentioned for the town halls. This list (See Appendix A) will give the individuals contact information for various resources such as locations for LSVT BIG/LOUD programs, exercise resources, PD specific podcasts, support groups (national and local), books, assistive technology, and senior centers. Providing individuals with local and national resources will allow them to connect with others and provide them with means to seek out any support that is needed for PwPD or their caregivers. The plan for distribution of this list consists of attaching it to monthly newsletters, providing it to healthcare professionals, and mentioning it during local support groups.

Implementation of virtual town halls and the provision of a comprehensive resource list surrounding PD will be beneficial for PwPD, caregivers, and healthcare professionals within the state of Delaware. Town halls will provide individuals with the opportunity to connect with others and grow their network of support, leading to the likelihood of increased QOL. Giving PwPD and their caregivers holistic support will allow both parties to navigate the likely uncharted territory of Parkinson's with a greater understanding of the disease and the support network that is needed for disease maintenance.

Goals & Objectives Achieved during the Capstone Project and Experience Goal 1 Over the 16 week capstone experience, I will further develop my OT clinical practice skills by treating a full caseload of clients in an outpatient neurological setting and obtaining weekly feedback from my mentor regarding my progress towards developing these skills.

Objective 1 Provide OT services to a full caseload of outpatient neurological patient population, including performing evaluations, developing and implementing treatment plans, patient and caregiver education, and discharge planning.

Objective 2 Collaborate with other healthcare professionals regarding the care of clients in this population.

Over the 16 weeks I was able to further develop my clinical practice skills for the specialized practice area of outpatient neurorehabilitation. I improved my clinical reasoning skills and increase my confidence. From about week four on I was able to treat a full caseload on my own. I learned a lot from other professionals at my site which include other OTs, physical therapists, and speech language pathologists. One of the goals I set for myself was to get more experience with initial evaluations. In the clinic, I was been able to complete at least one initial evaluation each week in addition to discharges and progress notes. I also broadened my knowledge of various modalities for treatment including Kinesiotaping, electrical stimulation, and fabrication of orthotics. I implemented evidence-based practice throughout my capstone experience to provide my clients with treatments that were backed by research. For example, one client had a diagnosis of essential tremor and I was able to research various treatment methods to implement during sessions. Another aspect that I gained confidence in is patient and caregiver education. I saw firsthand how critical this is in the outpatient setting for carryover to the client's home.

Goal 2

I will assist in both the treatment and support of individuals with PD by participating in various learning opportunities and creating a cumulative community resource list that will broaden my own knowledge of the disease during my 16 week capstone experience.

Objective 1 Complete various learning opportunities regarding PD including attending educational lectures, observation, and obtaining certification in LSVT BIG treatment

Objective 2 Create a cumulative community resource list (See Appendix A) for individuals with PD and caregivers encompassing the state of Delaware and surrounding areas.

Objective 3 Collaborate with other individuals within the community to broaden the available support for individuals with PD.

Throughout my doctoral capstone experience I was able to collaborate with a neurologist who specializes in movement disorders to advance my knowledge of PD while also contributing to individuals with Parkinson's in the community. Through collaboration with the neurologist and my mentor, I was able to identify the need for a cumulative community resource list. To determine what should be included on the resource list I obtained feedback from my mentor, other health professionals, and individuals with PD at support groups. Getting feedback was helpful to determine what individuals would resources would be beneficial for community members. For example, after speaking at a support group one member asked about obtaining a resource for home modifications and I was able to locate a resource for him and then add it to my list. To learn more about various resources I reached out to support group leaders, researchers, and various fitness instructors. I went through three versions of my list before it was widely distributed. Through completion of a literature review, I was able to support the need for various educational resources for individuals with PD and their caregivers.

Throughout my capstone experience I broadened my knowledge of PD. Shadowing for a day with a neurologist who specializes in movement disorders was a great way to learn about the disease from someone who diagnoses individuals. I sat in on maintenance appointments where medications were reviewed as well as monitoring symptoms, all of which were identified in my literature review as critical steps for individuals with PD to take. I attended the annual Parkinson's Symposium for the healthcare system. At this symposium, the resource list I developed was distributed. Prior to beginning my capstone, I had planned to do more for the Town Halls that the neurologist is in the process of planning but this aspect was more self-directed and I took initiative on developing the resource list. Through the development of this list I received input from individuals with PD themselves and other healthcare professionals. I was attended various support groups for PD within the area and communicated with group leaders to market my list and provide information on my capstone. I also had the opportunity to become certified in LSVT BIG and implement this treatment with clients in the clinic. I saw firsthand how beneficial these amplitude-based exercises were for clients with PD.

Goal 3

I will complete various learning opportunities such as observations within the health system and participating in continuing education courses to broaden my knowledge within the scope of OT practice over 16 weeks of my capstone experience.

Objective 1 Complete observations within the inpatient and acute care settings to expand my knowledge

Objective 2 Participate in learning opportunities including attending lectures on various topics, educational courses, and attending support groups.

Participating in other learning opportunities throughout my capstone experience allowed me to further advance my knowledge in areas including OT management of concussions, obtaining my LSVT BIG certification, attending stroke support groups, and observing other professions. I spent two days observing in both inpatient rehabilitation and acute care. Both days were great learning opportunities as I haven't had any prior experience in those settings of OT. Through observation of OT in these settings, I found a new interest in them which will be beneficial in my future career.

Summary

Being able to treat individuals with PD while also completing research on the diagnosis and collaborating with the neurologist regarding development of my project was a great way to broaden my knowledge of the disease in multiple facets. I was able to treat clients with PD while simultaneously developing the resource list (See Appendix A) to better serve individuals within the community. The findings of the literature review supported the need for this list and it will fill a need for individuals within the community. One of the most challenging things throughout my capstone experience was to balance the project development portion of my capstone in addition to clinical practice. In the beginning I found that I was struggling to balance being in the clinic treating clients all day and completing documentation with the project development aspect of my capstone. As the weeks progressed I became more efficient with my point of service documentation which allowed me to utilize open times throughout the day to complete other aspects of my project.

The community resource list I created was distributed to other healthcare professionals within the community and I integrated their feedback. It has now been distributed to attendees from the Parkinson's Symposium from within the community and I am hopeful that it will be a helpful tool for individuals with PD and caregivers. The list will continue to be edited and redistributed as needed by my mentor. In terms of the Town Halls, the hope is that they will come to fruition in the coming months with justification coming from the results of my literature review.

Through the completion of my doctoral capstone experience I have been able to further prepare myself for my career as an occupational therapist. Completing this 16 week experience in a specialized area of clinical practice has allowed me to improve upon not only my clinical skills but also my own confidence. I have completed various learning opportunities that helped me to go out of my comfort zone. In addition to the clinical portion of my capstone, completing research and collaborating with other health professionals regarding treatment of a specific diagnosis has been a great learning experience.

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Appendix A Community Resource List

Resources for Parkinson's Disease

Including Delaware, Southern New Jersey, Southeast Pennsylvania, Eastern Maryland, and National Resources

LSVT BIG/LOUD Locations (Lee Silverman Voice Therapy) LSVT BIG/LOUD Locations-Outpatient

Christiana Care Rehab Services

https://christianacare.org/services/rehabilitation/physicaltherapy/lsvtbig/

- Chadds Ford (PA): (855)-250-9594
- Wilmington: (302)-320-6600
- Newark: (302)-838-4700
- Middletown: (302)-449-3050
- Smyrna: (302)-659-4500

University of Delaware PD Clinic

• (302)-831-3195 https://sites.udel.edu/nmhc/our-services/the-parkinsons-clinic/

Neuro Fitness Therapy- Wilmington

- (302)-753-2700
- <u>http://neurofitnesstherapy.com</u>

Dynamic Physical Therapy

- Newark (302)-691-5603
- Fenwick: (302)-424-1810

Novacare

- Smyrna: (302)-653-8389 <u>https://www.novacare.com/contact/find-a-location/de/smyrna/smyrna-matrix/</u>
- Millsboro: (302)-947-0781 <u>https://www.novacare.com/contact/find-a-location/de/millsboro/millsborolong-neck/</u>

Aquacare PT

- Millsboro: (302)-945-4250 https://aquacarephysicaltherapy.com/location/millsboro-de/
- Milford: (302)-491-4196 https://aquacarephysicaltherapy.com/location/milford-de/

Excellens Physical Therapy

Lewes: (302)-200-9920 <u>https://aquacarephysicaltherapy.com/location/lewes-de-excellens/</u>

Beebe

• Lewes (LOUD only): (302)-645-3278

- Millsboro: (302)-260-7346
- Millville: (302)-539-6404
- Georgetown: (302)-217-3000/ (302)-856-9729

Tidewater PT and Rehab Associates

- Ocean View: (302)-537-7260
- Harrington: (302)-398-7982

PT Works DE

• Milford: (410)-446-2589

Lakeside PT

- Lakeside PT Milford: (302)-422-2518
- Astra Care Physical Therapy Georgetown: (302)-253-8698
- Lakeside Physical Therapy Laurel: (302)-280-6920

Coastal Care PT

• Selbyville : (302)-524-8333 <u>http://coastalcarept.com</u>

Nanticoke Rehab Services

• Seaford: (302)-990-3300

Poynton Marsh Speech Services (LOUD)

• Lewes: (302)-644-1220

LSVT Home Health

Fox Rehab (877) 407-3422 Offers PT, OT, Speech https://www.foxrehab.org

Christiana Care Visiting Nurse Association

-2116 S Dupont Hwy Ste 2 Camden, DE 19934 (302) 698-4300 (302) 855-9700

-1 Reads Way Ste 100 New Castle, DE 19720 (302) 327-5200

Bayada: Wilmington (302)-351-1244

First State Rehab at Home: Wilmington (302)-304-9729 https://firststaterehabathome.com/physical-therapy-treatments/lsvt-big

LSVT Inpatient

Christiana Rehabilitation at Wilmington Hospital (302)-320-6920

Encompass Rehabilitation- Middletown (302)-464-3400

Cadia Healthcare https://www.cadiahealthcare.com/service-category/rehabilitation/

- Pike Creek: (302)-455-0808
- Silverside Road: (302)-478-8889

PAM Rehabilitation Hospital of Dover

• (302)-672-5800

https://postacutemedical.com/facilities/find-facility/rehabilitation-hospitals/pam-rehabilitation-hospital-dover

LSVT Residential

Cokesbury Village: (302)-509-2029

https://www.actsretirement.org/communities/delaware/cokesbury-village-hockessin/health-services/

ACTS Country House Retirement Community: (302)-501-7109

https://www.actsretirement.org/communities/delaware/country-house-wilmington/

PD Specific Exercise Resources

Rock Steady Boxing-

Neuro Fitness (Wilmington): (302)-753-2700 <u>http://neurofitnesstherapy.com</u> Forever Fit (Dover): (302)-698-5201 http://www.foreverfitfoundation.com/services/Rock-Steady-Boxing-of-Delmarva---Parkinsons-Disease-Symptoms-Relief.htm Cornerstone Martial Arts (Hockessin): (302)-228-2215 https://cornerstonehockessin.com/classes/Boxing

Speed Geezers at University of Delaware

-"Offer classes on MWF or Tuesday/Thursday which consist of HIIT training on either recumbent or upright cycles for 30 minutes (5 min warm up and 5 min cool down). During these intervals, the clinical exercise physiology masters students are monitoring RPE, HR and BP. After we have completed the intervals, we then move on to group resistance training using machines, dumbbells, TRX, kettlebells, medicine balls, etc. Currently, we have availability in our Tuesday/ Thursday classes at 10am and 11:30am" -as of 3/15/21 <u>Contact Information:</u> Dr. Brittany Overstreet bover@udel@edu or Brittany Glazar bglazar@udel.edu

Parkinson's Wellness Recovery (PWR!) Virtual Classes

https://exerciseforbrainchange.org

-Offer virtual exercise classes at different levels of intensity with membership options -Offers a free trial class

-Classes on demand and live!

PWR! Moves-Forever Fit (Dover): (302)-698-5201

http://www.foreverfitfoundation.com/services/PWRMoves---Parkinsons-Disease-Symptoms-Relief.htm

-Parkinson's Wellness Recovery (PWR). The only location in Delaware. "Designed to help people with PD get better and stay better with exercises designed specifically for their individual needs"

Dance 4 PD: Contact Marion Hamermesh or Judith Sachs at <u>DEdance4PD@gmail.com</u> -Host virtual dance classes for individuals with PD every Tuesday at 2pm free of charge. Email to be added to the list to receive the Zoom link!

Knockout Boxing & Fitness-Ability Boxing, classes offered 3 times a week at both locations <u>https://knockoutboxingde.com/25895-2/</u>

- Newark (302)-737-3708
- Middletown: (302)-828-0028

Speak Out

Christiana Care SLP Department: (302)-320-6732

University of Delaware: (302)-831-3195 (Includes "Loud Crowd" for carryover of skills)

Poynton-Marsh Speech Services, LLC

(302)-644-1220 https://www.mpmspeech.com 1632 Savannah Road, Suite 5 Lewes, DE 19958

General Exercise Resources

Y for All Program ymcade.org -Offer adaptive workouts with trainers

Newark Parks and Recreation Exercise Classes

-Yoga (virtual and in person), Low impact exercise, Aquafitness (302)-366-7000 <u>https://secure.rec1.com/DE/newark-</u> <u>de/catalog/index/1d53ca2a415b27b1030e97ab6ffc4af3?filter=c2VhcmNoPSZhZ2VHcm91cCU1</u> <u>QjE1JTVEPTE=</u>

Yes U Can https://yesucanusa.org -Pool program -1:1 exercise programs -Adaptive sports/outings -Respite care

Free Tai Chi Series on Youtube by Dr. Paul Lam

Includes various lessons designed to gently work the entire body! Includes videos to complete seated as well- <u>https://www.youtube.com/watch?v=xOj_KMpBlik</u>

Adaptive Equipment

Below are just a few of the resources for adaptive equipment available and there are plenty more! **Performance Health** <u>https://www.performancehealth.com</u>

Delaware Assistive Technology Initiative (DATI)

1600 Rockland Rd Wilmington, DE 19899 (800) 870-DATI www.cds.udel.edu/at/dati

Amazon https://www.amazon.com

Article from Parkinson's Foundation outlining various daily tasks

https://www.parkinson.org/sites/default/files/Assistive%20Devices.pdf

Northcoast Medical https://www.ncmedical.com

General Delaware Senior Resources

Services for Aging and Adults with Physical Disabilities

- Offer a broad range of services to support seniors, individuals with disabilities, and their caregivers
- See Guide to Services for Older Delawareans and Persons with Disabilities
- https://dhss.delaware.gov/dhss/dsaapd/services.html

Aging in Place Specialists LLC

(302)-444-8318 Serving southern Delaware, Offers in home physical therapy and wellness programs <u>https://aginginplacede.com</u>

City of Wilmington Seniors Programs

(302)-576-2489 www.wilmingtonde.gov

Delaware Division of Prevention and Behavioral Health Services (302) 633 2600

(302) 033 2000

The Parkinson's Clinic at University of Delaware

-Nurse Managed Primary Care Center (302) 831-3195

DART First State

Paratransit Service-Senior Citizen Affordable Taxi (SCAT) (800) 652-DART, Option 2 https://dartfirststate.com/information/paratransit/pdf/ADAForm.pdf

Support Groups

Parkinson Disease Education & Caregiver's Discussions

-Group meets on fourth Tuesday of each month from 10-11am at Harbour Lights (Lewes) Cheer Center, 34211 Woods Edge Drive / Virtual support is also available via Zoom-Contact Marge Fleming Smith to obtain link: <u>mflemingsmith@yahoo.com</u>

Parkinson's Education and Support of Sussex County

https://www.facebook.com/Parkinsons-Sussex-County-DE-Support-Group-484403591626407/ -Meets first Monday of each month with an exercise class at 1pm and formal meeting at 2pm -Currently meeting over Zoom

-Email to be added to their contact list to receive weekly newsletter!

Contact: Patricia Slygh (410)-322-3000 / <u>pcslygh@comcast.net</u> or Glen Henderson (301)-704-0466 / <u>hensol@verizon.net</u>

Virtual PD Support Education Group

Through Christiana Care Rehab at Smyrna, Meets once a month on Wednesdays 11am-11:45am <u>Contact:</u> Cynthia Huffine <u>CHuffine@ChristianaCare.org</u>

Virtual PD Support & Education Group

Through Christiana Care at Wilmington Hospital Meets on the first Wednesday of each month 3-4pm (302)-320-6920

Support Group for Newly Diagnosed Individuals

At Christiana Hospital Meets on the third Thursday of each month at 5:30 pm (302)-623-4050

Virtual PD Support & Educational Group

Through Christiana Care Rehab at Springside Meets on the fourth Friday of each month 12-1pm **Contact:** Stacy Gandia (PT) sgandia@christianacare.org

Research Opportunities

AbbVie M15-736

"A study testing a formulation of carbidopa-levodopa given subcutaneously through a cannula for 24 hours a day, through an infusion system that uses a pump.

You may be eligible if:

- You are age 30 or older.
- Taking oral medications containing levodopa (total daily dose of LD equivalents from LD-containing medication and COMT inhibitors must be ≥ 400 mg).
- Experiencing motor fluctuations and have more than 2.5 hours of OFF time/day.
- Must be able to demonstrate the understanding and correct use of the delivery system.

You can call/portal message Dr. Martello, or study coordinator Jennifer Knox at (302)-623-3834 for more information." -Current as of 3/29/21

Parkinson's Disease-Brain Imaging Study

- "The Motor Neuroscience and Neuroimaging Laboratory at University of Delaware is seeking participants for a research study that investigates how the brain and behavior change in Parkinson's Disease"
- "Your participation would require one visit (~4-4.5 hours) to the University of Delaware and include:
 - MRI of the brain
 - Motor and cognitive testing, questionnaires
- \$100 Compensation is provided
- You may be eligible if :
 - You have been diagnosed with Parkinson's Disease OR
 - You are a healthy adult who could act as a control participant
 - Ages: 45-85
 - Male or female
- "For more information, email or call us. Please provide your name, phone number, and the best time for us to reach you. "
 - Roxana G. Burciu, Ph.D. Email: <u>rgburciu@udel.edu</u> / Phone: (302)-831-3066

Maryland Resources

Maryland Association for Parkinson Support Inc.

https://www.marylandparkinsonsupport.org/programs -Hosting virtual support and exercise groups

New Jersey Resources

APDA (American Parkinson Disease Association) New Jersey Chapter

https://www.apdaparkinson.org/community/new-jersey/ (732)-846-0131

Offer various online resources and support/exercise groups that are meeting virtually

Pennsylvania Resources (Delaware County)

Right at Home: In home Care & Assistance

https://www.rightathome.net/delaware-pennsylvania/special-care-situations/parkinsons-disease (610)-566-6650

-Offers caregiving services including: nutrition and meal planning, personal supervision and home safety, daily mobility, exercise, transportation, and family caregiver relief

The Parkinson Council -Philadelphia group at Penn funding research, education, and programs surrounding PD (610)-668-4292 <u>https://theparkinsoncouncil.org</u> -Resources for COVID-19: <u>https://theparkinsoncouncil.org/covid-19-resources/</u>

National Resources

National Parkinson Foundation (NPF)
1-800-473-4636
Mid-Atlantic Chapter <u>https://www.parkinson.org/MidAtlantic</u>
-Services District of Columbia, Maryland, Virginia, West Virginia, Delaware, and Eastern Pennsylvania
-Host various events throughout each month! Check website for latest offerings

Michael J. Fox Foundation (MJFF)

https://www.michaeljfox.org/our-promise 800-708-7644

American Parkinson Disease Association 800-223-2732 https://www.apdaparkinson.org

National Institute Of Neurological Diseases and Stroke

https://www.ninds.nih.gov/Disorders/All-Disorders/Parkinsons-Disease-Information-Page 1-800-4PD-INFO (473-4636)

The Parkinson Alliance

800-579-8440

Podcasts, Books, and TV

Substantial Matters: Life and Science of Parkinson's

The Parkinson's Podcast

When Life Gives you Parkinson's <u>https://podcasts.apple.com/us/podcast/when-life-gives-you-parkinsons/id1404983468</u>

Parkinson's Life Podcast https://parkinsonslife.eu/category/podcasts/

Michael J. Fox Foundation Parkinson's Podcast https://www.michaeljfox.org/podcasts

Michael J. Fox Foundation Educational Webinars

https://www.michaeljfox.org/webinars

-Hosted live on the third Thursday of every month at 12pm. Register at the link above

ParkinsonTV: https://parkinsontv.org

-Offers two seasons online covering various topics with PD

Entertainment/Helpful Resources

Ordering and Delivery of Groceries www.instacart.com

Medication Delivery

Check with your insurance to inquire about medication delivery if available to you! There are also adaptive pill bottles that allow for easier opening!

Virtual Tours of Museums

-Louvre https://www.louvre.fr/en/visites-en-ligne

-Smithsonian https://naturalhistory.si.edu

-Van Gogh Museum http://www.360stories.com/ and http://www.insider.com/

-Opera https://operavision.eu/en/library/operas