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Parkinson's Disease: Gaining Hope and Help

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Parkinson's Disease: Gaining Hope and Help

By


Chloe Lantz

This thesis is submitted in partial fulfillment of the requirements for Honors in the Discipline in
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Thesis Advisor (signature required) 

Second Reader Conrad Lee Kanagy

Third Reader (if applicable) 

[only if applicable such as with interdisciplinary theses]

Parkinson's Disease: Gaining Hope and Help

Parkinson's disease (PD) is currently affecting roughly one million individuals in the United States alone, with about 60,000 more being diagnosed with the disease every year (Parkinson's Foundation, n.d.). Alarming statistics, as well as a personal connection and interest, led to the development of this project. A couple who I respect greatly is currently living with the husband's diagnosis of PD. The way that Parkinson's has quickly deteriorated his body has not visibly stopped the love and support they have for one another. They fight every day against a disease and the functional decline that accompanies it, but report being steadfast in their relationship with each other. Additionally, before the COVID-19 pandemic, I had the opportunity to volunteer at Rock Steady Boxing Lancaster, where Sue Ludwig, a certified personal trainer, uses boxing techniques to support those with Parkinson's. I have met many people through this experience who continue to inspire this project. I have continued my work at their new space, Crush PD, as a volunteer, participant, and eager learner.

Aside from my personal connection to Parkinson's disease, this project was informed through the lens of occupational therapy (OT), as I am a current fourth-year OT student at Elizabethtown College. In academia, we learn about the value of occupations, independence, and therapy interventions to increase the overall occupational health and wellbeing of those we serve. In the development of this project, I saw an innovation in the treatment of Parkinson's disease. Working side-by-side with Crush PD fitness, my OT perspective values the functional aspect of every movement. The specific exercises they do lead to increased independence specific for individuals with a PD diagnosis (Sangarapillai, 2021). I personally see occupational therapy as a field of constant innovation, and in this project, I was searching for and learning about ways to be innovative in education and neurological treatment for those with Parkinson's. My project

began with a thoughtful and comprehensive review of the literature to ground my topic and to frame my approach. Additionally, the purpose of the literature review was to assess valuable aspects of Parkinson's disease education and community programs as therapeutic sources for clients and professionals that work with this population. After the review of available conceptual and empirical work on the topic of Parkinson's Disease, I developed a blog and podcast to share information with the consuming public, both professional and lay individuals, about topics, resources and ideas related to PD. My project also endeavored to immerse myself in learning, experiences and interactions relative to the topic. I continued my work at Crush PD Fitness and also received certification in LSVT Big. This manuscript highlights my journey through this scholarly project.

Literature Review

This literature review was done to comprehensively frame my project, entitled Parkinson's Disease: Gaining Hope and Help. I began by discussing the occupational therapy (OT) lens which guided this endeavor. Next, the disease process and symptoms of PD were detailed for a thorough understanding of this neurodegenerative illness. Then various interventions and treatment strategies known to this population was investigated. Finally, I articulated nuances of this project, such as volunteerism and social media outreach.

Occupational Therapy: Project Lens

Occupational therapy "is defined as the therapeutic use of everyday life occupations with persons, groups, or populations (i.e., the client) for the purpose of enhancing or enabling participation" (American Occupational Therapy Association [AOTA], 2020, p.1). A trained occupational therapy practitioner (OTP) has a distinctive way of seeing the world. People, populations, and groups are viewed as occupational beings. Every behavior has a function. Tasks

or exercises that seem basic can prove to be very functional, such as a squat in preparing someone to get in and out of a chair for example. As occupational therapists, we work to gain insight into a whole person and be client-centered (AOTA, 2020). With that, each practitioner (OTP), both therapists and therapy assistants, craft a personalized plan for each client, using meaningful activities as treatment strategies. As a helping profession, we are in the business of doing what we can for others; if an activity is meaningful, the treatment will be better accepted for its relevance to the client and more successful for their functional outcomes (AOTA, 2020). Particularly in the realm of Parkinson's every person presents with different symptoms at varying times. The variability of symptoms and resultant functional problems demonstrates how and why an individualistic intervention plan is so important. An OTP's lens develops through coursework and continues through practice. Using occupations (or meaningful activities) and working toward optimum functional life, occupational therapy affords services that positively impact health and well-being (AOTA, 2020)

Domain of Practice

According to the *Occupational Therapy Practice Framework* (AOTA, 2020) the domain of practice for occupational therapy involves "...occupations, contexts, performance patterns, performance skills, and client factors" (pg. 6). Each area of the domain of practice is interconnected and dynamically related (AOTA, 2020). Occupational therapy involves all aforementioned aspects of life and work that make up and contribute to daily functioning. The domain of practice specific to this work involves occupations, contexts, and client factors. Maintaining independence in life, although subjective, relates to focusing on completing the nine occupational categories that are highlighted within the field. Contexts are also a vital part of the holistic view of a person with PD. Additionally, gaining an understanding of client factors that

influence participation in treatment strategies and how they influence outcomes is necessary to be understood. With that being said, occupations should first be defined and highlighted to provide context for this work.

Occupations

Occupation outside the world of occupational therapy is seemingly most commonly associated with jobs or work life by the general public. In the realm of occupational therapy, occupations are those which are meaningful to someone (AOTA, 2020). An occupation can range from brushing your teeth to sleeping, to playing soccer; it all just depends on what someone needs or wants to do that gives their life meaning. Occupations through the professional lens are divided into nine categories: (1) activities of daily living (ADLs), (2) instrumental activities of daily living (IADLs), (3) leisure, (4) health management, (5) rest and sleep, (6) education, (7) work, (8) play, and (9) social participation (Table 1; AOTA, 2020). In connection with my project and community programs for Parkinson’s therapy, ADLs, IADLs, leisure, health management, and social participation are the domains of occupation that are commonly addressed.

Table 1

Domains of Occupation as Defined in OTPF 4th ed.

Activities of Daily Living (ADLs)	Self-care tasks
Instrumental Activities of Daily Living (IADLs)	Daily tasks for home and community management
Leisure	Non-obligatory tasks done for enjoyment
Social Participation	Interacting with others
Health Management	Activities to take care of personal health (physical and mental)

Note. Adapted from (AOTA, 2020).

Activities of daily living (ADLs) and instrumental activities of daily living are both parts of everyone's day-to-day life that are often routine. ADL tasks involve self-care tasks like toileting and grooming. IADLs are activities that are necessary for life but are often focused on home management, financial responsibilities, and other areas like taking care of a pet. Leisure is another area that is necessary to maintaining a healthy life and could be gardening or reading a book; everything is person-dependent and individualized based upon values and interests. Health management is taking the initiative to manage one's health such as going to doctor's appointments or exercising. Health management is particularly important due to an emphasis on mobility and safety (AOTA, 2020). Health has been defined by the World Health Organization (WHO) as "a state of complete physical, mental, and sound well-being and not merely the absence of disease or infirmity" (WHO, 2006, p. 1). In terms of how to promote health management, one must work to take proper medications at the right time, eat a healthy diet, and maintain physical and emotional health by exercising and interacting with others (AOTA, 2020). A way to do that is by utilizing social and community support groups that allow for engagement with others; while, in terms of Parkinson's disease, exercising is important as well. The social nature of community programs not only fulfills other occupational categories, but it incorporates social interaction in the community, with family, with peers, and creates friendships to lean on. The social support that is given throughout community resources is a vital aspect of care and quality of life.

Functional mobility is the ability to move in ways that allow someone to move from one place to another or transfer from one object to another (AOTA, 2020). Functional mobility is something that tends to decline with age as muscles begin to weaken and joints lose stability (Grimmer et al., 2019). The dopamine deficiency that Parkinson's disease causes exacerbated

functional mobility problems due to loss of core stability, leading to balance issues (Lang & Espay, 2017). The loss of mobility creates safety concerns and frequently loss of independence. Occupations are imperative to independence (AOTA, 2020). Therefore, occupational therapy focuses on meaningful and necessary occupations to mobilize someone to be their best self, achieving a sense of overall well-being. As Parkinson's is a degenerative disease process, defining the symptoms and changing traits of the disease are warranted at this juncture.

Parkinson's Disease

Parkinson's disease impacts greater than 10 million people in the entire world currently (Parkinson's Foundation, n.d.). Parkinson's disease is a neurodegenerative illness impacting the central and peripheral nervous systems. PD involves the loss of dopamine neurons in the brain's substantia nigra that impacts the initiation of movement (Tysnes & Storstein, 2017). In addition to the loss of dopamine, Parkinson's disease also involves the development of Lewy bodies that contain α -synuclein (Recasens et al., 2013). The connection between Lewy bodies and PD is ongoing and something that many researchers do not fully understand. The level of understanding currently surrounds the idea that the accumulation of α -synuclein Lewy bodies surrounds striatal dopaminergic neurons at their presynaptic terminals (Recasens et al., 2013). The aggregation of α -synuclein in Parkinson's disease is similar to that of dementia, in terms of Lewy bodies, but the difference is that the aggregation is in different parts and is detrimental to the dopaminergic neurons (Jankovic & Tan, 2020). Parkinson's disease mainly involves the substantia nigra's dopaminergic neurons which do not lead to cognitive impairments, but rather neuron communication issues. The lack of dopamine release contributes to the many motor-related problems that individuals face with Parkinson's disease, such as bradykinesia, a resting tremor, and a masked face (Recasens et al., 2013).

Symptoms that Impact Function

The lack of dopamine that is a result of dwindling neuropathways leads to a host of symptoms in individuals with Parkinson's disease many of which impact occupational functioning. Motor and nonmotor symptoms are both found in this progressively debilitating disease. One of the main motor symptoms that is associated with Parkinson's disease is a resting tremor. It was by way of the resting tremor that Parkinson's was originally discovered and named the "shaking palsy" (Hayes, 2019). The tremor is typically presented on one side of the body, usually only in one upper extremity (Dirkx & Bologna, 2022). The tremor is seen whenever someone has their hand in a certain position at rest, is often referred to as pill rolling tremor, and is typically worse under stress (Dirkx & Bologna, 2022). If the hand is moving, the tremor is not normally evident (Hayes, 2019).

Bradykinesia or the slowing of movement simplifies a motor task and is a characteristic of Parkinson's disease (Tolosa et al., 2021). The slowness of movement is a classic symptom of PD and is seen in many different areas of function. It also limits an individual's ability to produce voluntary movements (Tolosa et al., 2021). Bradykinesia is highly evident in the masked face that is presented in many individuals with PD, which is called hypomimia. The appearance of a masked face is a direct result of slow-moving face structures as a result of bradykinesia. The eyes appear to be staring as the blink-rate slows and the face muscles stay more still leading to less emotional expression (Hayes, 2019). The speech begins to get "smaller," or quieter, and with less expression. Again, a result of bradykinesia is the slowing of movement leading to hypophonia (Tolosa et al., 2019). The lack of facial movement also impacts feeding, due to increased difficulty swallowing. Additionally, as the disease progresses the mouth will start to droop and stay open (Hayes, 2019). The muscles involved in moving the jaw and contracting to

swallow are also impacted, leading to sialorrhea, also known as drooling. The individual cannot voluntarily swallow easily, leading to the saliva running out of their mouth because it is not properly dealt with (Hayes, 2019).

Gross motor movements are also impacted by bradykinesia. Sitting and rising from a chair becomes difficult in coordinating all of the muscles involved in the task (Hayes, 2019). An individual's gait pattern becomes abnormal in regard to stride length and arm swing. Individuals with PD, tend to have a diminished stride length that begins to look like a shuffle. The arms do not swing rhythmically and eventually, the arms do not swing while walking (di Biase et al., 2020). In addition, when the steps begin to get smaller, the individual's trunk can sometimes keep moving, without their feet. When this happens, multiple quick steps that look like a running shuffle, called festination are used to catch up to the body movements (Tolosa et al., 2019). On top of that, the freezing of movement is also a likely occurrence for most people with PD. In that case, the motor function will just stop altogether and a person "freezes," essentially (Tolosa et al., 2019). Individuals with Parkinson's disease also commonly complain about experiencing dizziness. Park and Kang (2021) highlight dizziness as another chief complaint from individuals with PD. Dizziness can stem from orthostatic hypertension in most cases or could relate to PD in a non-specific manner (Park & Kang, 2021). All of these motor symptoms pose a safety risk and can ultimately lead to the individual falling, especially as a result of postural instability (Hrytsuliak et al., 2022).

In addition to motor symptoms, Parkinson's disease also has associated non-motor symptoms. One of the most common is anosmia, or the loss of smell (Hayes, 2019). Dysautonomia, a problem involving a flawed autonomic nervous system is also common with Parkinson's disease, which brings about problems in the regulation of heart rate. Dysautonomia

is often the cause of orthostatic hypertension as mentioned earlier, which causes dizziness, (Hayes, 2019; Park & Kang, 2021) and can impact safety with functional mobility. Hayes (2019) also calls attention to the gastrointestinal and urinary issues involved in Parkinson's disease, including increased feelings of bloating and the need to urinate. Many individuals with Parkinson's disease also suffer a mental battle with anxiety and depression as a direct result of the disease (Jankovic & Tan, 2020). Fatigue is another non-motor symptom that many individuals with Parkinson's disease present with as well (Hill et al., 2020).

Quality of Life

Through an occupational lens, the number of symptoms equated with Parkinson's disease only questions how they impact quality of life (QOL)? As many researchers have shown, PD impacts many aspects of functional mobility as highlighted above. A popular quote from the Michael J. Fox Foundation states: "when you've met one person with Parkinson's, you've met one person with Parkinson's" (Magna, 2019). This quote exemplifies that although there is a multitude of common symptoms, each individual is different, and their quality of life is impacted differently. Independence is subjective as is quality of life, but due to the nature of the symptoms of PD, it can be inferred that the more advanced the symptoms, the greater impact they have on QOL. Therefore, this leads to the need for treatments to quell the symptoms and provide social support.

Treatment Strategies

One of the major challenges to the diagnosis and life with Parkinson's is that there is no cure. Even when it comes to treatment, researchers have yet to find a way to stop dopamine neuron depletion and halt the disease (Lang & Espay, 2017). With that being said, many treatment strategies involve neuroprotective measures to slow the disease process, while others

treat the symptoms that arise from the disease. One of the most effective symptom-related treatments involves the medication, Levodopa (Lang & Espay, 2017). This pharmacological treatment targets the remaining dopamine neurons and facilitates dopamine production (Hayes, 2019). The existence of more dopamine in the brain allows for the symptoms of PD to be quelled for a period of time, dependent on the dosing schedule. Levodopa is also typically used with carbidopa to increase the bioavailability of Levodopa. This drug is prescribed to prevent instant metabolism of levodopa allowing the full dosage to be utilized in the body (Jankovic & Tan, 2020).

Treatments that involve neuroprotective measures typically are rooted in exercise. In a pretest-posttest study with 9 participants that examined functional mobility after LSVT BIG treatment, findings showed that exercise measures are ways to supplement the pharmacological means of therapy (Millage et al., 2017). After a review of the literature surrounding disease modification, it has been claimed that exercise can be neuroprotective, thus making it a beneficial treatment for neurodegenerative diseases (Lang & Espay, 2017). The neuroprotective factors of exercise include helping frontal lobe executive function, increased dopamine binding at D2 receptors, gray matter volume maintenance, and other small findings show that exercise should be beneficial to anyone with a neurodegenerative disease (Cruise et al., 2011; Lang & Espay, 2017). Additionally, research studies using animals have found that exercise can reduce neurotoxin release in the brain, leading to less dopamine neuron depletion, and slowing the progression of Parkinson's disease (Millage et al., 2017). Exercise has also always been something that has been recommended across the ages, especially in older adults. Similarly, a study with 28 participants with PD, completed an exercise program and findings showed that exercise can help to maintain muscle strength and cardiovascular health, as well as minimize

depressive symptoms (Cruise et al., 2011). Several programs have been developed to incorporate exercise for improved functioning, the Lee Silverman Voice Therapy being one of them.

LSVT Big/Loud

Lee Silverman Voice Therapy (LSVT BIG), designed by Silverman, is an exercise-based model that must be used by a certified LSVT BIG therapist, trained in the big movements of the trunk and extremities (Dashtipour et al., 2015). This treatment was created in an effort to combat the “amplitude deficits” seen in Parkinson’s disease. The exercises provided in these therapy sessions relate back to the core of occupational therapy as they all serve a functional process (Millage et al., 2017). Since Parkinson’s disease has many problems related to the amplitude of movements, specifically getting smaller, LSVT BIG looks at maintaining and promoting larger movements. The use of this training involves repetitive movement patterns that are intensive to get the heart rate up while developing foundational range of motion necessary for functional independence with such things as walking, transfers, and dressing into use in everyday life. It typically involves a series of 16 one-hour sessions for 4 weeks to get the full training (Janssens et al., 2014). The skilled treatment with certified OTs or physical therapists (PTs) is augmented with home exercises and programs to build skills.

LSVT BIG can be incorporated in formal therapy sessions or in community classes as seen in the study by Millage et al. (2017) which employed both formal one-on-one LSVT BIG therapy as well as community-based group LSVT BIG training. This study looked at the outcomes of this training using four performance-based outcome measures: “Gait Speed, Berge Balance Assessment, Functional Gait Assessment, and Unified Parkinson’s Disease Rating Scale Motor Section”. The findings exemplify the benefits of LSVT BIG training as each participant improved on one or more outcome measures. Additionally, three months after the training period

most of the participants had not lost any performance skills. Similarly, a case series of 3 participants completing LSVT BIG training using similar outcome measures, found that just after 4-weeks of training there were improvements in functional mobility (Janssens et al., 2014). It was found that the community based LSVT BIG training was also very helpful in motivating individuals to incorporate the exercises into their routine and perform at their highest level. Furthermore, it provided a comforting social place that fostered a group that held each other accountable in their fight against the disease (Millage et al., 2017).

The LSVT BIG program is something that could be used as soon as Parkinson's disease is diagnosed, as researchers explain that often these therapy referrals do not come until there are mobility concerns (Millage et al., 2017). Many findings are that individuals in the earliest stage of Parkinson's experience the greatest improvements from the LSVT BIG training, which would explain the need for earlier referral (Millage et al., 2017). Additionally, a study completed with 12 participants with PD, which looked at outcomes of motor function post-LSVT BIG, found that there were significant improvements in gait measurements and that in the future using body sensors would be a viable option to gain more performance-oriented information (Flood et al., 2020).

There is also Lee Silverman Voice Therapy which was originally developed to help individuals with their voice. This part of the Lee Silverman Voice Therapy is called LSVT LOUD (McDonnell et al., 2018). The training provided here is again provided by a certified therapist. The training is to help to improve an individual with PD's voice quality so that it is louder. Most of the time, individuals with PD think that they are speaking normally, but in reality, their voice is quiet. The target of LSVT LOUD is to train the sensorimotor pathways in the brain to perceive the amplitude of the voice again and work to make it audible and clear

(Mcdonnell et al., 2018). So, what are other activities with individuals who have PD that can help to increase overall health?

Activities To Promote Health

Health promotion is vital to quality of life and occupational satisfaction. Health management is one of nine occupations outlined in the *Occupational Therapy Practice Framework: Domain and Process (OTPF; AOTA, 2020)* and exemplifies the need to remain healthy (2020). By participating in health management occupations such as utilizing community support, taking proper medication, and participating in exercise, a person is able to maintain or improve their ability to participate in meaningful occupation (AOTA, 2020). For individuals with Parkinson's disease, there are a host of community and exercise-based opportunities to assist in keeping symptoms at bay.

Yoga

Yoga has been found to be beneficial for individuals with Parkinson's disease. Specifically, Power Vinyasa yoga involves moving from one pose to the next quickly (Ni et al., 2016). This type of yoga is low impact, but high speed which helps to attack the bradykinesia which slows and impairs function for those with PD. In a randomized control trial with 41 participants comparing power training and fast yoga programs, findings have shown that Power Vinyasa yoga improved the balance of individuals with PD, which decreased their risk of falling and improved their mobility overall (Ni et al., 2016). Additionally, regular yoga static poses are used as ways to promote core stability and strength muscles (Ni et al., 2016). An additional form of yoga intervention is called Merging Yoga and Occupational Therapy for Parkinson's Disease (MY-OT-PD) (Hill et al., 2020). This intervention connects occupational therapy practices with yoga practices to create a therapeutic way to combat fatigue that is typical with Parkinson's

disease. In the mixed-methods study with 17 participants findings found that MY-OT-PD has worked to help significantly reduce fatigue after completing the intervention. Study participants showed significant improvements on the Modified Fatigue Impact Scale (MFIS) which shows MY-OT-PD's efficacy as a way to help individuals with PD. Occupational therapy practitioners should be willing to promote the use of MY-OT-PD, as well as other forms of yoga, to help clients with PD overcome fatigue levels, thereby limiting their risk of falling (Hill et al., 2020).

Dance

Dance is another form of exercise that has been used with Parkinson's disease. Just like yoga, dance employs long lines and exaggerated movements which help those with micro-movements to retrain the brain for a more normalized range of motion. Dance has been able to assist individuals in voluntary movements, to make the initiation of movement come more easily, thus improving balance and instability, limiting falls (Mcgill et al., 2014). Additionally, dance has also impacted cognition improving memory and attention skills in individuals with Parkinson's disease (Ulman et al., 2020). As dance employs long lines and large movements, so do other forms of exercise, including boxing.

Boxing

Boxing is also a form of exercise and an occupation of leisure that has been found to be beneficial to fight the disease. Many people have reported enjoying this type of therapeutic exercise because of its association with sports and "fun" (Horbinski, 2021). Rock Steady Boxing is a program that was developed by Newman in 2006 to combat Parkinson's disease (Wilson, 2018; Rock Steady Boxing, n.d.). A non-profit organization that came from a diagnosis of PD and a want to fight back, the Rock Steady Boxing training is a way to improve agility while participating in a dynamic leisure pursuit (Rock Steady Boxing, n.d.). The training focuses on

hand-eye coordination and endurance by moving the whole body to complete boxing training (Wilson, 2018).

Boxing is also a highly adaptable exercise that has allowed for customization for the different individuals who are dealing with the residual symptoms of the disease (Morris et al., 2019). One person could be standing and punching the heavy bag, while one person could be sitting. The adaptability of boxing has led it to be a favorite (Morris et al., 2019). Boxing increases flexibility while keeping their bodies moving (Power, 2017).

Boxing also changes the release of chemicals in the brain such as brain-derived neurotrophic factor (Sanfarapillai et al., 2021). This maintains the remaining dopamine neurons that are in the basal ganglia, and potentially make new ones to lessen the severity of the disease. Diminishing the residual symptoms improves functional capacity and limits safety risks such as falling.

Boxing training and Rock Steady Boxing has not only helped alleviate the physical symptoms of Parkinson's disease, but it has also relieved some of the non-motor symptoms of the disease. As mentioned earlier, depression is something that comes along with Parkinson's disease. Rock Steady Boxing provides a way for someone to feel hope (Wilson, 2018). After the results of an electronic survey of 2054 participants, many individuals reported an improved social life with newfound social support in the program (Larson et al., 2021). Additionally, participants explained that feelings of depression, anxiety, and fatigue, which are all symptoms of PD, diminished after partaking in RSB (Larson et al., 2021). Many individuals had never boxed before, and this type of exercise gave them a way to feel great about what they are doing. Many individuals are doing the movements and laughing about how they look while doing it (Wilson, 2018). Boxing is also helping the quality of life by giving people the hope that the

disease can be slowed down and that they are not a lost cause due to a diagnosis (Sangarapillai et al., 2021). Boxing in this regard promotes mental health as well as physical health and is a way for individuals to be immersed with other people throughout the community.

Community Outreach

No matter what storm someone weathers in life, a supportive community is always beneficial. Community programs can include exercise classes, dance classes, and yoga classes as mentioned above, but they also can include support groups that further enhance social participation. Here social participation is a vital occupation that those with Parkinson's disease and their caregivers need to maintain quality of life (QOL). In a cross-sectional study with 20 participants who attended a support group, compared to 20 participants who did not, the individuals who engaged in the group experienced less depression and anxiety and reported a higher QOL (Artigas et al., 2015). Continuous support is where community programs fit in; they are a way of supplementing formal therapies and complementing social supports (Gauthier et al., 1987). In a study by Guathier et al. (1987), findings revealed that group therapy approaches are beneficial to people with a neurodegenerative disease as they typically experience not only motor symptoms, but depressive symptoms as well. The group approach allows for a supportive nature that fosters a rehabilitation environment too (Guathier et al., 1987). Additionally, by providing group-based therapy, there is less need for facilitators (Guathier et al., 1987). The programs listed above all represent therapeutic modalities as well as support groups. A local gym, centered around Parkinson's embodies these qualities.

Crush PD Fitness. Crush PD Fitness is a gym in Lancaster, PA which provides services for those with Parkinson's disease. Sue Ludwig, the owner of this gym, has familial ties to Parkinson's disease and has since given a TED Talk about PD, began this program through

“...the roots of PWR! Moves and the want to fight against the disease...” that was so close to her heart (S. Ludwig, personal communication, November 10, 2021). Through the exclusive nature of working just with Parkinson’s disease, the individuals who attend classes have much in common. There is a distinct sense of community among the participants at Crush PD Fitness that a visitor can immediately experience (S. Ludwig, personal communication, November 10, 2021). I have volunteered at Crush PD Fitness throughout this semester and before the COVID-19 pandemic and have been amazed at the work there. Sue Ludwig is a certified personal trainer, well versed in Parkinson’s disease rehabilitation. She has attended many different trainings and been certified in programs such as Rock Steady Boxing, Delay the Disease, and PWR! Moves (S. Ludwig, personal communication, November 10, 2021). She also has a background in yoga and Reiki training. Sue has taken her extensive education and crafted a program to assist people in their fight against Parkinson’s disease. The classes involve cardio, strength training, mobility training, boxing, and other areas of exercise to promote health and well-being for everyone, but many moves are targeted at PD breaks down (S. Ludwig, personal communication, November 10, 2021).

Crush PD Fitness currently gets most of its clients by working with neurologists on referrals. Sue had promoted her programs at PD support groups as well, but that has since slowed due to the COVID-19 pandemic (S. Ludwig, personal communication, November 10, 2021). Most people come to Crush PD through these efforts or recommendations by members there. It is an inclusive environment that does not turn people away based on money or ability level. The fitness center runs on help from volunteers and Sue’s pure dedication to her clients (S. Ludwig, personal communication, November 10, 2021). The setting does not currently have any registered occupational or physical therapists which could add an additional asset to the setting.

From an occupational therapy (OT) standpoint, the work that Sue is doing supplements formal therapy. She makes the moves and exercises that she is doing, functional, a key element of how occupational therapists view life. For example, Sue employs many squats in the exercises which replicate sit to stand transitions from a chair. As an OT student, I can understand how the functional aspect motivates the participants even more. Sue will often say “this will help with getting up the stairs or getting out of the car,” and that motivates the individuals to try harder (S. Ludwig, personal communication, November 10, 2021). The classes at Crush PD Fitness are promoting fitness while giving support to clients and families alike.

Podcast and Educational Outreach

A problem in the Parkinson’s disease community currently is the seeming lack of educational resources for them, as well as health care professionals with whom they work with. Although Parkinson’s disease is a widely prevalent disease, the lack of education that is easily understandable leads to further confusion about the disease (Udow et al., 2018). Additionally, it is such a complex disease that is difficult to explain in simple terms with the time that is granted to healthcare providers while interacting with clients (Udow et al., 2018). As touched on earlier, many individuals with Parkinson’s disease are not being referred to therapy programs until symptoms are impacting their motor function (Millage et al., 2017). With that being said, researchers exemplified the need for more education for healthcare providers to help improve the quality of life of individuals with Parkinson’s disease (Millage et al., 2017). This point is further highlighted in a study surrounding interprofessional education of 1468 participants to further enhance their understanding of PD and the need to collaborate with other healthcare professionals while dealing with such a dynamic disease (Cohen et al., 2015). The study showed that professionals that underwent the education improved their competency on PD and reported

more team collaboration (Cohen et al., 2015). With that being said, evidence-informed practice is continually highlighted, and here is a prime example. The more educational resources available, the better the disease will be understood and treated.

Dr. Conrad Kanagy, a professor of sociology at Elizabethtown College and minister at Elizabethtown Mennonite Church has PD. He detailed his diagnosis process to me and it was not a short, one-step process, but rather a year and a half long journey that was not easy, nor cheap. Doctors dismissed his symptoms, insurance turned down testing, and other tribulations lead to valuable time being wasted per his report. As a highly educated individual, one might assume he would have had an easier process, but he did not. How do people without the advantages he has had, get an accurate diagnosis and the real help they need? The answer is education.

Currently, the educational sources that are available are either highly scientific and for healthcare professionals or are created for consumption by the public, detailing personal journeys of people with Parkinson's disease. There are podcasts and blogs that explain what it is like living with Parkinson's disease, but not about resources in the community to help deal with the disease. There are scholarly articles about research being done on Parkinson's disease epidemiology and neuropathology, but many healthcare professionals, unless fully immersed in the disease may not utilizing these avenues of education, because they are not easily accessible. With that being said, occupational therapists are rarely, if ever, mentioned in any of these podcast episodes. Physical therapy is mentioned, exercise is mentioned, but rarely occupational therapy. There is a need for more educational resources about occupational therapy and for occupational therapists in relation to Parkinson's disease. A few current podcasts are available to healthcare professionals as well as individuals with Parkinson's disease on Spotify by searching

“Parkinson’s disease” (Table 2). There is a seeming divide between resources and the need for additional information, especially targeting occupational therapists.

Table 2

Parkinson’s Podcasts

Scientific Parkinson’s Podcasts	Personal Journey Podcasts
Parkinson’s Disease Caring Podcast https://open.spotify.com/show/2SHggQulTegCUkWp3BPJ0f?si=6e02662b53144343	Parkinson’s and Me-Young Onset Parkinson’s Disease and Parkinsonism https://open.spotify.com/show/1LzPKUkyGOXl1XdIL3GZVd?si=fdb3f5b79bb24b55
OffTalk- Managing Parkinson’s Disease OFF Periods https://open.spotify.com/show/6mSQZSunYYCMpPb94T1xHC?si=49717b8994cc46e2	“Park Right Here” with Katrina...my personal journey with Young-Onset Parkinson’s Disease https://open.spotify.com/show/3IvufaLLaweTcgwOr22wTW?si=6e0fb6c20e5e45e4
The Parkinson’s Project https://open.spotify.com/show/0GeMG8WVN82UOhwYcrzty?si=6ea7e3137c464160	The Parkinson’s Life Podcast https://open.spotify.com/show/2YuoFlFariXEGFLRKtyZRd?si=c64e4d8720ae42c4
Power Over Parkinson’s https://open.spotify.com/show/6CQ5VGDSXK0kF0WGWZHar8d?si=1332d2087d874cf7	2 Mike’s Parkinson’s Podcast https://open.spotify.com/show/0HYDjAvchwHgQ8YekxMN8O?si=636d1cb9be2f48d9
Substantial Matters: Parkinson’s Podcast https://open.spotify.com/show/7dO47sFw9vBjnhsdg7zEaN?si=4c5fbd2ab7cb4cb7	The Parkinson’s Experience Podcast https://open.spotify.com/show/1gciW5NG481HlrEaMsL2Xa?si=6c78231192e4467d

Note. Podcast links sourced from Spotify.

My project endeavored to create a podcast/blog that brought the research and the individuals affected together. The podcast targeted therapists and other healthcare professionals, specifically occupational therapists, as well as those with a Parkinson’s diagnosis. The intent was that all could benefit from the increased education related to Parkinson’s and community programs, so that educational efforts could help to “crush the disease.”

Methods and Approach

The methods and approach section was organized in sequential order of how this project came to fruition. The origin of the project began in the literature by delving into the research available. From there, I was able to get trained in LSVT BIG to further supplement my knowledge of treatments available for PD. Lastly, the process of developing a podcast and blog surrounding educating professionals and those with PD is mentioned and detailed.

Literature Review Process

To complete this project, I first began reviewing the literature presented above. Throughout the literature review, I integrated information about the background of Parkinson's disease, treatment options, and resources available such as podcasts for individuals with PD and for those serving those individuals. Information for this aspect of the paper came from resources such as Google Scholar, Medline, and CINAHL. Additionally, information was sourced from the Parkinson's Foundation website to gain information about the statistics surrounding PD. From there, I looked at the current podcasts about Parkinson's disease that were available on Spotify, one of the most popular websites for podcasts. I chose to look at podcasts, as they are one of the most consumable forms of informative public discourse currently and can be listened to anywhere and at any time.

LSVT BIG Certification

While completing the literature review, I took it upon myself with advice from my advisor, to get certified in LSVT BIG. As an honors student, I was able to use grant money to complete this certification. I underwent the process of writing a grant proposal and was given the money to complete my training. The certification for this was available to me as an OT student for \$300 and was successfully completely online, due to the COVID-19 pandemic. The process

included watching 12 hours of video and taking supplementary knowledge checks. After the training portion of the course, I took a final certification exam to officially become certified in LSVT BIG (LSVT Global, 2022). I am now officially certified, which means once I become a licensed clinician, I can practice LSVT BIG with individuals with PD. Taking the certification course taught me a host of information. I learned treatment strategies, further information from the literature, and just how important formal therapy at the onset of Parkinson's is.

Volunteering at Crush PD Fitness

In addition to the background work, I did for the literature review, I also volunteered my time at Crush PD Fitness in Lancaster, PA. I served in this capacity to better understand Parkinson's disease from a personal and professional level. With that being said, volunteering was like utilizing the Person Environment Occupational Performance (PEOP) Model in my head (Law et al., 1996). I was looking at people, with PD (Person), in at Crush PD (Environment), during the occupation of health maintenance (exercise)/ leisure/ social participation (Occupational Performance) and analyzing just how the different moves they were doing related to functional activities. Through this process, I was able to further develop my occupational lens to understand how PD impacts an individual so that I could increase my credibility when hosting my podcasts and writing subsequent blogs.

Podcast Participants

From the beginning of this process, I had determined that I would be creating a podcast and a blog as informational resources for professionals and individuals impacted by PD, which led to needing participants to be involved in the blog. I was fortunate to have contact with two individuals very immersed in the world of PD: my advisor, Dr. Conrad Kanagy, and the owner of Crush PD Fitness, Sue Ludwig. I asked them both verbally if they would be willing to participate

in a podcast episode with me and obtained verbal consent from them to participate and use their information for my project.

Podcast

The podcast was the first part of this project that was actualized. After discussions with Dr. Kanagy, a fellow podcaster, I chose to use the website *Buzzsprout* as my podcast hosting website. A hosting website is where the media, in this case, audio, is held for your podcast and can be sent out to podcast directories such as Spotify, Apple Podcasts, Podchaser, etc. to be consumed (Gray, 2022). I then created the graphic that is seen as the cover photo for the podcast on *Canva*, a graphic design website. From there, I developed a script using *Buzzsprout's* simple template that allowed me to see the flow of a typical podcast episode. I made a script for each of the two podcast episodes I completed, one with Dr. Kanagy (Appendix A) and the other with Sue Ludwig (Appendix B). I then confirmed the time for the podcast with each participant and sent them an individual *Zoom* link that was used to complete the interview and record the audio. I utilized the Elizabethtown College Digital Humanities Hub recording studio and a Blue Yeti microphone to record my side of the podcast. Each podcast episode was recorded the same way and was roughly 25 minutes long. After each session ended, I downloaded the audio file from zoom to the desktop of my computer and used a converter software to convert the file from an m4a file to an mp3 file so that I could edit the audio. I edited the audio using Audacity and Garageband to make the audio as crisp as possible. From that point, I exported the audio file and imported it into *Buzzsprout* where I created the description and title for the podcast and published it. After publishing the podcast on the host website, it would be sent to the directories and posted to the listening sites. I promoted the podcast by sharing the link on Facebook and Instagram.

Blog

The blog, entitled *Parkinson's Disease: Gaining Hope and Help* was created to supplement the podcast. Similar to the podcast, websites require a hosting site, and I chose to utilize *Bluehost* to host my website and to create the URL for it. After the background steps were taken, I designed the website using *WordPress* one of the most common open-source website creators. Utilizing tools on WordPress and further plugins, I published the website. I wrote two blog posts and published them on the site as well. Once the blog was up and running, I also linked podcast episodes to it as well!

Outcomes

The results of this project are different than most other projects. The results are the product of the gap that was found in the literature. The gap showed that more educational resources were needed in relation to Parkinson's disease. I endeavored to help fill the gap by creating two podcast episodes and two blog posts based on the literature review for this project, my experience of volunteering, and my LSVT BIG certification. The results are ongoing as these mediums for information dissemination are now forever available on the internet and will continue to be accessed so any data currently is tentative and ever-changing. The link to both the podcast and the blog website can be referenced along with the current number of podcast downloads, which stands at 106 as of April 28, 2022 (Table 3).

Table 3*Links and numbers*

Podcast Link	https://open.spotify.com/show/2IeOQWfebHWWzzkSOKEmk5?si=a9260883640a4839
Blog Website Link	https://parkinsonshopeandhelp.com/
Current Podcast Downloads	108 (as of April 28, 2022)

Note. The number of downloads will be ever-changing.

In addition to the podcast and blog, this project has resulted in my certification in LSVT BIG. When I officially become a licensed OTP, this will be on my list of credentials, and I will be able to practice LSVT BIG clinically. My ability to get certified in LSVT BIG adds one more clinician that will be able to help others.

Discussion

The question that started this project was how can I create an educational resource that brings both professionals and individuals with Parkinson’s disease together? To answer that question, I looked to the literature to understand PD in a deeper fashion and to better understand how treatment such as formal therapy or community-based practices could impact quality of life. Through the research, the themes emerged that there is not just one treatment strategy or therapy that will be the best way to fight PD, it is a combination of the resources available. Therefore, the question was how do we bring the resources available together and share information about them? I found that one way to advocate and proactively engage others with information about Parkinson’s Disease was via a podcast and a blog. Podcasts are a way to get “... information and entertainment, in bit-size chunks, right at our fingertips” (Ryan, 2018) and are a very current informational source. By utilizing this type of resource, information is available in an accessible

fashion as occupational therapy is all about accessibility, this project was grounded in that. It was a way to bring complex information into a more accessible and understandable format.

In hindsight of my project, I found that you can really think of this project with the PEO model in mind (Law et al., 1996). To start, you look at the person. The person here is actually two groups of people: individuals with PD and healthcare providers. The environment in this case is diverse and relative to where persons with Parkinson's are living and engaging and where OTPs are working, which is where the podcast fits in. A podcast can be listened to from anywhere which is why it is a valuable informational resource. Additionally, the blog aspect of the project supplemented the podcast and allowed for the environment piece to be further expanded. If someone prefers reading, they have access to the blog instead of the podcast as a way to make the information constantly available. Lastly, the occupation aspect of the model looks at healthcare providers and people with PD and their quest to maintain independence. Through talking to Dr. Kanagy, I gained understanding from a fighter's point of view. He explained his journey and treatment strategies in his experience with Parkinson's to work towards quelling the symptoms of the disease. When talking to Sue Ludwig, she shared information about exercise and how valuable it is to rebuild neuropathways and fight the symptoms of the disease. Additionally, Sue explained how community resources, such as her program fit into the care continuum and how OT and PT can be supplemented by the exercise programs that she provides. Altogether both episodes emphasized gaining or giving resources relative to the disease.

For someone with PD, the care continuum is a massive part of fighting the disease. As learned through this project, occupational therapists can utilize our own training and resources, such as LSVT BIG, to help our clients. Additionally, other community resources are available,

such as support groups or fitness gyms, that should be considered as a referral source for individuals with PD as they move beyond in and/ or outpatient treatment arenas and back into occupational engagement in their hometowns. By shedding light on community resources and their value, we, as occupational therapists, can work to connect our practice with them to continue the care that we give and to hold the disease accountable.

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Appendix A

PRIOR:

- Ask Dr. Kanagy how he would like to be referred to
- Ask if questions are appropriate and he would be willing to answer them

[Music intro]

[Speaking introduction]

Hello and welcome to this new podcast called Parkinson's Disease: Gaining Hope and Help, the show that is here to help disseminate information to the masses about people's journey with PD, resources for those with PD, and information for professionals, specifically focusing on occupational therapy, so that as occupational therapists we can understand the disease more to better assist clients. I'm your host, Chloe! To share a little bit about myself, I am a 4th-year occupational therapy student at Elizabethtown College, working on a project that involves getting more resources out in the world for OTs working with Parkinson's and for those that deal with the disease day in and day out.

In today's episode, we will talk about a fighter's own personal journey with getting diagnosed with PD, how he has fought against it, and tips and inspiration with our guest Dr. Conrad Kanagy. We'll discuss the ins and outs of the lengthy process of diagnosis and how to keep your hopes up despite new challenges.

Section I (Duration: 10 minutes)

- Invite Dr. Kanagy to introduce himself

So Conrad where would you like to get started in speaking about your journey with PD?

- Conrad, Could you give us a small synopsis of the process it has been to get to a diagnosis of Parkinson's Disease?
 - Jump in here if he has any information that I could comment on
 - Touch on the lengthy process, how quick diagnosis and therapy/exercise as soon as possible is optimal for the best outcomes

Section II (Duration: 10 minutes)

- Conrad, what are the therapy strategies that you have utilized?
 - Have him touch on RSB/Crush PD
- What has worked well for you?
- How do you implement different therapeutic strategies during your busy life?

Section III (Duration: 5-10 minutes)

- What tips or advice do you have for our listeners?
- What do you wish you would have known to help advocate for yourself better?
- What has led you to fight back against the disease?

Recap

[Call to action]

Thank you Conrad for joining us today in our first ever episode of this podcast! I appreciate all of the support that you have given me and this project, and I cannot wait to see where it goes from here! With that being said, feel free to check out our blog at [parkinsons hope and help. com](http://parkinsons.hope.and.help.com) !

[Outro or teaser for next episode]

- In the next episode, we will be talking to a certified personal trainer, who has devoted her life to helping those like Conrad, at her gym CRUSH PD FITNESS, specifically for individuals with PD.

Appendix A. The script I developed and used for the first podcast episode.

Appendix B

PRIOR:

- Ask Sue how she would like to be referred to
- Ask if questions are appropriate and if she would be willing to answer them

[Music intro] (Maybe, I can input in post-production)

[Speaking introduction]

Hello and welcome to this new podcast called Parkinson's Disease: Gaining Hope and Help, the show that is here to help disseminate information to the masses about people's journey with PD, resources for those with PD, and information for professionals, specifically focusing on occupational therapy, so that as occupational therapists we can understand the disease more to better assist clients. I'm your host, Chloe! To share a little bit about myself, I am a 4th-year occupational therapy student at Elizabethtown College, working on a project that involves getting more resources out in the world for OTs working with Parkinson's and for those that deal with the disease day in and day out.

In today's episode, we will talk with Sue and discuss her immense passion for working with people with PD as well as the program she has developed at her own business, Crush PD Fitness.

Section I (Duration: ~10 minutes)

- Invite Sue to introduce herself
- So Sue where would you like to get started in speaking about your journey in helping individuals with PD?
- Sue, could you give us a brief overview of the work that has led you to Crush PD Fitness?
 - I can jump in here if there is any information that I have done research on such as LSVT Big/PWR moves and comment along with that

Section II (Duration: ~10 minutes)

- Sue, tell us about Crush PD?
- How do you recruit clients? Referrals? Recommendations?
- How have you seen these strategies help clients?
- Any success stories you really enjoy sharing?
- Why is the community resource you have created, along with other community resources for PD so beneficial?

Section III (Duration: 5-10 minutes)

- How, in the future, could healthcare professionals such as occupational and physical therapists work with programs like what you have developed to better assist people with PD?
- What tips or advice do you have for our listeners?

Recap

[Call to action]

Thank you Sue for joining us today in our second ever episode of this podcast! I appreciate all of the support that you have given me and this project, and I cannot wait to see where it goes from here! Additionally, I want to thank everyone at CRUSH PD who has allowed me to come in and volunteer and make great connections with them, I cannot wait to find time to spend time there again! With that being said, feel free to check out our blog at Parkinsons hope and help. com !

[Outro or teaser for next episode]

- The next episode is TBD...

Appendix B. The script I developed and used for the second podcast episode.